

CHAPTER 1: THE PATIENT

1.1 INTRODUCTION

When the suspicious lump is diagnosed as cancer, the former citizen becomes a patient. Suddenly she has to decide about different treatment modalities and cope with the impact that this will have on her life. She has to contend with unpleasant side effects and try to adjust to an altered body image. She may experience a loss of role and suffer ostracism in the workplace and socially. This chapter explores the impact of these and other related issues on the patient and on her quality of life. It investigates anxiety and depression, sexual problems, the impact of cancer on family and social life, the role of supportive care and lists helpful tips and strategies for helping patients cope.

It has been found that quality of life is a much bigger issue in cancer than in other equally life threatening diseases.

1.2 PSYCHO-ONCOLOGY

Psycho-oncology has been a formal discipline for just over a decade. It embodies a range of activities about the phenomenology, prevalence, the role of psychological factors in the onset and progression of cancer, the stress response in relation to cancer, quality of life, improved pain control, researching a healthy population who may be at genetic risk for developing cancer, etc. as well as treatment of psychological problems in cancer patients among whom psychological treatment features prominently. Research in psycho-oncology has burgeoned during the last decade, but this is not the case in Africa and South Africa (Schlebusch 1998).

Given the projected increase in the number of cancer patients and cancer survivors, there are pressing needs to further research the implications of psychological factors as one of the groups of modulators in the etiology and management of cancer (Schlebusch 1998).

1.3 PROBLEMS THAT CANCER PATIENTS EXPERIENCE

When people are invited to talk about cancer and the feelings that it evokes, a number of dominant themes emerge (Ray 1982):

1. Fear of death as either an inevitable or a possible outcome of cancer.

This theme is elaborated in terms of the pain and suffering that is thought by many to be a necessary part of the process of dying from cancer. People also associate weakening and loss of dignity with death.

2. Cancer is regarded with abhorrence because of its invasiveness.

People describe the disease as similar to “a tree spreading its branches” or refer to it as “eating you away”.

3. A third theme is the uncertainty associated with the disease.

Few people have much knowledge of cancer and its implications. Although tremendous advances have been made in the scientific knowledge that exists about cancer, predictions about the prognosis and course of a patient’s disease can only be made in broad terms. This uncertainty leads to feelings of helplessness and vulnerability.

4. Cancer creates feelings of conflict and ambivalence.

People express inconsistent attitudes and are often aware of this inconsistency. It is in part a reflection of personal ignorance, but it also represents a conflict between what the person thinks he or she knows rationally and what, on the other hand, the person feels subjectively. For example, the same person might profess a strong faith in the achievements of medicine, including the treatment of cancer among these, and yet at the same time feel that cancer is all-powerful and synonymous with death.

Mertz (1998) listed the following problems that cancer patients experience:

Invasive tests	Financial problems
Loss of autonomy	Emotional restriction
Pain and fatigue	Side effects of treatment
Physical mutilation	Relationship with staff
Physical limitation	General relationships
Loss of job	Insurance denied

Many of these issues will be discussed in depth further on in the chapter.

In a descriptive study of breast cancer patients undergoing adjuvant therapy following surgery, a sense of emotional disruption, stemming from fatigue, nausea and irritability, was described. Most patients also underwent major decreases in their levels of work and social activities coupled with major increases in emotional distress. Worsening family and sexual relationships were reported by 25 to 40 % of patients (Meyerowitz 1983).

A number of factors have been identified that consistently predict low quality of life. Patients with a poorer prognosis have reduced life satisfaction. Unpleasant and debilitating treatments, such as chemotherapy and radiotherapy, also reduce quality of life, although these effects appear to be reversed once the treatment ends. However, for some patients who take medications on a regular basis, quality of life can be substantially and chronically diminished by the treatment side effects. Treatment side effects are a particular problem for patients suffering from cancer (Taylor 1990).

1.3.1 ADJUSTMENT TO CANCER- GENERAL

Individuals living with cancer have the following needs: Practical, spiritual, psychosocial, informational, emotional and physical.

Coping is directed towards the resolution of difficulties, but it can be effective or ineffective, adaptive or maladaptive, in terms of its outcome. Can ways of coping be used to distinguish those patients who do adjust well from those who do not? First, we can predict that those who have coped unsuccessfully in the past, with the challenges of life as a whole, would be less able to cope with the demands of cancer and mastectomy. High neuroticism and trait anxiety are in fact correlated with poor adjustment to cancer, as are low ego strength, depression, low well being, pessimism, poor self-esteem and a discrepancy between expectations and actual attainment in life. General measures of personality however, make no reference to the nature of the immediate situation and cannot take into account specific factors, and patients who are generally well adjusted may sometimes react atypically to the threat of cancer and treatment. Unfortunately the patient's response to other and totally different situations of stress in the past is not very helpful in

understanding or predicting her response to the stress of having breast cancer. Each stress experience has a very specific meaning (Ray 1985).

Because it is a chronic and mostly life-threatening disease, cancer poses a series of both physical and psychological threats to its victims, the intensity of which can sharpen and ease repeatedly throughout the treatment process and long thereafter. In recent years, the focus of medical care in cancer has broadened to incorporate not just basic issues of survivorship, but also quality of life (Knapp 1995).

Knapp (1995) has identified the following steps in the adjustment to cancer: These tasks represent some of the core psychosocial areas of quality of life and they are also at significant risk of disruption throughout the cancer experience:

1. Numbness occurs at initial diagnosis and recurrence.
2. Periods of anxiety will overlie the emotional shock. Individuals in this state of mind often process medical information inadequately or incorrectly (Heinrichs 1983).
3. Fear of pain, disfigurement and death.
4. Fears specific to the treatment: surgery, radiotherapy or chemotherapy often develops. Many patients believe that the treatment is worse than the disease.
5. Transient mood disturbances and periods of anticipatory grieving. Even when the prognosis is good, the patient may mourn the loss of sense of immortality and control over the course of his life.
6. Searching for explanations of the illness.
7. Episodes of externally directed anger occur.
8. The patient is at high risk of developing psychological morbidity.
9. The ability to manage stress and loss become a critical factor.
10. Any therapy that compromises reproductivity or sexuality may pose added psychological consequences, because these domains are a partial basis of self-image for many adults.
11. Negative psychological impact may then spill over into interpersonal functioning, not only in the area of sexuality but also into family and social relationships.

Good psychological functioning permits an individual to adapt and cope with an awesome array of physical and social assaults. Healthy psychological functioning, that is freedom

from anxiety and the ability to adapt and adjust to different illness states, is crucial for the maintenance of a good quality of life (Fallowfield 1990).

In certain circumstances illness can be seen as a reaction to stress, loss or other psychodynamic events (Jaffe 1977). According to Moos (1977) seven major adaptive tasks must be confronted and managed at the time of an illness:

The illness – associated tasks are:

1. Dealing with pain and incapacitation.
2. Dealing with the hospital environment and treatment procedures.
3. Developing functional relationships with the hospital staff.

The general tasks are:

1. Preserving an emotional balance.
2. Preserving an adequate self-image.
3. Maintaining relationships with family and friends.
4. Preparing for uncertainty.

Tarr & Pickler (1999) conducted a study to explore the process by which families of children with acute lymphocytic leukemia “become” cancer patients. The central process of “becoming” was defined as trying to live as “normally” as possible; accepting that life is not the same; understanding what you have to do; accepting what you can’t change and living with dissatisfactions. This process was mediated by families’ external contexts, including marital relationships and support networks, experiential contexts, including positive and negative experiences during treatment and previous illness experiences, and internal contexts, including personal survival strategies and personal outlooks and attitudes. The process illustrates the pattern of experience that occurs in families faced with the diagnosis of their child’s acute lymphocytic leukemia. Understanding this process may be useful to care providers when treating patients with cancer.

1.3.2 COPING WITH STRESS

Coping refers to the “things people do to avoid being harmed by life’s strains”. They try to overcome difficulties and minimize the impact of unpleasant events by using skills and

habits that have been developed over a lifetime. It is behavior directed towards the solution or mitigation of a problem, and the term coping should not strictly speaking be used, as it sometimes is, to describe emotional responses that lack this purposive element (Ray 1985).

Types of goals in coping:

1. Instrumental coping:

Brings about an objective change in the situation.

2. Meaning-directed coping (palliative):

Even without any objective change in the situation, the person may be able to change the way in which she perceives the situation to make it more acceptable for her.

3. Emotion-directed coping (palliative):

Anxiety, anger or depression interferes with the person's behavior in the situation. It may be beneficial to tackle these emotions even when nothing can be done to change outcomes or the way in which they are evaluated.

Both instrumental and palliative coping serve to protect the person from distress, and the latter may in many situations be the only possible way in which adaptation can be achieved and psychological equilibrium be maintained. Indeed it is forms of coping that modify meanings and emotions, rather than objective events, that have been most emphasized in the past literature. It is these forms of coping that are primarily reflected in the "defense mechanisms" first proposed by psychoanalytic writers (for example Freud), but which, since then, have been very widely adopted by clinicians and researchers in the field of adjustment. Within this psychoanalytic framework the defenses are viewed as mechanisms that protect the ego from conflict, achieving this aim by "deceiving" the self and distorting reality (Ray 1985).

The most commonly found mechanisms include the following:

Repression: inhibiting the awareness and expression of impulses or feelings that would cause anxiety.

Denial: disavowing unwelcome impulses from within or unwelcome facts in the outside world; focusing on the pleasant.

