Chapter II

REVIEW OF LITERATURE
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The word cancer refers to a group of diseases that has struck fear in people’s hearts for centuries. Its fatal outcome, absence of known causes or cures, and association with pain and disfigurement made it particularly frightening.

Physicians regarded the diagnosis too painful to reveal to the patient and conspired, often too unsuccessfully, with the family to create the illusion of a lesser illness. The patient often feels especially isolated as the family members and the physician shared the truth of the diagnosis while maintaining the charade of a minor illness with the patient. In *The Death of Ivan Ilyich*, Tolstoy provides a poignant literary example of how Ivan Ilych recognised his fatal disease while those around him maintained a pretense that he was just severely ill, except his devoted servant who comforted him by his honest acknowledgment of the condition.

Things changed as radiation and chemotherapy began to cure several neoplasms of children and young adults. Clinicians began to experience that candid and truthful communication enhanced trust in the physician. In addition to these, the concept and practice of terminal care underwent reexamination with the European hospice movement and pioneering works of Elisabeth Kubler-Ross. Yet cancer is still used as a metaphor for an insidious, destructive force in society.

From the existential point of view, the course of the illness of cancer is a major transition, a major life event for a person. Bain (1978) posited that whether a transition will lead to personal growth or maladaptive coping depends on the magnitude and intensity of the transition, the amount of role changes, and institutional and social net works.

Although the chronic and terminal phases of illness are different in many respects, both are very powerful in their impacts on patients, families, and caregivers. It has become increasingly apparent that chronic illness has a major impact on all areas of patients’ lives. In addition to the symptomatology associated with the effects of illness and its treatments, the majority of cancer patients experience emotional difficulties including anxiety, endure difficulties in living, fear about the course of their
illness and impending death. Dramatic role shifts are the norm, rather than exception. Sexual relationships suffer. Conflicts around child-rearing are not uncommon. Financial difficulties are prominent. (Kopel et al., 1988).

Psychosocial factors have been studied from various perspectives to understand their bearing on the treatment and survival in cancer. The results have not been too conclusive. Cody et al. (1994) conducted a large-scale study investigating the psychosocial aspects of lung cancer. A sample of newly diagnosed patients with inoperable lung cancer were entered into the study. They found that there was no significant relationship between psychiatric disorders and survival. They also found no association between locus of control or the degree of social support and outcome. There was no significant relationship between attitudes of denial, stoic acceptance, and helplessness/hopelessness and survival. Fighting spirit was associated with a better quality of life. The results did not support the hypothesis that psychosocial factors play an important role in determining survival in patients with advanced lung cancer.

On the other hand, Levy et al. (1985) found that the three psychosocial variables of being passive and not complaining, reporting inadequate support from the environment, and reporting symptoms of fatigue, accounted substantially for the variance in the activity of natural killer cells; better the adjustment to the illness, poorer the response of the immune system.

The mediating effects of the various psychosocial factors on each other was also a point of interest in research. Guillory (1993) tested a theoretical model that postulated cancer survivorship as a function of age, marital status, life satisfaction (quality of life, social support, self concept and spirituality) and physiological status (immune status, stage of disease and treatment modality) in a population of disadvantaged African American women who had previously been diagnosed with breast cancer. It was found that social support rather than quality of life provided the majority of variance in the life satisfaction score. Uncertainty over the future was found to be the major factor of survivorship and social support was an enhancer of mastery over cancer. Spirituality was found to be positively associated with immunoglobulin levels but the magnitude of the relationship did not reach the accepted significance levels.
Klemm (1994) explored the relationship of daily hassles, demands of illness, and social support to the psychosocial adjustment of people with newly diagnosed, primary lung cancer. It was found that the participants report relatively high social support, low hassles, moderately low demand of illness, and positive adjustment.

Intervening variables in psychosocial factors were also explored by researchers. Aymanns et al. (1995) studied the interrelationship between the coping behavior of cancer patients and perceived amount and adequacy of family support, as well as how these predict psychosocial adjustment to cancer. The results of their study suggest that cognitive strategies of coping may be more effective in 'mobilizing' family support than behavioral strategies. Moreover, the perceived adequacy of various support modes prove to be influenced by cognitive coping preferences independent of perceived amounts of support. They also identified a particular coping - support pattern as 'highly risky'. This pattern is characterized by generalized support deficits, strong tendencies towards rumination, and weak tendencies towards minimizing disease-related threat.

Ell et al. (1992) examined the relationship between social relationships and social support and survival following a first diagnosis of breast, colorectal, or lung cancer in 294 cancer patients. Results suggest that the emotional support provided by primary network members was a critical factor explaining the relationship between the indicators of social relationship and mortality. In the past, patients went to the doctor with a sense of doom at the mention of cancer, along with a sense of shame and the associated desire for secrecy.

Acute psychological distress is to be expected as a patient confronts the implications of cancer: possible death, pain, dependence on others, disability, disfiguring changes in the body, and loss of function, all of which endanger his or her relationship to others. The initial crisis is just the first of many, each requiring resiliency and rapid adaptation. Most patients cope adequately, keeping distress in a manageable range; some do not. To treat and prevent pathologic reactions, it is important to understand their causes, which are of three kinds: societal, biomedical, and patient-related (personal and interpersonal) Lederberg and Massie (1993).
Societal factors play an immediate and important role in a patient’s psychological adaptation to cancer but are seldom obvious to the patient.

Recent studies have shown a major effect of social class on cancer incidence and outcomes. Lifestyle and behaviors, social environment, personality and coping style, life events and emotional state - all do have significant impact on the etiology of cancer and its treatment. The impact of 'mind on body' concept has resulted in behavioral and lifestyle interventions in cancer care. The best traditional and medical treatment aimed to better the on going quality of life. But the demands of technology have elbowed aside the time - and labor - intensive psychosocial interventions (Ledersbeg and Massie 1993).