Reaction formation: acting out the opposite of unacceptable feelings.

Displacement: attaching an unacceptable motive or emotion to an alternative object. This can provide some release without the conflict that would be involved in directing the feeling at its original object.

Sublimation: channeling an unacceptable impulse into a socially acceptable behavior.

Rationalization: disguising the true reasons for a behavior; presenting plausible but distorted accounts of beliefs.

Isolation: cutting off the unpleasant emotional aspects of a total experience; acknowledging unpleasant ideas, but not the unpleasantness associated with them.

Intellectualization: focusing on abstract ideas or detailed minutiae and adopting an objective and “scientific” attitude towards the situation.

Projection: disowning thoughts and feelings that a person has and projecting them onto others; attributing to others his or her own unacceptable motives.

Regression: acting inappropriately for a person’s age; not accepting self-responsibility and turning to others for emotional support.

Suppression: directing awareness away from a conflict, threat, or unpleasant experience.

Alternatively these reactions can be analyzed in terms of general styles or dispositions:

Repression-sensitization: Repressors are those people who characteristically take an ostrich-like stance when threatened. The significance of the situation is discounted in some way and the person tries to maintain her present equilibrium rather than adjust to a new one by simply not recognizing that circumstances have changed.

Sensitizers are open to and even on the lookout for unpleasantness. They recognize and focus on threat and make an attempt to find a new equilibrium that takes account of changed circumstances.

Locus of control: The person with an external locus of control tends to see their fate as being determined by chance or by powerful others, rather by than their own efforts. In contrast, the person with an internal locus of control is typically one who sees herself as “holding the reins”, with her own actions determining outcomes. Both these dimensions are useful, in that they can predict behavior, but the character of a given person’s coping is not necessarily consistent across either time or situation. It is now widely acknowledged that personality variables such as these indicate only broad tendencies. Thus, the same person

may be both a repressor and a sensitizer, or have either an external or an internal locus of control, depending on the context (Ray 1985).

1.3.3 COPING IN CANCER PATIENTS

Denial is most often discussed in the literature in connection with cancer patients:

- Patients may fail to draw the obvious conclusion from the evidence of the treatment they are receiving and avoid taking the opportunity of confirming any suspicions that they have.
- Some may even deny the fact of their cancer even though this has been communicated to them directly.
- Alternatively, denial can take the form of an acceptance of the diagnosis but with a refusal to acknowledge its implications.

Though denial is an important strategy for dealing with cancer, it may not be quite as prevalent as it seems. In some vulnerable patients it may be the only viable response, where the alternative would be fragmentation and despair. Where there is little possibility of controlling the objective threat, then its open acknowledgement may serve little purpose. This is generally true of cancer and denial may enable the patient to face the future with hope and optimism at little cost. However denial before diagnosis, when delay may worsen the prognosis by giving the cancer a chance to grow and metastasize, is maladaptive.

A study of coping in breast cancer described defense employed in terms of six basic styles:

- Displacement: For example where the patient showed an excessive concern for her husband but not for herself.
- Projection: In the form of hostility to the staff.
- Denial with rationalization: The most common strategy found in the study. Patients adopted the view that all was well and provided justifications for this view.
- Stoicism and fatalism.
- Prayer and faith.
- A style where several of these defenses were employed simultaneously.

The researchers attributed the apparently good adjustment of patients in their sample to the use of the coping devices described, emphasizing that distress does not automatically follow from exposure to a stressor, but depends on how this is perceived, interpreted and defended against (Ray 1985).

In a sample of 90 women, their responses were analyzed in terms of a number of ego-defenses and then related to delay in presenting with the breast symptom. Denial and suppression were found to be positively associated with delay, while intellectualization and isolation were negatively related (Ray 1985).

In another study, coping strategies were defined in terms of patients' general attitude towards their illness:

- Denial.
- A fighting spirit.
- Stoic acceptance. Over half the responses obtained were stoic acceptance. Patients who coped in this way were less likely to change the nature of their response.
- Anxious-depressed acceptance.
- Helplessness and hopelessness (Ray 1985).

An analysis of general coping responses to serious illness by Verwoerd (1972) suggests three categories, oriented towards cognitive ways of coping with the situation:

1. Strategies that involve a retreat from threat.

Examples are withdrawal and regression.

2. The exclusion of threat or its significance.

For example suppression, denial, rationalization and depersonalization.

3. Mastery of the threat.

Includes strategies such as intellectualization and acceptance of loss.

Ray and coworkers (1982) described a schema of the coping strategies of patients, which incorporates features of many of the other approaches, but within a structured framework:

- Rejection-assertion:

Rejection-assertion is a way of coping that reflects a view of the situation as basically unacceptable. The patient rejects its implications and attempts to revise these to meet her personal needs and desires. In the context of cancer, there may be little that the patient can do to assert her demands over the facts. Her attempts at control are often frustrated and lead to bitterness and resentment.

- Control:

When control is the coping mechanism, the situation is not seen as a battle but as a challenge. The patient rather than rebelling against it, view it as a problem to be managed.

- Resignation-helplessness:

This patient faces the threat, but sees herself as relatively powerless, with events and outcomes being determined by fate. There is a sense of “what will be will be” and so there is no incentive to struggle against the situation or to attempt to control it.

- Trust-dependency:

Trust-dependency is related to resignation helplessness in that the patient regards herself as relatively powerless, but events and outcomes are seen here as being determined not by fate but by other people. She relies on her faith in the physicians and the nursing staff.

- Avoidance:

The patient acknowledges the existence of the threat, but avoids situations or thoughts that will remind her of it. Withdrawing attention from it neutralizes the threat.

- Minimization-denial:

The patient sees the situation as relatively secure. As far as she is concerned there is little or nothing to worry about and nothing that needs to be done.

Successful coping requires a balance between what one can accept and confront and what can harmlessly be ignored or postponed. There is some evidence that coping that is oriented towards control has a positive role in adjustment. Confrontation was associated with low distress, while suppression, fatalistic submission, social withdrawal and passivity characterized patients who did less well (Weisman 1976). Information seeking was one way of establishing control and a study of coping, showed that this was associated with less negative effects, in contrast to recourse to wish-fulfilling fantasy. The latter is an avoidance strategy and is associated with a poor acceptance of the illness.

The coping strategies of patients that facilitate psychological adjustment must be identified next. There is some evidence that avoidant coping is associated with increased psychological distress. On the other hand, cognitive restructuring is associated with good emotional adjustment. Coping by fantasizing, expressing emotion or blaming the self is associated with poor adjustment. Information seeking and threat minimization is not related to adjustment. Weisman and Worden (1976) found poor adjustment to be associated with efforts to forget the cancer, fatalistic views of cancer, passive acceptance, withdrawal from others, blaming of others and self-blame.

The previously mentioned findings concerning denial imply that coping strategies may be most effective when they are matched to the particular problems or points in time when they may be most useful. There is evidence that people spontaneously match coping strategies to aspects of a stressful event. For example, people are more likely to use problem-solving strategies for aspects of a stressor that are amenable to direct control and to use emotion-focused coping for aspects of a stressful event that remain uncontrollable. Also, research suggests that multiple coping strategies may be most effective in managing some stressful events. In conclusion, active coping strategies seem to be more consistently associated with good adjustment than avoidant strategies, so long as there are aspects of the disease amenable to active coping efforts (Taylor 1990).

One of the criteria for successful adjustment has been the length of time it takes people to return to their pre-stress activities. Often a chronic illness interferes with the conduct of daily life activities. To the extent that a person is able to resume those activities, adjustment is said to be better. However, there is an implicit bias in this criterion to the effect that the person's prior living situation was in some sense an ideal one. This is not always true. In fact, substantial life change may follow a stressful event and this may be a sign of successful rather than unsuccessful adjustment. Most frequently, researchers have measured adjustment in terms of psychological distress. When a person's anxiety or depression is low, adjustment is judged to be successful. In summation, then, there have been several criteria of successful adjustment, which were formally incorporated into quality of life measures (Taylor 1990).

1.4 HEALTH AND PERSONAL CONTROL IN QUALITY OF LIFE

After cancer, a person's sense of security and well being in their internal and external environments may be permanently altered. Often the meaning given to cancer is more destructive than the disease itself. Leigh's (1992) physical recovery from cancer treatment took six months, but her psychological, emotional and social recovery took years.

Research has also found lower psychosocial morbidity to be associated with positive active responses to stress, to high internal locus of control and to beliefs that one can personally exert direct control over an illness. Similarly, low levels of helplessness have been associated with superior psychological and behavioral functioning and reduced symptom severity (Taylor 1990).

Campbell (1976) conducted a large-scale study on quality of life. Good health was found to be the most important domain and there was a strong relationship between health status and satisfaction. Poor health seems to be a condition of life that is uniquely difficult to accept. Most people seem to have a capacity to live with economic or personal vicissitudes and to develop some degree of satisfaction with their circumstances. But poor health is a condition that people find very difficult to feel satisfied with.

Not surprisingly, age and socioeconomic status were correlated with health status. Nevertheless, a certain amount of accommodation appeared to take place during the aging process. This moderated the negative impact of poor health in later life, so that relatively high levels of life satisfaction were reported. Furthermore, a strong sense of personal or internal control over life was also associated with good health, happiness and life satisfaction (Campbell 1981).