Nelson et al (1994) identified four subtypes of psychosocial adjustment in a sample of 122 breast cancer patients who had completed the Psychosocial Adjustment to Illness Scale. Three of the subtypes derived reported normal affect levels but different patterns of relative strengths and dysfunction, while the fourth subtype appeared to be highly distressed and globally maladjusted. The authors concluded that even non-emotionally distressed patients can have very different profiles of adjustment and may benefit from individually tailored psychosocial intervention.

The divergence of view points and conclusions in the research on the psychosocial factors is obvious. In this chapter, an effort is made to review the relevant literature on the variable explored in this study. It has been organized under the major variables such as Coping, Death Anxiety, Social Support, and Family Burden.

Coping

The diagnosis and treatment of cancer calls for the utmost in coping in a person. Because medicine has increased the effectiveness of its treatments, cancer patients are living longer, but are having to cope with the problems of chronic illness from which they will not recover (Kopel et al, 1988).

Much had been written in regard to the psychosocial dynamics and processes involved in those individuals coping with the crisis of terminal diseases like cancer including the various emotional responses and behaviors exhibited by patients and their
families such as shock, denial, rage, depression, fear, and confusion (Silverberg, 1988). Individuals use various styles to cope with the disease and its treatment. Studies have been done in the west to identify these styles and the effectiveness of each. Greer et al (1979) reported four categories of mental adjustment to breast cancer which had bearing upon the length of survival, fighting spirit, denial, stoic acceptance, and helplessness/hopelessness. They found that survival was more common among patients who reacted with denial or a fighting spirit than in patients who exhibited stoic acceptance or helplessness/hopelessness.

Later the Faith Courtauld Research Unit using factor analytic procedures on cognitive, behavioral, and psychological data identified four broad coping styles based on levels of anxiety, depression, health, locus of control, and behavioural coping responses. It was found that patients with an anxious/depressed style of coping manifested high levels of anxiety and depression and a limited use of cognitive coping. Denial was a second coping style in which patients blocked out feelings associated with cancer displaying little emotional distress and avoiding strategic coping. A third style - confrontational coping - was identified in patients who believe in their personal ability to control their health. They were found to be flexible and resourceful, displaying little anxiety or depression, engaging in palliative and confrontational coping. A fatalistic outlook, believing “what will be, will be”, is the hallmark of the fourth coping style. Those who had this coping style displayed no belief in having personal control over their health, or significant anxiety, or depression. These four coping styles fit into two broad categories described in the literature as problem-focused coping and emotion-focused coping (Lazarus and Folkman, 1984). The problem focused coping involves efforts made to manage or alter the problem that is causing the distress and the emotion-focused coping attempts to regulate emotional responses to problem that is appraised as there is only limited possibilities perceived for environmental change. Most patients use a combination of both these methods (Royak-Schaler, 1991).

Thoits (1986) has identified perception focused coping in addition to the problem-focused and the emotion-focused styles. Kotler et al (1994) describes yet another coping style with stress that has been observed in cancer patients and in highly
dependent insecurely attached individuals. This coping style includes the suppression of negative emotions and avoidance of support seeking. It has also been suggested that this pattern of response is potentially dysfunctional as it tends to perpetuate distress and may increase vulnerability to a broad range of illnesses.

Dunkel et al (1992) analyzed data from 603 cancer patients and identified five patterns of coping: seeking or using social support, focusing on the positive, distancing, cognitive-escape avoidance, and behavioural escape-avoidance. Coping through social support, focusing on the positive, and distancing were associated with less emotional distress; whereas use of cognitive and behavioural escape-avoidance was associated with more emotional distress.

Coping mechanisms employed by the patients and their relatives may either enhance the therapeutic process positively or adversely affect the outcome (Spinetta, 1984).

For example, long term survival has been correlated with the external expression of negative emotions towards one’s illness and one’s treating physicians and short term survival has been correlated with suppression and denial of psychological distress (Bacon et al, 1952).

Breast cancer patients in Timko and Janoff-Bulman’s study (1985) who believed in their ability to control breast cancer and attributed it to their own behavior (improper diet, taking birth control pills, or an injury to the breast) were more likely to believe they would avoid a recurrence. These women experienced better psychological adjustment than did those who attributed their breast cancer to their personality or to other people, factors over which they had limited control. Improved adjustment and well-being was noted particularly for women who coped with their disease through increasing exercise and leisure activities. Increasing these activities is also likely to improve a woman’s sense of control over her health (Taylor et al, 1985).

Watson et al (1991) studied the relationships among emotional control, adjustment to cancer and depression and anxiety in breast cancer patients concluded that a highly significant association exists between scores for the tendency to control emotional reaction and a fatalistic attitude towards cancer. A significant association was also observed between anger control and a helpless attitude.
Carver et al (1993) found that optimism related inversely to distress. Acceptance, positive reframing, and use of religion were the most common coping reactions, denial and behavioral disengagement were the least common reaction. Acceptance and the use of humour prospectively predicted lower distress; denial and disengagement predicted more distress.

Evans et al (1993) studied the relationship among coping responses, social support, personality factors, and psychological well-being in 40 adult Leukemia patients. They found that significant association between psychological well-being and Endurance, Affiliation, Cognitive structure, Autonomy, and Nurturance. The findings were related to fighting spirit and confronting coping style, concepts associated with well-being and longevity in cancer patients.

O’Donnell (1994) studied the relationship between psychological responses to the diagnosis, emotional suppression, adjustment to illness, neuroimmunological measures and disease recurrence within 5 years of patients with early breast cancer attending radiotherapy. It was concluded that in this group of early breast cancer patients, suppression of anger was a strong predictor of disease remission. The evidence that external locus of control was associated with ‘poor adjustment’ and both variables acted independently of suppression of anger to reduce progression was considered to require replication.

Coping, psychosocial well-being, situation-specific anxiety and cancer-related worry were assessed in 197 consecutive cancer patients attending follow-up visits by Lampic et al (1994). High levels of coping styles ‘anxious preoccupation’ and ‘helplessness/hopelessness’ were associated with low levels of psychosocial well-being, more specific anxiety and more cancer related worry. High levels of ‘fighting spirit’ and ‘fatalistic’ were found to be associated with high psychosocial well-being and, for ‘fighting spirit’ also with less cancer-related worry.

A person with cancer has in addition to the psychological trauma a number of physical symptoms all of which the patient has to cope with even though medical help is available. Some of these may be due to cancer itself while others may be the side effects of the various types of treatment. He/she may have anemia, bleeding due to thrombocytopenia, constipation, diarrhea, difficulty in swallowing, dry mouth, fatigue,
hair loss, infections, itchy skin, mouth and throat ulcers, nausea and vomiting, pain, respiratory problems, skin reactions, taste alterations, urinary tract problems - to mention a few (Yasko and Greene, 1987). Of all these, pain is the most common and most severely distressing symptom experienced by cancer patients and their family caregivers. An important aspect of coping with cancer pain is the ability to make meaning of this experience (Ferrell, 1994).

Religion also has been found to have an effect in the coping style of the individual. Jenkins et al (1995) concluded that religion may facilitate coping in some patients and impede it in others.

The present study makes an effort to explore into the various coping strategies and behaviours of the patients with cancer and to understand the associations these might have with the other variables under study. Coping in this study is assessed using a checklist of items which are considered coping behaviors and strategies. They include overt activities that the person engages himself or herself in, cognitive strategies acquired by the individual, and the various techniques that one uses to make one’s illness experience more bearable.

An effort is also made to analyze the influence of other factors on the person’s coping and the association between coping and the other variables.

**Quality of Life**

Although most of us intuitively understand what the phrase ‘quality of life’ connotes, it has been exceedingly difficult for social scientists, health service researchers, and clinicians to define it precisely. A wide range of variables are used as measures of quality of life - from physiologic indicators such as weight loss to standardized psychological measures of emotional distress (Hollandsworth, 1988).

Quality of life refers to those aspects of life and human function considered essential for living fully (Mor et al, 1994). Definitions proposed by two research groups are 1) quality of life as the subjective evaluation of life as a whole and 2) quality of life as patients’ appraisal of and satisfaction with their current levels of functioning compared to what they perceive to be possible or ideal (Cella, 1993).
The multidimensional aspects of the quality of life construct adapted from Tchekmedyian NS, Hickman M, Siau J, and Aisner J. are as follows.

Quality of life for cancer patients received impetus in the 1970s as interest in psychosocial care of cancer patients was taken up by the disciplines of oncology, social work, psychiatry, psychology, and nursing. There is increased opinion about cancer treatment, increasing number of cancer survivors writing and speaking openly about their experiences, trend towards greater knowledge and participation of patients in treatment decision, increased acceptance of and participation of mental health
disciplines in cancer care and the role of psychological and behavioural factors in cancer prevention - all of which have lead to the enhancement of quality of life of cancer patients. Any therapy in cancer patients should be evaluated with tools that measure not only tumor response and survival, but quality of life as well (Donovan et al., 1989).

Patients and physicians have to expand their vision of outcome measures to include quality of life variables for several reasons. In 1977, the first quality of life measurement in clinical group in US was undertaken by Holland and the Psychiatry Committee of the Cancer and Leukemia group (Holland and Zittom, 1977). Since then, patients and physicians have had to expand their vision of outcome measures to include quality of life variables for several reasons. First, patients have developed physical and emotional side effects associated with their diagnosis and treatment which have impact not only on the way they function in the world but also their willingness to remain on a trial. Secondly, patients have demonstrated a need for support services to remedy or lessen the deleterious effects produced both in short term and long term experience following systemic therapies (Schain, 1992).

Bullinger (1992) identifies 3 research questions regarding quality of life:

1. Describing how patients feel within the disease trajectory and across treatment regimes, 2. Evaluating which therapeutic strategies for stabilizing the disease and obtaining symptom control are most beneficial for enhancing patients' quality of life and 3. Identifying the potential for enhancing patients' quality of life with new medical and nonmedical intervention.

Chaturvedi (1991) studied issues considered as reflecting quality of life and how important these items were in the event of a serious illness. Peace of mind,
spiritual satisfaction, and social satisfaction were considered to be very important by nearly two-thirds of the subjects studied.

Gilber (1991) compared the quality of life of 51 cancer patients who dropped out of chemotherapy, 19 who refused treatment, and 70 who had completed chemotherapy. Quality of life was measured by the psychosocial adjustment to illness scale and the brief symptom inventory. Findings indicate that the quality of life of patients who refused chemotherapy was no different from that of patients who dropped out of or completed treatment. Quality of life for patients who dropped out of treatment was worse than for patients who completed chemotherapy.

Hjermstad and Kaasa (1995) reviewed the literature on quality of life of adult cancer patients and they suggest that there is an increasing interest in measuring quality of life in cancer patients. They concluded that information on psychosocial issues and the patients’ quality of life give a more comprehensive evaluation of the treatment outcome than survival and relapse-free intervals alone.

Hughes (1993) studied the impact of diagnosis and treatment on patients’ physical and psychosocial wellbeing. The data obtained indicated that patients’ perceptual uncertainty and various aspects of their functional status declined over the initial course of treatment but their quality of life was unaffected. The results also showed no relationship between type of breast cancer treatment and patients’ uncertainty, quality of life and functional status.