According to Knapp (1993) there appears to be evidence that a perception of personal control is often associated with positively reported quality of life. Overall control was found to relate to both psychological and physical outcomes. Those who generally found more control over their lives experienced less depression, less impairment of activities of daily living, less pain and less severe symptomatology. Individuals with a stronger sense of internal overall control were less likely to report decreases in their social and recreational

activities. The cancer diagnosis and treatment process may negatively affect specific aspects of quality of life, such as sexuality. She also found that cancer patients frequently indicate that they have a good quality of life, with the exception of those in chronic pain or those in active therapy.

1.5 THE PERSONAL MEANING OF ILLNESS

Unconsciously, if not consciously, we feel that anything can be achieved as long as we try hard enough or want it badly enough. We regard death as something that comes to other people; or to ourselves, but in some far distant future. An illness like cancer cuts through these illusions of omnipotence and immortality and courage is needed to carry on without them and somehow not only to accept but also to transcend our limitations. Illness provides opportunities for growth on the part of both the physician and the patient. It provides a context in which the nature of the human condition can be learned and the character necessary to negotiate reality can be developed. This is of course an ideal as opposed to a description of what actually occurs (Ray 1985).

The most obvious interpretations of a cancer diagnosis are negative ones – a loss, a threat, or a punishment. Their unfavorable impact is likely to be especially marked for patients with other risk factors such as social isolation, low socioeconomic status, past history of psychiatric illness, alcohol or drug abuse, other recent life stresses and a tendency to be rigid and pessimistic in outlook. However, striking exceptions are sometimes seen, when a diagnosis of cancer seems to enable a patient to transcend longstanding emotional maladjustment. Many patients see positive aspects to their illness as well as negative ones: it may represent a challenge to be fought and overcome (Barraclough 1994).

“I had lost my innocence and in the fullest sense I realized how very close I’d come to my own mortality (Runowicz 1995).”

Even people who have a good prognosis after a relatively uncomplicated course of treatment did not experience cancer as a limited episode. The person enters what can meaningfully be described as a new stage of life as a consequence of the crisis (Mages 1979).

Rijken et al. (1995) compared the structure of the concept subjective well being between three groups of elderly women (cancer patients, women with chronic ailments and healthy women). Physical health is extremely important to elderly populations. It is crucial to maintain a state of independence, which is highly valued by the elderly. The most notable finding was that perceived physical health appears to be more strongly related to global subjective well being, when the objective health status is worse.

When a woman first learns she has cancer, she and her loved ones turn to the oncologist for information about her illness, leaning on the combined strength of her medical support team for direction and encouragement in the demanding fight simply to stay alive. The woman who survives cancer faces rocky, uncharted territory. Often she must contend with the disabling consequences of therapy and face the ongoing concerns about living with a frightening chronic disease. Slowly she begins to realize that her body may not look, feel or function exactly the way it did prior to her illness. And she may find herself reevaluating her relationships, her career, her goals, and even her sense of purpose. On top of this comes the ever-present threat of recurrence, a fear that stalks, to varying degrees, every cancer survivor (Runowicz 1995).

1.6 GENERAL FACTORS WHICH INFLUENCE QUALITY OF LIFE

Rustoen and coworkers (1999) used the Ferrans and Powers Quality of Life Index and the Cancer Rehabilitation Evaluation System (short form), to examine which domains of quality of life are most strongly affected in patients with newly diagnosed cancer. Additionally they examined whether quality of life was related to gender, age, educational level, cohabitation, time since diagnosis, treatment or type of cancer. The patients were satisfied with their lives, especially with the family and marital domains. They were least satisfied with health, functioning and sex life. Those cohabiting had significantly higher quality of life compared with those living alone. In contrast the younger group (19 – 39 years) living alone had significantly lower quality of life than the older groups living alone. Elderly people reported their quality of life to be better in almost all sub-scales. Time since diagnosis was not associated with quality of life, while treatment was associated with quality of life. Gender and educational level were only associated with one or two domains in quality of life, respectively.

The major concerns and needs of breast cancer patients was assessed by Wang and coworkers (1999). Their major concerns and needs were health, family, finances, work, the future, self-esteem, counseling and support for themselves and their family. Married women and those younger than 50 were more likely to have concerns about their family. Nonwhites had more concerns about finances and work than white women did. Older women and married women, however, had fewer concerns about finances and work than younger women did and those who were not married. Fewer nonwhites than white patients expressed concerns about their future. Young women were more concerned with self-esteem than older women. More nonwhites than whites and more married than unmarried women expressed needs for family counseling and support. Help for interpreting information was required more frequently by nonwhites than whites. Nonwhite women also tended to require more referrals than whites.

1.7 THE RELATIONSHIP WITH MEDICAL PERSONELL

1.7.1 GENERAL

Stefaneck (1994) assessed the psychological consequences of communication problems between patients and providers. A substantial portion of patients (84%) reported difficulties communicating with their medical team. The difficulties reported suggest that although providers offered information and explanations, many patients had problems comprehending information. Many patients reported problems with asking questions and expressing feelings to providers, behaviors that could prompt clarification of the information received. Also, communication problems were more common among less optimistic patients. Patient-reported communication problems were associated with increased anxiety, depression, anger and confusion at a three-month follow-up. The data suggests that interventions to enhance communication between patients and providers may improve psychologic adjustment to treatment.

Cancer impacts on all aspects of the patient's life. Most cancer patients have special concerns about their physical appearance, self-esteem and sexual lives. Too often health professionals focus their attention only on the disease process, its diagnosis and treatment. Often it is the lack of information and an inability to communicate with cancer patients

about these concerns which lead physicians and other health professionals to neglect important aspects of patients' care (Vaeth 1980).

Patients rely heavily on their physician to weigh the potential benefits and risks of therapy alternatives and provide clear treatment recommendations (Fetting 1988).

There are certain things about how patients operate that would be useful for physicians to know. The first is that patients' fears and more rational expectations may be strongly influenced by the experiences of a relative or close friend with cancer. These expectations may be in the form of a general belief that cancer cannot be stopped or in the form of specific expectations about the possible spread or complications of the disease. Physicians could find out what those expectations are simply by asking whether the patient knew anyone with cancer and what had happened to them. This would enable the doctor to clarify mistaken ideas and to gain a picture of how the patient may interpret certain events or symptoms during chemotherapy. It might also be possible to pick out those patients who have very distressing and pessimistic expectations about cancer and treatment so that they can be watched more carefully.

A second fact that medical personnel need to be aware of is that patients are constantly making inferences from details of their physical state, treatment procedures, and remarks by their doctors, about what the disease is doing. The patient as evidence of therapy success or failure may interpret things such as levels of side effects or changes in these, low or high white cell counts. The doctor or nurse needs to be aware of this possibility, and to be ready to offer explanations where none are asked, and to also question patients about their interpretations of things, which are happening in the treatment. For example, patients should be told, before they start chemotherapy, about the schedule of tests they will be given, so that they will not assume something is wrong when given a routine bone scan.

Thirdly, physicians need to know that most patients with metastatic disease are able to face what is happening with their disease. When they have adequate information, they make accurate judgements about how well their treatment is working. If patients appear to deny or be unaware of what is happening with their disease, this may be more a social pretense than what they actually think.

Finally health care workers need to know that the disease and treatment may create family problems which are serious enough to need outside assistance. For example withdrawal or acting out in children, because they are angry with their parent for being sick (Ringler 1983).

Poor communication, rather than poor treatment, is the basis of most complaints and most patients simply want to be treated with respect and sensitivity (Cousins 1989).

1.7.2 RELATIONSHIP WITH THE SURGEON

The treatment of illness does not take place in a vacuum, but within the framework of the relationship between the patient and the physician responsible for her care. A key aspect of this relationship is its hierarchical nature. The degree of inequality varies depending on the people involved, but the physician inevitably does have the more powerful role. There are a number of bases to his power. He can first, provide resources that even if they cannot promise a cure, still offer the patient some hope of return to health. The patient is in a sense, a supplicant for these resources. Second within our social system physicians are cast as figures of authority, having the right to make important decisions regarding their patients' welfare, within the constraints of a general ethical code and certain limits prescribed by law. It has been suggested that the profession is "invested at the level of bodily health, with powers similar to those exercised by the clergy over men's souls". Third, the physician has a competence acquired through training and experience that most patients undeniably lack, giving his pronouncements a greater weight than those of any layman.

When a patient consults a physician, the latter makes recommendations for action and the patient is generally regarded as having to comply with these recommendations. A lack of compliance is regarded as a failure to comply. It takes more determination to tell a physician outright that you are not going to regard his advice than, to accept a prescription and subsequently discard the tablets. Hospital treated illness is more serious and the possible costs of noncompliance in terms of health are therefore greater.

Without this authority the physician would have less prospect of persuading patients to accept treatment whose rationale they do not understand, or treatments that are unpleasant, and from this point of view can be regarded as a quality to be fostered. It can also be of psychological benefit to the patient, by lifting from her shoulders the responsibility of evaluating courses of action and making decisions, a responsibility that she might not be able to cope with intellectually or emotionally.