In a comparative study Schaz et al (1993), women diagnosed with stage I and stage II breast cancer were grouped into high risk and low risk groups. They found that high risk women had significantly more problems with greater severity than low risk women in all areas such as physical, psychological, medical intervention, sexual and marital. Instruments to measure the quality of life were used in this study.

Early in the 1980s, Spitzer et al (1981) developed a tool specifically to evaluate the quality of life of patients with cancer. This instrument contains a uniscale for the global evaluation of quality of life, along with separate components that evaluate the physical and emotional aspects of quality of life.

Until Quality of Life tools are routinely used in all studies and their implications better understood, it is not possible to fully inform the patients or
understand the consequences of their choices in treatment. Thus medical therapies in
cancer patients will be evaluated with tools that measure not only tumor response and
survival, but quality of life as well (Miller, 1994).

Some of the instruments used in the study of quality of life of cancer patients
are:
Generic instruments such as Medical Outcome Study (MOS), Sickness Impact Profile
(SIP), RAND Health Insurance Study Scales, and Psychosocial Adjustment to Illness
Scale (PAIS). Cancer specific instruments such as Quality of Life Index (QLI),
Rotterdam Symptom Checklist, Functional Living Index -European Organization for
Research and Treatment of Cancer- Quality of Life Questionnaire (EORTC- QLQ),
Cancer Rehabilitation Evaluation Systems, and Functional Assessment of Cancer
Therapy, Cancer site specific instruments such as Breast Cancer Chemotherapy
Questionnaire, Linear Analog Self Assessment for Breast Cancer, and Performance
Parameter (Head and Neck) (Ganz 1994).

For the purpose of measuring quality of life, the researcher in this investigation
uses a scale which assesses the patients' evaluation of his/her attitude towards
himself/herself and the changes that the person perceives in the various aspects of
his/her life. Effort is made to associate it with the other variables under study
exploring the possibility of mutual influences.

Death Anxiety

A patient with cancer faces psychological problems such as 1) fears of
termination of treatment, 2) Preoccupation with minor physical problems, 3)
adjustment to physical losses and handicaps, 4) difficulty with reentry into normal
life (the Lazarus syndrome), 5) perceived loss of job mobility, 6) persistent sense of
vulnerability to death and illness (the Damocles syndrome), and 7) persistent guilt
(Ledersberg and Massie)

In addition to the physical symptomatology associated with the effects of the
illness and its treatment, the majority of cancer patients experience emotional
difficulties including anxiety, depression, anger; and/or guilt. They endure difficulties
in living, and are generally frightened about the course of their illness and impending

The diagnosis of cancer is always associated with having to anticipate one’s death. The cancer patient experience this anticipation and the fear of death that follows, the ‘fear of a catastrophic, destructive force bearing upon me and I can’t do a thing about it’(Kubler-Ross, 1969). Most people say that they are afraid of the unknown, they are afraid of separation, pain and suffering, unfinished business, leaving loved ones behind. The fear and anxiety of death is compared with an iceberg. There is a small part above the water; the most significant part is hidden, invisible under water - unconscious. Patients may not experience the anxiety in its full terror during the day time. But they tend to wake up at 2 am-3 am with severe anxiety, sometimes verging on panic.

Most patients, especially those suffering intense pain, anticipate and experience anxiety about death. Quill (1991) who had participated in the suicide of one of his patients reports that the patient feared a lingering death and what this involved ‘increasing discomfort, dependence, and hard choice between pain and sedation’. The dying person may have a distinct and rather pervasive sense of having lived a life that is unfulfilled, unresolved and unfinished tasks or goals yet remain to be completed. Many critically ill patients still appear to be preoccupied with either an often powerful need to achieve or a tendency to look backward and reassure themselves that they have achieved in order to bolster their rapidly declining self esteem and feelings of inadequacy (Silverberg, 1988).

The illness career of the cancer patient has been characterised as a ‘living/dying’ experience in which, faced with the intolerable incompatibility of life and death the patient and his or her family attempt to maintain control and ‘normalise’ everyday activity (Muzin et al., 1994). There is a vast difference between having the cognitive awareness that death is universal and we each will some day die, and being a person confronted with the terminal illness. People who are dying must reorient themselves by adjusting to all present and impending losses. The dying person experiences death.
and loss on various levels. There is a social death in which the dying person must learn to separate from the living. The phenomenon of losing our status and who we are is known as phenomenological death. Psychological death involves the loss of personality, the essence of a person. Psychological death occurs as the patient acknowledges that he or she will no longer exist. Simultaneously, a biological death is occurring, and physical deterioration is an ever-present reminder that at the end of his experience, all that will be left are a person’s remains.

For terminally ill people, forced to confront their own imminent death, immense anxiety composed of specific fears is a major emotional response. There are fears of the unknown, loneliness, loss of self control, loss of all loved ones, and loss of bodily functions. There are fears of pain and suffering, sorrow, regression, mutilation, decompensation, and premature burial. Caregivers and family members have the onerous task of helping the dying to break down their anxiety into components to make it manageable.

In this study, the researcher assesses the emotional reactions and the cognitive responses that are evinced by the patients towards the concept of death and the anticipation of one’s own death. The researcher hopes to find out the degree to which death anxiety manifests in the patients and the factors which mediate its experience.

**Family Burden**

It is increasingly recognised that the diagnosis and treatment of cancer is a ‘family affair’ with implications for the adjustment and functioning of the entire family unit. The primary support person, generally a spouse or other family member, is faced with the formidable challenge of coping with the reality and implications of a loved one’s illness while simultaneously taking on the considerable demands of caregiving (Mor et al, 1994). Both the chronic and the terminal phases of cancer though different in many respects, are powerful in their impact on patient’s family and caregivers (Kopel et al, 1988). The impact of a member’s cancer upon the other family members can be disastrous or manageable—depending upon the nature of the family and the support that physicians, other professionals, and the society at large provide for the family.
Burden typically refers to the management of the specific tasks to be performed. To understand the impact of care giving, it is important to examine both objective burden (physical tasks and financial responsibilities) and the subjective stress of the individuals. Burden refers to the extent to which caregivers perceive their emotional, social life, physical health, financial status as suffering as a result of caring for an ill relative (Cummings, 1992).

Studies such as the one by Harrison et al (1995) examining the impact of diagnosis of cancer on key relatives found that relatives show more concerns than the patients themselves.

With extensive treatment and hospitalisations, financial burdens are added; little luxuries at first and necessities later on may not be afforded any more. The immense sums that such treatment and hospitalisations cost force many patients to sell the only possessions they had; they are unable to keep a house which they built for their old age, unable to send a child for education and unable perhaps to make many dreams come true. There may be the added loss of a job due to many absences or the inability to function, and mothers and wives may have to become breadwinners, thus depriving the children of the attention they previously had.

Thus it becomes imperative on the part of the professional to look into this aspect of care giving undertaken in most cases by the family members. A caregiver is the individual responsible for the majority of care giving tasks, including emotional support and supervision of the family member with cancer. The primary caregivers across the studies were mostly women caring for spouses or their parents (Laizner et al, 1993).

During the periods of active treatment, patients require assistance with self-care and frequently were dependent on family members for transportation, assistance with procedures, help with medications, and symptom management (Laizner et al, 1993) Lewis (1990) identified 9 types of support focussed services that may help caregivers who are challenged by the multiple demands that occur throughout the course of dealing with cancer in a family member. They include:

- Diagnostic and treatment information,

- Interpretation of the course of illness and anticipatory guidance,
- Interpretation of the patients' emotions,
- Interpretation of the illness to school-age children,
- Cognitive processing of the meaning of the illness for individuals and family members,
- Access to services for physical care,
- Problem focused services,
- Referral services for exceptionally distressed families,
- Skill building classes.

A diagnosis of cancer in the family involves the management of the changes in and disruptions to daily life for the family members as well as the patients necessitating relatives to make role adjustment and lifestyle adaptations to meet the demand created by the illness (Mor et al., 1994). The primary support person, generally a spouse or the other family member, is faced with the formidable challenge of coping with the reality and implications if a loved one's illness while simultaneously taking on the considerable demands of care giving.

An important aspect is the feeling of loss of hope and the conflicts that the family members or the caregivers face during the terminal phases of the illness. During this phase, the financial burden is tremendous. When Karnofsky score, which measures the performance status of the patient, is plotted against cost of care during the terminal phase of cancer, it is observed that the cost shows a vertical increase and the functioning a dramatic decline, suggesting a heavy financial burden on the family without encouraging outcome (Miller, 1994). To add to this point is the findings of Lubitz (1993) that the total cost in cancer treatment in the active and palliative phases of treatment, 52% is consumed in the last 60 days of the patient.

The impact of a member's cancer upon the other family members can be either disastrous or manageable depending upon the nature of the family and the support that physicians, other professionals, and society at large provide for the family (Henrichs, 1993). Very often members of the patient's family become so overwhelmed by grief and feelings of their impending loss that they become immobilized in their ability to help either the patient or themselves. This is particularly apt to be the situation in the case of a surviving male spouse who, because of powerful masculine gender role
conditioning does not know what he is feeling, or is unable to accept or respond to the feelings of his dying spouse. This inability of many men to respond in feeling fashion to a critically ill family member is often rigorously defended against by such common male defensive maneuvers as aggression and acting out behaviors. The widespread disinclination of many men to express emotion as easily as women is often perceived by the hospital staff as an inability on the man's part to genuinely care or love his dying wife. Such perception then causes staff members to ignore the man, thus pushing the husband to intensify his defensive behavior further, making it more and more improbable that his needs will be recognized and met (Silverberg, 1985).

Both patients and their families are intricately involved in the coping process that the disease presents (Chekryn, 1984). Hind (1985) found that more than 30% of families that were caring for patients with advanced cancer exhibited psychosocial symptoms that were severe enough to benefit from supportive services. In the study by Maguire (1981), husbands of breast cancer patients were found to experience significantly more distress before and after surgery than a group of men whose wives had been treated for a benign breast disease. One year after their wives had been treated for breast cancer, 36% of the husbands still had symptoms of anxiety. Cancer also causes disruption to the relationships that exist between the patients and the various family members. Lichtman et al (1984) reported a deterioration in the mother-daughter relationship in 17% of their subjects; the poorer the prognosis and psychological adjustment of breast cancer patient, the greater the disturbance in the relationship.

Family members use various strategies to cope with the illness of a member. Compas et al (1996) examined the cognitive appraisals and coping in children, adolescents, and young adults faced with the diagnosis of cancer in a parent. All the three age groups perceived low personal control and high external control over their parents' illness and used relatively little problem-focused coping. Emotion focused coping was related to greater avoidance and to higher symptoms of anxiety-depression.

According to Roth et al (1990), successful care giving has eight characteristics. To be present totally, to offer hope and respect, to hear with heart,
be authentic and flexible, to seek self-honesty, to cultivate response-ability, to keep an open mind, and to journey side by side.

Kurtz et al (1995) found that the disposition of care giver optimism was a strong predictor of care giver reaction to the burdens of caring, and seemed to play the role of a personality characteristic which was for the most part independent of patient variables.

The care givers’ wellbeing depends upon a number of factors broadly classifiable under two areas - objective stresses and situational context. Objective stresses include factors such as the stage of illness and prognosis, demands of care giving, duration of illness, and patient’s distress. Contextual variables include family-care giver characteristics such as age, gender, previous experience with cancer; family relational variables such as quality of marriage, marital communication, family stage, and social support (Sales et al, 1992).