This portrait of a relationship in which the physician has the authority and the patient is passive and dependent, is one that is conflict free. It assumes that the perspectives of the physician and the patient are compatible, and their roles are complementary, and that the patient is willing to hand over control to the physician in return for his efforts to define and solve her problems. However, although some patients conform to this model, others are more questioning in the relationship and seek to preserve their autonomy. Medicine is a specialized subculture in which the layman and the professional inhabit "separate worlds of experience". While the patient may respect the physician's greater expertise, she may have reservations about how this expertise is being applied to her own particular situation. Her perspective on illness may be very different from his. He applies general rules and categories and functions as a professional on the basis of his training and experience. The patient, in contrast, is personally involved and brings to her role other aspects of her being. Thus, while the physician and the patient may agree in the abstract on the ultimate goal of cure, they may have different ways of defining the problem and different ideas about viable solutions. Some consultations can thus involve a struggle for control, from these different perspectives, even though the struggle may be subtly expressed. Its existence is recognized whenever physicians talk of persuading patients to do something for their own good, or of overcoming their resistance. The struggle for control is also manifest when patients complain that they have not been sufficiently informed of the facts about their illness and treatment, thus depriving them of the opportunity to make their own judgement.

In the case of breast cancer and mastectomy, the kind of conflict that might arise is one where the surgeon recommends the operation on the basis of its curative potential, while the patient is concerned also with that treatment's personal, social and sexual implications. Many patients are happy to take their surgeon's advice on trust, assuming that he knows what is best for them. But there are patients who refuse mastectomy or who acquiesce with

misgivings. The latter may be resentful and bitter after surgery, never having been truly convinced that the extra safety to be derived from the removal of the breast would compensate for the distress they feel at its loss (Ray 1985).

Some surgeons would like a patient to participate in the decision-making process. They may hope that she will agree to whatever recommendation is made, but would like to feel that this agreement has the force of an informed consent (Ray 1985).

1.7.3 RELATIONSHIP WITH THE NURSE

Generally speaking nurses have a more explicit and well-articulated concept of their role than physicians do. This role has two distinct but interwoven aspects: a technical function in taking care of the physical needs of patients and an expressive function that comprises the kinds of concerns implicit in a personal orientation. The former refers to the support of the patient's physical treatment and care and the latter refers to the effort she makes to reduce the patient's emotional tensions. The importance of caring for the total patient, that is for her psychological as well as her physical needs, is very commonly recognized. The nurse informs the patient, reassures her, conveys warmth and interest, and helps to clarify problems and solve them but this is to some extent an ideal, as opposed to actual practice. Nurses may want to provide total care, but feel that they do not have the opportunity to do so. Most of the available time may be taken up by physical tasks and even if it is not, it is often seen as inappropriate for the nurse to stay by the patient just to talk (Ray 1985).

A nurse may be reluctant to give information and have detailed discussions with patients, for fear of incurring the displeasure and criticism of a physician who regards himself as responsible for what to disclose and what guidance to give. Another problem is that nurses, like physicians, may have emotional difficulties in coping with their role, and these may be greater because of the closer and more extended contact that they have with patients. In caring for the sick, nurses are routinely exposed to grief, doubt and uncertainty and such stresses are particularly acute when working with cancer patients (Ray 1985).

Specialist nurses counsel mastectomy patients from the time of diagnosis and maintains contact after she has left the ward. This continuity of care enables her to deal with problems

as they arise and she can talk to the patient about her feelings when she is ready to do so. Often, just the fact that the patient has the opportunity to express her fears and is encouraged to think in an objective manner about them seems to alleviate her distress. If the patient's reaction to the mastectomy is extreme, the specialist nurse will enlist the help of a consultant psychiatrist.

1.7.4 RELATIONSHIP WITH OTHER PROFESSIONALS

Professionals with training in psychology or social work can also support the patient in the same way as the specialist nurse. Counseled patients' anxiety, hostility and depression declines more rapidly. They are more active and realistic in their outlook and they are more open about the difficulties that they face because of their illness. Counseled patients show reduced denial and less negative affect.

1.8 THE PATIENT'S OPINION, NEEDS AND WISHES

1.8.1 GENERAL

Patients need to be treated as individuals because for each person, the cancer is a very personal experience. A cancer patient often feels that the cancer is a threat to her life, her courage and her faith in God: her entire existence. She sometimes feels that she is treated as a carcinoma left breast and not as a human being. She needs to maintain some measure of control over her life and she needs to come to terms with her illness. She also needs to be able to discuss her feelings and experiences.

Patients often need the acknowledgement that they are respected as human beings. This is especially true when medical staff is trying to put up intravenous lines, or carry out other potentially painful procedures without success and procedures have to be attempted repeatedly. One kind word can often make a huge difference.

A growing body of evidence indicates that believing one has control over outcomes in life plays an important role in maintaining and improving an individual's health and sense of well being. Street (1997) investigated patients with early breast cancer with regard to

relationships among patient involvement in deciding treatment (i.e. whether to undergo breast removal or breast conservation), perceptions of control over treatment decisions and subsequent health-related quality of life.

Sixty patients with stage I or II breast cancer allowed their consultations with surgeons to be audio recorded. Following these visits, patients reported on their involvement in the consultation, optimism for the future, knowledge about treatment and two aspects of perceived decision control, the perception of having a choice of treatment and the extent to which the doctor or patients was responsible for the decision. The patients who had more actively participated in their consultations, particularly in terms of offering opinions, assumed more responsibility for treatment decisions during the year following surgery than did less expressive patients. Also, the patients who reported more involvement in their consultation later believed they had had more of a choice for treatment. The patients who believed they were more responsible for treatment decisions and believed they had more choice of treatment reported higher levels of quality of life than did the patients who perceived themselves to have less decision control (Street 1997).

1.8.2 PARTICIPATION IN CLINICAL TRIALS

According to Williamson (1996) there can be important mismatches between what clinicians and local health services provide and what some patients would have wanted. There are also concerns about the way research is conducted and how patients come to take part in it (Batt 1994). Both in treatment and research, patients sometimes conclude that they and their interests meet with scant respect (Hancock 1996). Therefore research that picks up trends in patients' views and detects new issues, as professional practices or patients' expectations change, is a necessary complement to professional assumptions and aspirations (Williamson, 1996).

Ambiguities between the "objective" world of science and the inner world of feeling come to the fore when participation in clinical trials are discussed. Alderson (1994) explored dilemmas between accepting randomization to a treatment arm of a randomized controlled trial and wanting "the treatment that is best for me". The results also suggested that greater

knowledge led previously treated patients to reject certain research trials. Approximately half of the previously treated patients wanted to make their own decision.

Patients wanted to take part in treatment or research that would fit with their moral values, their work and social circumstances, and their responsibilities. Evidence is increasing that involving patients in making decisions and choices improves outcomes. But it is imperative to remember that the personalities of patients vary (Alderson 1994).

From the patients' point of view, the highest ethical standards must always be in place. Informed consent must be obtained from all participants (Williamson, 1996). Psychosocial and psycho-oncological research should learn from patients not merely study them (Pickering, 1995).

1.9 TREATMENT MODALITIES FOR CANCER AND THEIR IMPACT ON THE PATIENT

It must be remembered that patients with advanced disease have a limited life expectancy irrespective of treatment. Therefore, of the two objectives – palliation of symptoms and prolongation of life – the main emphasis has to be given to improving the quality rather than the length of the patient's remaining life. A point may be reached where aggressive active therapy diminishes the quality of life to a level where stubborn perseverance ceases to be humane.

All three general areas of human functioning: physical, social and psychological, can be affected by cancer treatment. Unfortunately, treatments without side effects are presently virtually non-existent. Some degree of morbidity is caused with every kind of cancer treatment and this, together with progressing disease, has clear implications for issues of quality of life (Knapp 1995).

Given the recognition that cure is not a realistic expectation for stage IV disease with conventional treatments, the patient and her physician should then define the goals and expectations of therapy. These goals could then help to define the philosophical approach to staging and treatment priorities. One would logically assume that the order of the priorities would most likely be: (1) comfort, (2) function and (3) longevity. Most patients and

physicians would likely agree that achieving survival longevity without comfort and function would not be worthwhile (Aisner 1994).

Most women with advanced disease treated with combination chemotherapy regimens, whose disease responds, experience only a partial response of their disease. A minority of the women has a complete response, i.e. complete disappearance of all signs and symptoms of disease. For those women whose disease responds to therapy, one might reasonably ask how long such toxic or potentially toxic therapy should continue. There are no good studies to define the answer to these questions and many of the cooperative group trials have continued the therapy until the time of progression, sometimes in excess of two years. Such an approach seems contrary to the initial priority goals set out for the treatment of metastatic disease: comfort, function and then longevity. An alternative approach may be to give a fixed number of cycles (e.g. four to six, or until a maximum response is achieved) and then allow a woman a “rest” period off all chemotherapy to enjoy the benefits of response (Aisner 1994).

It has been found with prostate cancer patients that all areas of quality of life are significantly better for patients in remission and on treatment than patients with disease progression (Albertsen 1997). Disease symptoms under control are therefore very important for a good quality of life.

1.9.1 SURGERY

Hospitalization and surgery may be as terrifying, for some patients, as other concerns. Surgery has been described as “a planned physical assault” on the body, although one to which the patient has consented. After she leaves the hospital, the post-mastectomy patient moves toward adjustment to her illness and to the loss of the breast. Many women have difficulty in making the adjustment and postoperative depression is a common sequel to mastectomy and is marked by anxiety, insomnia, depressive attitudes, occasional suicidal thoughts and feelings of shame and worthlessness (Ray 1985).

The breast does not have a well-defined physiological function at the time of life when a woman is most at risk from breast cancer, but its loss can cause difficulties of adjustment at

a number of other levels. It can affect a woman's body image, her perception of her identity as a woman, her social image and the way in which she presents herself to others and her marital or other sexual relationships (Ray 1985).

No matter how much a woman reads about breast surgery or how much support she receives from relatives and friends, it never is enough to prepare her for the shock of looking down at her own mastectomy scar. Each person experiences a different and unique level of grief when she loses a breast to cancer. And every woman needs time to mourn her loss and reconcile her feeling. We live in a society that worships breasts, not for their function, but for their form. The decision to undergo reconstruction after surgery has to do with a woman's sense of self, with restoring what has been lost (Runowicz 1995).

Patients, who are offered a choice regarding the type of surgery that will be performed, have been found to have less anxiety and depression, than those who were not offered a choice. However, offering the patient a choice of surgery is not a simple matter and it has been recommended that discussion should be supported by written or tape-recorded information. This information provided the patient the ability to discuss issues with family, friends and the patient's general practitioner (Stefanek 1994).

Indications for breast reconstruction following mastectomy begin with a reasonable assurance that the primary cancer has been eradicated. Therefore, stage I patients without evidence of spread beyond the breast either locally or distantly are the best candidates for reconstruction. But the possibility that a patient may succumb to a distant metastasis in the future is no justification to deny reconstruction in the intervening years (Harvey 1980).

The old-fashioned concept that women seek reconstruction because they cannot adjust psychologically to their plight is outrageous. People want to look and feel normal. Feeling good about oneself is terribly important to all people (Harvey 1980).

Surgery may have sequelae beyond the initial post-operative period. Axillary clearance can lead to painful and often permanent swelling of the arm (lymphedema). Lymphedema can be disfiguring and may have serious consequences if a cut or abrasion on the affected limb causes subsequent infection. Surgery for cancer is often deforming and follow-up surgery is

often required to try and correct these deformities. One example is reconstructive surgery after mastectomy.

1.9.2 CHEMOTHERAPY

Despite the clinical benefit that may be associated with reduction of tumor volume, chemotherapy may produce physical or psychological distress that could compromise a patient's quality of life. Conversely, chemotherapy may palliate symptoms produced directly by the tumor, such as pain, dyspnea, or cough, or lessen psychological distress by reducing hopelessness. These effects may improve quality of life, providing benefits that are not reflected by the traditional outcomes assessed in cancer clinical trials, including tumor response, toxic effects and performance status (Seidman 1995).

Chemotherapy is a systemic treatment directed at rapidly growing cancer cells. The basis for cell death is generally targeted at the level of cell division. Therefore all normal cells that have a rapid turnover are also affected. Additionally, most chemotherapeutic agents have a narrow therapeutic index, which means that the difference between the effective dose and the toxic dose is extremely small.

Chemotherapy provided women with a sense of control over their lives and a feeling that they were doing something active to deal with the cancer. The patients identified that receiving chemotherapy helped them to deal with the sense of helplessness that accompanied the diagnosis of breast cancer (Levine 1988).

Most chemotherapy regimens are administered intravenously, some by continuous infusion over days or weeks, necessitating the insertion of a port and that the patient wear a continuous infusion pump. Frequent blood tests and counts need to be performed, so that needles are continuously assaulting the patient, which can be very distressing to some people.

Although more effective methods of controlling some of chemotherapy's side effects are available, it is not unusual for a patient to undergo periods of anxiety, depression and nausea in anticipation of each course of treatment (Knapp 1995).

The treatment of metastatic breast cancer involves the sequential selection and delivery of hormonal therapies and cytotoxic chemotherapies. The available therapies for metastatic breast cancer are rarely curative, although high rates of response and modest prolongation of survival may be achieved in association with varying degrees of treatment-related toxicity. Therefore, the selection of appropriate therapy requires a reasoned consideration of the likelihood of benefit from therapy balanced with the impact of therapy on the patient's quality of life. Several instruments have been developed to measure quality of life in cancer patients, but none has been universally accepted, and they require time and resources to administer. Few randomized trials have incorporated quality of life assessments. Thus the clinicians must balance the antitumor activity, performance status and the usual toxicity measures, as surrogates for quality of life associated with each specific therapy. Studies have confirmed the clinical impression that antitumor activity of treatment generally correlates with quality of life outcome (Carlson 1998).

A number of cytotoxic agents have activity in the treatment of metastatic breast cancer. Although the active single agents differ substantially in their toxicity profiles, the dose-limiting toxicity is usually myelosuppression. Recently, several agents with substantial activity in breast cancer have become available, including the taxanes (paclitaxel and docetaxel), vinorelbine and gemcytabine (Carlson 1998). The benefit of these agents needs to be carefully balanced with the quality of life that patients experience while receiving these treatments.

For many cancer patients, chemotherapy, radiation or surgery causes a drop in estrogen production that leads to premature menopause. The symptoms and consequences of menopause can be disturbing: hot flashes, vaginal dryness, diminished bladder capacity, insomnia, as well as an increased risk for osteoporosis and heart disease (Runowicz 1995). Estrogen replacement for patients with hormone-related cancers is contra-indicated and therefore the options to try and control the symptoms of menopause are limited. This may further impair the patient's quality of life. Additionally menopause can lead to decreased sexual desire, mood swings, irritability and an inability to concentrate. Hot flashes are usually worse at night, resulting in loss of sleep, which in turn leads to irritability and moodiness during the day.

Although continuous therapy significantly prolongs the time to disease progression, it does not result in improved survival. Coates et al. (1987) demonstrated that continuous therapy resulted in improved quality of life compared with intermittent therapy.

1.9.3 RADIOTHERAPY

The patient referred for radiotherapy for the treatment of advanced disease or following surgical treatment for breast primary, encounters a complex of psychological and social problems. First, it is still quite common for “radium treatment” to be stigmatized. Any mention of damaged nuclear plants or disasters involving radiation is, usually accompanied by information explaining the potential dangers of the invisible rays. Patients get scared, but since patients receiving irradiation instead of extensive surgery, usually chose to do so, they are inhibited from discussing their fears. One of these irrational fears is that the patient herself may become radioactive and a danger to her family. Other popular myths are that radiotherapy to any part of the body can make the hair fall out, that it is painful and that it inevitably burns the skin. With modern techniques, radiation burns are usually avoided, although women with sensitive skin may expect transient erythema and desquamation. Radiotherapy can cause exhaustion, nausea and vomiting, and much of the distress experienced by patients may be linked to this (Ray 1985).

It was demonstrated by Parsons and coworkers (1961) that 75 percent of patients exposed to sham radiotherapy developed symptoms of nausea and fatigue, and this suggests that many symptoms may be a function of anxiety produced by the procedure and patients' expectations of its effects.

Radiotherapy is employed either curatively or palliatively. It is a local or regional treatment and side effects depend on the body-site involved. Commonly fatigue and local skin reactions occur in the short term. Chest radiation may produce cardiac irregularities. Whole brain radiation causes hair loss and decreased mental faculty. Long-term sequelae such as incontinence, fibrosis of critical organs like the lung or even pain and skin burns can add to the patient's distress.

“When my radiation treatments began, I was fitted with a body mold to immobilize me during therapy and my chest was tattooed with little black dots so that the nozzle of the radiation machine lined up exactly with my tumor. The walls of the room were two feet thick and lined with lead. And although the technicians were very nice, explaining every adjustment they made, I was terrified. From the moment they turned to close the vaultlike doors behind them, it was all I could do not to run behind them, screaming” (Runowicz 1995). Runowicz is a gynaecological oncologist.

There is the social inconvenience of radiotherapy, which involves long distances to travel, particularly if the patient lives in a rural area, since radiotherapy centers are usually situated in large towns. As treatment is often five days a week for up to six weeks, then the additional expense and fatigue associated with travel, particularly among older women, presents a genuine additional burden (Ray 1985). The alternative is hospitalization that could also be stressful to certain patients.

It is difficult to assess the impact of radiotherapy independent of the life threat following the diagnosis of cancer and the impact of a mastectomy. Forester and coworkers (1978) tried to evaluate psychiatric aspects of radiotherapy among 200 patients receiving radiotherapy for a variety of disorders. These patients were interviewed before, during and after treatment and assessed using the Schedule for Affective Disorders (SADS). Unfortunately they chose psychiatric patients as controls. The patients receiving radiotherapy had increased scores for depression and anxiety throughout treatment, but similar levels for anorexia, fatigue and insomnia as in the psychiatric control group were found. In addition the treated patients scored more frequently for social isolation. An interesting and unlooked for finding from this study was the type of radiotherapy machine influenced the grade of change in affective disorder. The patients treated on the linear accelerator seemed to adapt very well and scores for depression and anxiety returned to normal toward the end of treatment. In contrast, those patients treated on the betatron, a noisy and somewhat threatening piece of equipment, tended to fare worse.

Another relevant study is that of Margolis et al (1983). They interviewed patients who had chosen radiotherapy as an alternative to mastectomy and found that these patients seemed well adjusted and grateful for the treatment. Since the patients self-selected for this therapy,

they must be considered a biased sample and their reactions may be different from those of the general population.

It is likely that radiotherapy can have distressing effects, but that these are mostly of short-term duration (Ray 1985).

1.9.4 ENDOCRINE THERAPY

Endocrine therapy holds an important place in the treatment of breast cancer as it does for other hormone-sensitive cancers. The aim of endocrine therapy in breast cancer is to decrease or eliminate estrogen activity, as estrogen sustains the growth of hormone-dependant tumors. In premenopausal women this can be achieved by removal of the ovaries (surgically, radiotherapeutically or chemically), often in combination with antiestrogen therapy. In postmenopausal women, however, estrogen is produced predominantly by peripheral tissues rather than by the ovaries. Therefore, estrogen deprivation in this patient group is achieved by antagonism of estrogen at the receptor or reduction of estrogen levels by inhibition of aromatase (Lamb 1998).