Mor et al (1988) developed categorization to group the care giver needs. The needs are grouped under three categories.
1. Personal needs related to self care, including bathing and mobility.
2. Instrumental needs, related to meal preparation, light and heavy housework.
3. Administrative needs related to forms, financial advice, legal advice, and information about the disease.

In addition to these, another category named ‘other’ was added to the classification scheme for the areas of need not explicitly captured by the other three.

There are lot of demands made on the caregiver as care giving needs extreme humanness. To be present for another person without imposing one’s own beliefs, expectations, and without having any answers to give, requires a genuine inner clarity.
Conceptual model of variables associated with care givers' stress and coping (Sales et al, 1992) is as follows.

**Conditioning Variables**
- Health
- Income
- Social Support
- Satisfaction with social contacts
- Nature of Prior relationship
- Personality Factors
- Coping Strategies

**Response to Stress**
- Physiological
- Psychological
- Behavioral

**Conditions Conducive to Stress**
- Functional Status
- Patient's affective state
- Other manifestations of disability
- Nature of disability onset
- Prognosis
- Visibility

**Perceived Stress**

**Enduring Outcome**
*Psychological well-being*
- Life Satisfaction
- Depression
*Physical well being*
Caring demands a lot from the carerer. Hull (1991) examined the caring behaviors by hospice nurses that were perceived by the families that were important to contributing to their satisfaction. The four most important caring behaviors were:

1. 24 hour accessibility.
2. Effective and sensitive communication.
3. A nonjudgmental attitude

In our set up, most of the patients are cared for in their families than in facilities like hospice care even in the terminal phases of the disease.

Davis et al (1993) surveyed 91 adult patients with cancer and 78 spouses to investigate the amount of worry, active participation in the treatment, and social support. Findings suggest that spouses and patients worry equally about their own personal health, and spouses worry more about patients' futures than do the patients themselves. In addition to this, spouses and patients report participating equally in treatment process, yet patients report receiving significantly more social support than do spouses. The results point to the need for expanded attention to the concept of cancer as a 'family disease'.

Omne - Ponten et al (1993) measured the psychosocial adjustment among 56 spouses of women operated for breast cancer. These spouses were found to show emotional distress similar to the levels seen among cancer-operated women themselves.

Davies et al (1990) examined the experience of 8 families of advanced cancer patients receiving palliative care either at home or in the hospital. Using qualitative analysis the families' experience was conceptualized as a transition of fading away. The transition began with an ending, characterized by processes of redefining and dealing with burden. A period of chaos, confusion, fear, and uncertainty characterized the neutral zone. The end point of the transition was a new beginning where families focused on living day to day and preparing for death.

Harris et al (1995) examined the impact of diagnosis on key relatives of 108 newly diagnosed cancer patients. Relatives completed a self-report checklist of concerns and the General Health Questionnaire. Patients were administered a
corresponding Concerns Checklist as a part of a semistructured interview. More relatives than patients expressed each of the nine common concerns; the discrepancy was the greatest for concern about the patient’s emotional reaction, repeated by 95% relatives and only 18% of the patients. The total relatives’ concern score was significantly greater than the patient’s score. 48% relatives scored above the cut-off on the General Health Questionnaire suggesting significant psychological morbidity.

Family burden in this study is measured by assessing the family member on 7 dimensions: 1. Financial Burden, 2. Disruption of routine activities, 3. Disruption of Family Leisure, 4. Disruption of Family Interaction, 5. Effect on Physical Health of Others, 6. Effects on Mental health of Others and 7. Overall Subjective Well-being. An assessment of these dimensions, which have been considered as components of family burden, it is hoped, would give an adequate measure of the variable of family burden. The researcher would also explore the associations this variable has with the other factors studied.

Social Support

Social support may be viewed as a part of the coping process in living with a chronic strain such as a chronic illness like cancer (Thoits, 1986). Thus the complex medical management requirements of cancer, along with acute crises and the potentially fatal prognosis, may all interact synergistically to produce a negative effect on the patient’s psychological adjustment. However, this negative effect does not appear to be consistent among all patients. Consequently, the chronic strain/psychological adjustment relationships is likely to be mediated by moderator variables such as social support (Katz and Varni, 1993). Social supports are commonly defined as function performed for an individual under stress by significant others such as family members, friends, or professionals (Nelles et al, 1991). These functions are generally classified as
1) Instrumental aid such as goods and services, 2) Expressive aid such as caring and listening, and 3) informational aid such as education or advice concerning the disease or its treatment (Schaefer et al, 1981). Coping theorists identify three types of strategies for coping with stress - problem focused (actions focused on either oneself
or the environment to reduce stress), emotion focused (feeling or thoughts to control the negative reactions to stress), or perception focused (ways to redefine the stress so that it is less threatening) (Thoits, 1986).

Obviously coping and the functions of social supports have much in common. For example, both problem focused coping and instrumental aid are directed at changing or managing the stressful situation. Both emotion-focused coping and expressive aid are aimed at reducing the negative feelings accompanying the stressful event. Furthermore, both perception-focused coping and information aid are ways of altering the meaning of the stressful event. Thus, social support can be viewed as a form of coping assistance or as the ‘active participation of the significant others in an individual’s stress management efforts’ (Thoits, 1986). He further suggests that support works like coping by changing or eliminating the primary sources of threat to the individual. By implication, self-esteem, mastery, and identity are restored indirectly rather than directly. Thus, social supports that target problematic situations or responses will be more effective than those that target self-esteem directly.