In patients with advanced breast cancer endocrine therapy is considered to be the most important systemic treatment. The response rates to different endocrine treatment alternatives seem to be similar, but the drugs vary somewhat with respect to their side effect profiles.

The hormonal therapies have the quality of life advantages of limited and non-threatening acute toxicity, rare chronic toxicity, need for infrequent visits to health care providers, oral administration and, in appropriately selected patients, response and duration of response rates equivalent to those of the cytotoxic agents.

Tamoxifen is currently the treatment of choice for postmenopausal women with hormonally responsive breast cancer. It has a response rate of 76% in ER+ PR+ (hormone receptor positive) breast cancer and has very few side effects. Tamoxifen binds reversibly with the estrogen receptor, forming an inert complex that blocks estrogen-mediated protein synthesis. The toxicity is usually minimal but headaches and/or hot flashes sometimes

occur. Development of endometrial cancer and corneal changes has been found in long term users and needs to be monitored carefully.

For patients with hormone-dependent breast cancer, inhibition of estrogen production is an effective form of therapy. Aromatase is an enzyme that is responsible for the peripheral manufacture of estrogen from androgens and cholesterol. Aromatase inhibitors like aminoglutethimide, letrozole, anastrozole, formestane and vorozole inhibit peripheral aromatase and suppress estrogen levels in postmenopausal women. Second-line treatment options, for locally advanced or metastatic breast cancer, include megestrol and anastrozole, with aminoglutethimide available as a third-line agent (Lamb 1998).

In the only trial to report quality of life (Dombernowsky 1998), no major differences were observed between patients receiving letrozole or megestrol. Letrozole was found to be significantly superior to megestrol with respect to overall survival and consistently achieved better response rates than megestrol.

1.9.5 PALLIATIVE CARE

For patients with metastatic disease, the aim of treatment is not curative but palliative. The most important endpoint is therefore a good quality of life.

The aim of the palliative treatment of cancer is to control the disease in order to make life as active and as symptomless for as long as possible with the least adverse effects of treatment. There is no intention to eradicate the cancer and so it has been accepted that the patient's life will almost certainly be severely shortened as a result of the disease. Communication is therefore a particularly sensitive issue and requires much skill and compassion and understanding (Rubens 1993).

Important aspects of communication:

- Adequate, frequent and sensitive communication with the patient.
- There has to be precise and frequent communication between different members of the medical team.

- Communication with the patient's family, keeping in mind that patients can become isolated under these circumstances.

General principles of communication (Rubens 1993):

- Honesty at all times, but this does not mean unsolicited candour.
- Attention must be paid to signals from the patients which indicate that there is a limit to how much information they wish to receive.
- For a satisfactory basis for communication there must at least be:
 - An explanation of the disease status.
 - What the aims of treatment are and its likely side-effects.
 - Emphasis on quality of life.
 - Fostering of realistic hope.

Within the various approaches to palliative care, the most contentious is the use of cytotoxic drugs. Rubens (1993) devised a scoring system to attempt to assess what the utility of treatment has been. Points are awarded for symptom relief, objective response, improved activity status and the reversal of immediately life-threatening disease. Points are deducted for physical toxicity, psychological morbidity and social disruption. There must be a positive score for treatment to be worthwhile. Findings were that: for first line chemotherapy for advanced breast cancer, it was deemed to be worthwhile in 34% of patients, for second line treatment in only 11%; third and fourth line treatments were not worthwhile in any patient. A highly significant correlation has been found between these criteria and standard objective response criteria.

1.10 SYMPTOM DISTRESS

Symptom distress can be defined as the degree of discomfort reported by a patient in relation to their perception of the symptoms being experienced (McCorkle 1987).

Alternatively it can be seen as the physical or mental anguish or suffering that results from the experience of symptom occurrence and/or the perception of feeling states (Rhodes 1987). The reasons for assessing symptom distress include the identification of patients' needs and problems, and determining the effectiveness of different modalities of treatment.

Symptom distress refers to the meaning that illness holds for an individual (Kleinman 1978). Symptom distress alters the cancer experience and the individual's quality of life. Quality of life is often grouped in four domains: physical, functional, emotional and social well being. Factors that influence symptom distress are: disease state, gender, age, marital status, sense of coherence (an enduring and dynamic feeling of confidence), the type of treatment and the availability of home care nursing (McClement 1997). Additionally socioeconomic status, race, culture, role, education, health, knowledge, values and past experience may influence symptom distress. Considering the negative effect symptom distress can have on the patient and family, the management of symptom distress should be a priority of health professionals (Northouse 1995).

Symptom distress appears to be a significant prognostic indicator even when other psychosocial variables are considered (Germino 1987). High symptom distress scores can therefore alert clinicians to those patients who have limited time in which to deal with life completion issues (Degner 1995). This finding is also important because it may help to identify whether or not interventions do in fact improve patients' quality of life and/or survival.

1.11 EMOTIONAL PROBLEMS

The diagnosis and treatment of breast cancer are considered critical life-events leading commonly to depression, anxiety, problems in body image and self-concept and consequently social isolation (Fourie 1996).

The diagnosis of a chronic disease not only produces the need for behavior change; it also evokes many emotional changes that may require attention. The impact of chronic illness on the individual can be pervasive, affecting physical and emotional well-being work, sex and family life. Chronic disease can produce a variety of adverse outcomes, including pain and discomfort, fear and uncertainty about the future and a variety of adverse emotional effects, such as anxiety and depression. When left untreated, the emotional distress associated with chronic illness represents a substantial reduction in patients' quality of life and may further interfere with physical rehabilitation and return to work, leisure and social activities. Researchers are documenting the high prevalence of emotional distress in

chronically ill patients and are designing interventions to prevent or reduce this distress (Taylor 1990).

Of particular concern in this regard is the patient's premorbid personality and any chronic history of depression or anxiety disorders prior to the onset of chronic illness. Those with prior histories of such disorders have a higher risk for exacerbated emotional responses to chronic illness, because chronic illness becomes an additional stressful event for them. Their psychological resources may leave them unprepared and their coping skills may be insufficient to deal with these adverse effects (Taylor 1990).

Practicing clinical psychologists have extended their concern beyond the treatment of specifically psychiatric disorders, to include the psychological care of people experiencing distress through illness or injury. Traditionally these patients have tended to fall through the net, unless their distress is so great that it assumes the proportion of a psychiatric disorder that can then be treated in its own right. Because the physical disorder is the primary one, its existence has detracted from the salience of the very real emotional disturbance to which it can give rise. Moreover, emotional reactions in this setting, being the norm, seem to have been regarded as not meriting special attention and care. This situation is changing. Within general medicine, there is now renewed emphasis on the care of the whole patient and not just the disease (Ray 1985).

Some degree of depression following treatment is normal for all cancer survivors. Studies have shown that while major mental illness is uncommon, cancer survivors do have an increased incidence of emotional problems in coping with the trauma of their disease. Cancer survivors need time to mourn their life before cancer and to grieve over the fact that after cancer things are never quite the same. Having cancer changes a person in many ways. Each patient must work through her feelings of sadness and loneliness, isolation and fear. The mind can sometimes take much longer to recover from cancer than the body (Runowicz 1995).

What helps patients keep emotional distress under control may be very individualized. What patients can do to make chemotherapy less difficult may be quite similar for all patients, while what they can do that makes it less distressing may vary considerably from

patients to patient. For example, some patients reported that it was a great relief to talk to their husbands or friends about things that were upsetting them. In other patients, sharing sadness or worries with other people would only make them feel out of control. For them, it worked much better to conceal their upset from other people, and to keep busy with work so they didn't have too much time to think (Ringler 1983).

Most cancer patients, with the help of various coping strategies, manage to come to terms with their illness in ways that work reasonably well for them. Some, however, are unable to achieve a satisfactory emotional adjustment. Instead they develop reactions which impair their relationships with other people and prevent them from obtaining optimum benefit from anticancer treatments (Barracough 1994).

Massie (1989) found that not all of the emotional distress found in cancer patients could be labeled as "psychiatric illness". Additionally, several of the common problems, like excessive anger or denial, do not fit with formal classification systems for psychiatric disorders. Nevertheless, psychiatric disorders occur more frequently in cancer patients than in the general population, and it is important to recognize them, as there may be specific treatment available.

The findings of several large-scale surveys have reported on the frequency of psychiatric disorder in large populations of cancer patients. The findings can be roughly summarised as follows:

- No psychiatric disorder 50%
- Adjustment reaction 30%
- Formal psychiatric diagnosis 20%

"Adjustment reactions" can be found in about one third of patients and usually take the form of anxiety and/or depression. These reactions are not serious mental disorders and usually improve on their own accord over time. Anxiety and depression do produce significant extra suffering. Humane and well-organised general clinical care could often do much to minimise this distress. Depression and/or anxiety are also the most common forms of disorders that are

found in patients with a formal psychiatric diagnosis. It has been shown that the treatment of a patient's psychiatric illness often improves his physical condition as well.