The efficacy of different types of support may change over the course of the disease. For example, support may involve provision of information to help the patient initiate treatment shortly after the diagnosis (informational aid). Patients hospitalized for a long time may require assistance with household tasks to meet their family responsibilities (instrumental aid). Finally, the patient’s fears may increase the need for reassurance that others will continue to demonstrate love and emotional support (emotional aid) (Wortman and Conway, 1985). It is also clear that potential providers of support may not be equivalent - that those who share similar perceptions of or similar emotional responses to the patient’s situation may provide the most effective support regarding coping. According to Cohen and Wills (1985), social support functions within two theoretical frameworks namely the buffering model and the main or direct-effect model. Smith et al (1985) reported that majority of the patients found emotional support as the most beneficial type of support. Several authors have described the moderating effects of social support and social competence on an individual’s ability to tolerate stress such as that associated with life threatening diseases and physical handicap. Social support refers to the perceived or actual
positive regard expressed by significant others such as family, community and peers, leading to an increase in self-esteem and personal value (Katz and Varni, 1993).

Patients can be divided into four categories of emotional functioning - those who seem very stable and have a strong network of social support, those who are either very stable but lack strong support, or have strong social support but seem less stable, those who seem less stable and lack social support, and those who are clearly unstable with either a diagnosed mental disease or a chaotic life pattern (Gates, 1988). Three main sources of support have been generally identified: family support, support from physicians and other medical personnel, and support from other patients (Meyerowitz, 1980).

Till the twentieth century, most patients with cancer were cared for by their families. By the 1930s, cancer began to receive wider attention from the medical research community and soon several national cancer societies by professionals came into existence. In the US, training of social workers for assistance of patients with cancer provided the first professional discipline devoted to the care of the psychosocial issues of patients with cancer.

Other patients provide social support for patients with cancer through the self-help groups. Psychological support for women who had breast cancer was developed by Terese Lasser and Fannie Roseman in New York in the 1950s.

Social Support is one of the most essential needs that a patient and his family looks for to tide over the impact of the illness. Social support may be viewed as part of the coping process in living with a chronic strain such as a chronic illness like cancer (Thoits - 1986).

Social support in general has been defined as exchange of resources between at least two people perceived by the provider or the recipient to enhance the wellbeing of the recipient. (Schunsaker and Bronwell-1984) Social support is also an enduring pattern of continuous or intermittent ties that play a significant part in maintaining the psychological and physical integrity of the individual over time (Caplan, 1974).

As reviewed by Cohen and Wills (1985), social support has been found to function within two theoretical models. The buffering model proposes that social support buffers or protects the individual from the potentially pathogenic influences of
stressful life events and chronic strains. The main or direct-effect models posit that social support has a beneficial effect irrespective of whether individuals are under stress. When the measure of social support assess the perceived availability of interpersonal resources responsive to the specific need elicited by the stressful life events or chronic strains, thus supports a buffering model. A direct-effect model is supported when the measure of special support assesses an individual’s degree of integration within a large social network. The process through which social support acts as a buffer is still not explained convincingly. Blanchard et al (1995) reviewed literature pertaining to social support and its relation to psychosocial adaptation and survival in cancer patients (1987 – 1993). They found that though social support is posited as having a buffering effect for patients, the process linking these factors is unclear.

Smith et al (1985) conceptualized social support of cancer patients as the emotional and task oriented activities that act as buffers against the stressful correlates of a cancer diagnosis. This assessment of social support covers areas such as the type of networks used and the degree of benefit derived from interactions with specified support networks (spouse, family, friend, and children), the tasks that others perform during the patient’s illness which the patient viewed as helpful or unhelpful, the feelings of loneliness or isolation the patient experiences as the stressful effects of the disease on marital relationships.

The study done by this group on breast cancer patients reported that the overwhelming majority of patients said that the most beneficial type of support was emotional support – having someone who would listen and with whom they could talk about the illness. The instrumental support like taking care of the housework, preparing meals, and providing transportation was also seen as beneficial.

In the investigation of the relationship between social support and adjustment in women with breast cancer, Bloom (1982) defined social support as follows:

The women’s perception of her family’s cohesiveness as measured by four items from the Family Environment Scale (FES). Her social affiliations as measured by two items from the FES regarding perceptions of social contacts and amount of leisure activity. Social identity, defined as having a confidant.
In yet another study by Bloom and Spiegel (1984), social support was defined as the patient’s perceived quality of the emotional aids provided by the family as measured by FES relationship sub scales. The patient’s opportunity for social activity. They concluded that both aspects social support – emotional support and level of activity – affected the patient’s perception of wellbeing.

According to Bloom (1982) it is the perception of social support, measured by family cohesiveness and the frequency of social contact, that is the strongest predictor of healthy coping responses to mastectomy. Women who perceived that they have more support in their lives use fewer accommodating coping modes to adjust as measured by smoking, drinking, overeating, sleeping difficulties, disappointment, and anxiety. Those who use fewer of these modes have better self-concepts, undergo less psychological distress, and feel more powerful in the illness experience.

Funch and Marshal (1983) examined whether social involvement was linked to length of survival by measuring social involvement (defined as social ties) in the context of stressful experience. The results suggest that social involvement is a good predictor of survival.

Rose (1990) determined the dimensions and characteristics of components of support functions in 64 non-hospitalised adult cancer patients. They showed distinctiveness of primary network members by their overall preference for tangible aid from family, for modeling from friends who had cancer, and for open communications and clarifications from health professionals. Family and friends were equally preferred for dealing with affective reactions to the stressfulness of cancer. All sources were desired for self-esteem enhancement and relief from decision making, and problem solving responsibilities. This study shows what kind of support a patient expects from the primary, secondary, and tertiary social support systems available to him. Patients are also able to categorize their support needs based on the source from where they expect them.