Prevention of emotional problems (Massie 1989):

- Offer information about the illness and its treatment: "too little" information is a far more frequent complaint than "too much". Do not delay in passing on new information to the patient. Information given on one occasion is often forgotten or misinterpreted and may need to be repeated, or backed up with written material.
- Allow the patient to participate in treatment decisions, if they wish to do so.
- Let the patient express emotional distress, making it clear that it is perfectly normal to do so.
- Ongoing care from a few key doctors and nurses who will be there to monitor physical progress and emotional wellbeing throughout the course of the illness. The patient's own general practitioner should be one of these.

Research evidence shows that emotional problems among cancer patients often go unrecognised, unless they are specifically sought out, either through personal interviews or by means of screening questionnaires. Ideally such screening should be repeated at regular intervals for each patient because emotional problems can start at any time during the illness. Putting this apparently simple recommendation into practise requires consistent effort on behalf of the staff. Whether or not a formal screening programme is in place, it is important that all patients are asked from time to time how they are coping with the emotional side of their illness. They should also be given frequent opportunities to discuss their current concerns.

1.11.1 DEPRESSION

Depression is among the most frequent of emotional problems in cancer patients and it important to recognise this because it can often be treated successfully. Surveys show that up to 50% of patients at any one time report some depressive symptoms. Of these, 10 to 20 % have clinical depression. Depression is estimated to be four times as frequent in patients with

cancer than in the population as a whole. Depression in cancer patients can be difficult to diagnose and can be easily missed (Massie 1989b).

This high rate of depression may be partially accounted for by either a premorbid propensity for depression, neurological damage or reactions to the stressors associated with chronic illness. Depression is important not only because of the distress that it produces, but also because it may have an impact on long-term rehabilitation and recovery. Depression has also been linked to suicide in the chronically ill (Taylor 1990).

Because depression can continue in certain patients after physical recovery, it is important that the patient and the physician be aware of it. It has been shown that there is a significant tendency by physicians to miss the diagnosis of depression in their patients, when compared to the patients' own assessment of their condition (Fourie 1996).

Assessment of depression in the chronically ill can be problematic. First, many of the physical signs of depression, such as fatigue, sleeplessness, or weight loss, may also be symptoms of the disease or a side effect of its treatment. If depressive symptoms are attributed to the illness itself, depression may be masked and infrequently diagnosed. These problems are exacerbated in illnesses that can affect brain function such as cancer (Taylor 1990).

Mental symptoms of depression

Low mood with diurnal variation.

Tearfulness.

Guilt.

Feeling a burden to other people.

Loss of interest.

Inability to feel pleasure (anhedonia).

Poor concentration.

Agitation or retardation.

Irritability.

Social withdrawal & suicidal thoughts.

Physical symptoms of depression

Weight loss.

Anorexia.

Insomnia (with early morning waking).

Tiredness.

Malaise.

Pain.

Seven items that identify severe depression have been described (Taylor 1990):

- | | |
|--------------------------|----------------------|
| Indecision. | Suicidal thoughts. |
| Sense of failure. | Crying. |
| Dissatisfaction. | Sense of punishment. |
| Loss of social interest. | |

Depressed patients may consider themselves too worthless to merit help and do not complain about the symptoms of either the depression or the cancer. Additionally depression in the chronically ill often goes untreated because many people believe that one is supposed to be depressed after a diagnosis of chronic illness. Clearly guidelines must be developed concerning how much depression can be expected after diagnosis of a life-threatening illness and the point at which depression becomes severe enough to warrant intervention (Taylor 1990).

Physicians and clinicians should ask about family history of depression and prior episodes of depression in their patients. Screening instruments to identify depression can also be used. Although disease severity reliably accounts for part of the variance, it does not fully account for depression in chronically ill patients. Studies that control for disease severity have found that other negative life events, social stress and lack of social support are associated with depression in chronically ill patients. It is also possible that depression reduces the quality of social support during a prolonged illness (Taylor 1990).

Unlike anxiety, which appears to be episodic, depression can be a long-term reaction to chronic illness. For many illnesses, depression lasts a year or more following surgery or the diagnosis of the illness. The evaluation for these potential problems should be a standard part of care. A variety of interventions, from informal communication with a health care professional, to antidepressant drugs, have been proposed to alleviate emotional distress in chronically ill patients (Taylor 1990).

Biological complications of cancer such as hypercalcaemia and cerebral metastases, as well as steroids and chemotherapy, may lead to depression in vulnerable people. Additionally hypothyroidism and other physical illnesses can mimic depression (Massie 1989b).

1.11.2 ANXIETY

Chronically ill patients often experience anxiety and heightened levels of anxiety can interfere with physical and psychosocial functioning. For example anxiety is associated with poor functioning following radiotherapy. Some of the documented anxiety may be a premorbid propensity for anxiety, but there are also clear specific sources of anxiety during rehabilitation and treatment (Taylor 1990).

The following sources cause high anxiety during rehabilitation and treatment:

- | | |
|-------------------------|-------------------------------------|
| A diagnosis of cancer. | Waiting for test results. |
| Invasive procedures. | The side effects of treatment. |
| Life-style alterations. | Dependency on health professionals. |
| Fear of recurrence. | |

A certain degree of anxiety among patients with cancer is understandable. When anxiety develops for no apparent reason or persists in a disabling form long after the initial cause has passed, an anxiety disorder may be diagnosed. Some cancer patients remain disabled by anxiety about their illness even if they are doing well from a physical point of view. In someone with cancer, anxiety is often due to unexpressed fear of progressive disease and of death.

Mental symptoms of anxiety

- Worry.
- Irritability.
- Restlessness.
- Difficulty in falling asleep.
- Sleep disturbed by nightmares.

Physical symptoms of anxiety

- Breathlessness.
- Palpitations.
- Sweating.
- Headaches.
- A “lump in the throat”(that impedes swallowing).
- Nausea.
- Abdominal pain.
- Diarrhea.

High levels of anxiety are generally associated with coping mechanisms. A finding that has consistently been made for breast cancer patients is that they show strong coping mechanisms in relation to the effect that their illness has on them.

Another consequence of high anxiety levels is that it interferes with patients' understanding and assimilation of the information that the physician is trying to communicate to them. This can be especially problematic during the time when the diagnosis is being made.

While some cases of suicide among cancer patients may be understandable and justified, others represent the tragic culmination of distress which might have been relieved.

Once a woman has suffered through the rigors of treatment and faced the prospects of her own mortality, the fear of battling cancer again is almost too frightening to consider. Yet in the back of every cancer survivors' mind is the terrifying possibility that one day the disease will return. That's why many survivors tend to panic whenever some new bump or lump surfaces or they experience a small ache or pain. The risk of developing a second cancer is also higher for someone who has had cancer before (see Addenda 1, 2, 5 and 7).

No person can come through an experience as traumatic as cancer without changing. On the positive side, many patients actually come to see a beneficial side to their illness. The experience of cancer often leads many survivors to critically review their values and life's priorities. In confronting their own mortality through sickness and the hard-fought struggle for health, many women find they are better able to accept both themselves and the smaller glitches of life. It can be called "life rekindled" (Runowicz 1995).

Recent studies, however, indicated that although the diagnosis and treatment of breast cancer are emotionally traumatic events its effects are generally of limited duration. It seems as if the majority of patients recover well from this experience without serious long-term emotional impairment. There are indications that this adjustment takes place within the first three months after surgery (Fourie 1996).

1.11.3 ANGER

Besides depression and anxiety, breast cancer patients may also experience feelings of guilt and anger with associated aggression.

Anger, a typical reaction that is often found in conjunction with depression, is often directed at the physician who is held responsible by the patient for the loss of her breast and other unpleasant medical procedures like chemotherapy and radiotherapy. Some patients direct their anger at their spouses. But some breast cancer patients do not show any signs of anger or aggression because of the very strong denial of their condition (Fourie 1996).

Anger should be managed by listening to the patient's point of view, without responding in a defensive fashion, and, however ungrateful and unrewarding the patient may be, to try to offer consistent professional concern (Barraclough 1994).

1.11.4 GUILT

Feelings of guilt are a less common, but not an atypical emotional phenomenon for breast cancer patients. They regard the illness as a punishment for the sins of the past. Alternately feelings of guilt may result from misconceptions about cancer, for example that it is contagious or can be caused by a blow or an injury. Other possible reasons for feelings of guilt are anger towards medical personnel, jealousy of the good health of family members or her realisation that she has a greater dependency on them (Fourie 1996).

Others even feel guilty because they do not recover soon enough and are therefore disappointing those who are treating and caring for them. Feelings of guilt are also sometimes found in connection with anger and depression (Fourie 1996).

1.12 LOSS OF ROLE

“Overnight, survival became my one and only goal. I cancelled most of my commitments, as I simply wasn't sure I could deliver. Quite simply, the bottom had fallen out of my career. Getting through office hours took every ounce of energy I had left. No one expected me to be

at the office, but in order to heal myself I needed to feel some semblance of normalcy in my life (Runowicz 1995).”

Part of an individual’s concept of self is derived from the various roles he or she engages in, such as work. A great deal of personal gratification is obtained through the achievement, the social recognition and the social interactions provided at and by work. Any forced retirement due to illness severely threatens self-image, self-worth and self-respect, which can produce considerable psychological distress. On the other hand, employment is not always particularly satisfying for some people. Some jobs can be so stressful or time-consuming that they detract from life’s quality by intruding on other areas (Fallowfield 1990).

Multiple losses associated with the diagnosis of cancer often lead to loss of autonomy. Patients may lose their job, physical independence and social role. Older patients may have to give up their home. This enforced loss of role can often lead to boredom, with the resulting problems thereof.

When a person cannot cope with household duties and depends on others for the routine necessities of life such as shopping, cooking and cleaning, they may experience a fundamental role loss with a concomitant loss of self-esteem.

Role changes take place when the person with cancer is physically limited, so that the partner is forced to take over the patient’s previous role and responsibilities. A few patients complain that their partners make little or no allowance for their illness, and expect them to carry on as before (Barraclough 1994).

1.13 PAIN

One of the worst aspects of cancer pain is that it’s a constant reminder of the disease and of death. Many fear that the pain will become unbearable before death, and those of us involved in support networks have seen these fears proven true (Jacox 1994). Most generally, suffering can be defined as the state of severe distress associated with events that threaten the intactness of the person. The suffering of patients with terminal cancer can often be relieved by demonstrating that their pain truly can be controlled (Jacox 1994).

In 1982, Marcia Angell wrote “Few things a physician does are more important than relieving pain. Yet, treatment of pain in hospital patients is regularly and systematically inadequate.”

Personal control is undermined when cancer is diagnosed and is further reduced by ongoing pain, invasive or undignified procedures, treatment toxicities, hospitalisation and surgery. When pain reduces patients’ options to exercise control, it diminishes psychological well being and makes them feel helpless and vulnerable (Jacox 1994).

TABLE 1: EFFECT OF CANCER PAIN ON QUALITY OF LIFE (Ferrell 1991):

Physical

- Decreased functional capability.
- Diminished strength, endurance.
- Nausea, poor appetite.
- Poor or interrupted sleep.

Psychological

- Diminished leisure, enjoyment.
- Increased anxiety, fear.
- Depression, personal distress.
- Difficulty concentrating.
- Somatic preoccupation.
- Loss of control.

Social

- Diminished social relationships.
- Decreased sexual function, affection.
- Altered appearance.
- Increased caregiver burden.

Spiritual

- Increased suffering.
- Altered meaning.
- Reevaluation of religious beliefs.

Avoidance of pain is one of man's most basic drives and one of the primary reasons for seeking medical help. Chronic pain severely restricts a person's ability to function and enjoy life and poses considerable psychological, social and economic stresses. Pain is a very individual, subjective experience, ameliorated or enhanced by such things such as culture, conditioning, attention and emotional state. Chronic pain is often a diminishing, humiliating, even frightening experience for the patient and tends to supersede all other sensations. One of the most feared consequences of cancer is uncontrolled pain. The appearance of pain in a cancer patient usually indicates progression of disease, but it must be remembered that pain perception is very subjective. Pain can mask depression and can be the result of excessive anxiety (Fallowfield 1990).

Cancer is a major health problem, with one in every ten deaths globally attributable to cancer. In 1984 more than three and a half million people suffered from cancer pain daily (WHO 1986). However, only a fraction of cancer patients in pain, receive adequate treatment for their pain. The necessary technology exists to alleviate this health problem. It has been demonstrated that cancer pain can be controlled in over 85% of terminal cancer patients by the rational use of drugs. An "analgesic pain killing ladder", developed by the World Health Organisation, provides a clear plan of action for health care services (Stjernswärd 1986).

The WHO analgesic ladder:

Non-opioids	paracetamol and aspirin.
Mild opioids	codeine.
Strong opioids	morphine.

When a drug does not work, a stronger, rather than a different one is prescribed.

Drugs are given round the clock rather than as required.

Skevington (1998) assessed quality of life, using a new, multidimensional, multilingual, generic profile designed for cross-cultural use in health care, i.e. the WHOQOL. In this instrument, pain and discomfort is one of 29 areas of quality of life. These areas or facets are grouped into six domains. It was found that pain and discomfort made a significant impact on perceptions of general quality of life related to health. The presence of pain also affected perceptions of five of the six domains of quality of life. The only domain that was unaffected,

was the domain of spirituality, religion and personal beliefs. When quality of life is assessed, negative feelings are more closely associated with reports of pain and discomfort than any other facet.

Quality of life surrounding pain and discomfort consists of seven facets (Skevington 1998):

The availability of social care	Mobility
Activities of daily living	Positive mood
Sleep	Dependence on medication
Spirituality, religion and personal beliefs	

These are the criteria against which the success of pain treatments may be evaluated. As predicted, those who were pain-free had a significantly better quality of life than those who were in pain. A longer duration of pain is associated with increasingly poorer quality of life. Intense affective pain is particularly detrimental to a good quality of life (Skevington 1998).

Pain control merits high priority for two reasons. First, unrelieved pain causes unnecessary suffering. Because pain diminishes activity, appetite and sleep, it can further weaken already debilitated patients. The psychological effect of cancer pain can be devastating. Patients with cancer often lose hope when pain emerges, believing that pain heralds the inexorable progress of a feared, destructive and fatal disease. Chronic unrelieved pain can lead patients to reject active treatment programs, and when their pain is severe or they are depressed, to consider or commit suicide. Besides mitigating suffering, pain control is important because, even when the underlying disease process is stable, uncontrolled pain prevents patients from working productively, enjoying recreation, or taking pleasure in their usual role in the family and society. Pain control therefore merits a high priority not only for those with advanced disease, but also for the patient whose condition is stable and whose life expectancy is long (Jacox 1994).

1.14 FATIGUE

After treatment it's common to feel exhausted and spent. No one comes through an ordeal as traumatic as cancer and jumps right back into life. Every survivor experiences feelings of uncertainty and depression about the future. Although the exact cause for chronic fatigue

hasn't been elucidated, some believe it is brought about by the additional energy the body must expend on repairing injured cells. Another possibility is that bone marrow suppression is responsible (Runowicz 1995).

Recent multidimensional conceptualisations of fatigue in cancer patients suggest that fatigue is a subjective experience with significant physical (e.g. weakness), behavioural (e.g. alterations in sleep patterns and activity level), cognitive and affective (e.g. mood disturbance) components (Piper 1989).

Although fatigue is the most common symptom reported by cancer patients and has serious adverse effects on quality of life, it remains poorly understood. It is a subjective sensation often described by patients as a feeling of tiredness, lethargy or malaise. Cancer-related fatigue also has been characterised as asthenia (lack of strength). Cancer-related fatigue is probably multifactorial, with physical and psychological components. Fatigue is often distressing and can have serious adverse effects on quality of life. Fatigue may affect decisions to continue treatment or the ability of a patient to tolerate various forms of therapy. It can also significantly interfere with patient self-care abilities (Volgelzang 1997).

A survey was designed to characterise the epidemiology of cancer-related fatigue from the perspectives of the patient, primary caregiver and oncologist. More than three quarters of patients (78%) experienced fatigue (defined as a feeling of debilitating tiredness or loss of energy) during the course of their disease and treatment. Thirty-two percent experienced fatigue daily and 32% reported that fatigue significantly affected their daily routines. Caregivers reported observing fatigue in 86% of the index patients and oncologists perceived that 76% of their patients experienced fatigue. Although oncologists believed that pain adversely affected their patients to a greater degree than fatigue, patients felt that fatigue adversely affected their daily lives more than pain. Most oncologists believed fatigue is overlooked or undertreated and most patients considered fatigue a symptom to be endured. Fifty percent of patients did not discuss treatment options with their oncologists and only 27% reported that their oncologists recommended any treatment for fatigue. When used, treatments for fatigue were generally perceived by patients and caregivers to be successful. These data confirm the high prevalence and adverse impact of cancer-related fatigue, although it is seldom discussed and infrequently treated. For patients and oncologists, improving the quality

of life of cancer patients requires a heightened awareness of fatigue, a better understanding of its impact and improved communication and familiarity with interventions that can reduce its debilitating effects (Volgelzang 1997).

Uncontrolled studies have reported that fatigue is a common symptom among patients with advanced cancer. It is also a frequent complaint among the general population. The aim of the study of Stone and co-workers (1999) was to determine the prevalence of fatigue among palliative care inpatients in comparison with a control group of age and sex-matched volunteers without cancer. In addition the correlates of fatigue were investigated. The prevalence of "severe subjective fatigue" (defined as fatigue greater than that experienced by 95% of the control group) was found to be 75%. Patients were malnourished, had diminished muscle function, and were suffering from a number of physical and mental symptoms. The severity of fatigue was unrelated to age, sex, diagnosis, presence or site of metastases, anaemia, dose of opioid or steroid, any of the hematological or biochemical indices (except urea), nutritional status, voluntary muscle function or mood. A multivariate analysis found that fatigue severity was significantly associated with pain and dyspnoea scores in the patients and with the symptoms of anxiety and depression in the controls. It was concluded that subjective fatigue is both prevalent and severe among patients with advanced cancer. The causes of this symptom remain obscure (Stone 1999).

Studies of on-treatment fatigue in cancer patients have shown that fatigue is often experienced during and shortly following cancer treatment. Information about off-treatment fatigue in cancer patients is much less common. Andrykowski (1998) examined the extent of after-treatment fatigue following treatment for breast cancer. Women with breast cancer and age-matched women with benign breast problems, completed a set of fatigue questionnaires at an initial assessment (28 months post treatment) and a 4-month follow-up assessment. The breast cancer group reported more fatigue, more weakness and less vitality relative to the benign breast problem group at both assessments. No relationship was found in the breast cancer group between fatigue and extent of treatment or time since treatment completion. Elucidation of the psychobiological processes underlying this symptom and development of clinical management strategies remain challenging.