Gurowka et al (1995) studied cancer patients’ perceptions of supportive and unsupportive interactions with members of their social networks and factors that lead them to evaluate certain kinds of supports as helpful and others as unhelpful. Problem solving support was the most frequently mentioned class of support, followed by
emotionally sustaining ' and ' reliable alliance and commitment' behaviors. Unsupportive behaviors included avoiding the respondent/ problem, asking the respondent to repeat his/her story of cancer, and failing to provide an expected amount of quality of support.

Helgeson et al (1996) reviewed several research literatures that address the associations of emotional, informational, and instrumental social support to psychological adjustment to cancer. Descriptive studies were found to suggest that emotional support has the strongest associations with better adjustment.

This much valued emotional support is not easy to come by. Bolger et al, (1996) found that although significant, others provided support in response to patient’s physical impairments, they withdrew support in response to patient’s emotional distress.

Three main sources of support have been identified: family support, support from physicians and other medical personnel, and support from other patients. (Meyerowitz, 1980). In breast cancer patients for example, the patient – physician relationship and the preparation for physical discomfort and the loss of a breast have been found to improve adjustment (Maguire, 1975).

However, it can be argued that oncologists may not always in a position to be of such help as they themselves undergo great stress in their profession. The practice of oncology brings special strains to the physicians: the uncertainty inherent in treatment decisions, the unique toxicity inherent in treatments, especially those known to predispose to life-threatening complication such as bone-marrow transplants; and the repeated impact of patient deaths. Some personal distress is inherent in confronting decisions about withholding or stopping life-sustaining measures and in discussing these decisions with the patient and the family. The impact of the patients’ unrealistic expectations and the strain associated with the care of ‘problem patients’ are additional sources of stress. This is where the other professionals come into the picture when we discuss the provision of social support to the cancer patients.

During the 19th century, most patients with cancer were managed by their families. (This is still relevant to our country where family still continues to be the major caretaker for the patient.) Others were cared for in facilities provided by
compassionate nuns with support from the church, representing the beginnings of the hospice movement in Europe. Many concepts of humanistic and comfort care have their early roots in these homes for the people dying with cancer. By the 1930s, cancer began to receive wider attention from the medical research community. The International Union Against Cancer (UICC) was formed bringing together the several national cancer societies in existence. In the 1950s sub specialties such as hematology and oncology, and their pediatric counterparts provided new opportunities for continuity of care, psychosocial support and greater attention to supportive and palliative care. In the US training of social workers for assistance of patients with cancer provided the first professional discipline devoted to the care of psychosocial issues in cancer.

Psychological support for women who had breast cancer was developed by Terese Lasser and Fannie Roseman in New York in the 1950s. Both had undergone mastectomy and experienced profound isolation and distress which could not be discussed with others. The impact of their effort was particularly significant, occurring as it did at a time when mention of either cancer or the sexual organs was taboo in polite society and the news media. Their post mastectomy program was called Reach-to-Recovery. Such self-support group activities and organizations were not easily accepted by the medical profession. But in places and countries where peer support groups such as AA groups functioned, similar groups for post mastectomy patients were also acceptable.

Waxler et al (1991) examined a woman’s social contexts at the time of diagnosis of breast cancer and her chances of having survived the cancer four years later following up a cohort of 133 patients. They found that number of supportive friends, number of supportive persons, whether the women worked, whether she was unmarried, the extent of contacts with friends and the size of her social network have significant and independent effects on the chances of survival. Thus the social context, particularly contexts of friendship and work outside the home are statistically important for survival. This effect probably works through the permissive atmosphere conducive to the expression of feelings, which exist in the context of friendship.
Houston and Kendall (1992) examined this aspect by studying a cohort of patients with lung cancer. They found that patients who are encouraged to and permitted to verbalize their feelings by a friend or staff who is interested in, empathetic, and non-judgmental are better able to overcome feelings of anxiety and fear, and they progress through the stages of the illness process easily.

Ell et al (1992) examined the relationship between social relationships and social support and survival following a first diagnosis of breast, colon, or lung cancer in 294 patients. Results suggest that the emotional support provided by the primary network members was a critical factor explaining the relationship between indicators of social relationship and mortality.

Reports of changes in emotional support following surgery of breast cancer is often observed. This change can be attributed to one of the two factors: the stigma associated with cancer or illness imposed restrictions in one's activities. Bloom and Kessler (1994) in the longitudinal study of 412 women found that whereas the social activity hypothesis was supported, the stigma theory did not receive significant justification.

Rabowitz (1994) measured the impact of social and professional support on psychological recovery of women with breast cancer. It was found that perceived professional and social support did correlate with affect and self-esteem — but not with health locus of control. Those who perceived the highest combined social and professional support reported better affect, self-esteem, and more internal locus of health control.

Rose (1993) measures the processes and outcomes of emotional support in interactions between adult cancer patients and health providers. Emotional support processes were assessed as desired support, received support, and congruence. The older patients were found to expect intimacy as the most important, whereas the younger patients felt that being able to ventilate their feelings was the most important. In addition, the older patients received less emotional support from providers than did middle-aged patients, but younger patients were more inclined than the other 2 groups to feel that the emotional support they received was not congruent with support they desired.
Harrison et al (1995) examined the gender differences in patterns of confiding crisis by interviewing 129 male and 391 female cancer patients. Men were as likely as women to have confided their main concern in others but were much more likely to have used only one confidante (45% Vs 25% of women) while women made use of a wider circle of family, friends, and partner and used more confidantes overall. Results call into question the extent to which social support research using exclusively female sample can be generalized.

Gellert et al (1993) studied the impact of an adjunctive psychosocial support program on the length of survival with breast cancer. The support program consisted of weekly cancer peer support and family therapy, individual counseling and use of positive mental imagery. They found that the program did not significantly enhance the survival chances but provided beneficial effects on quality of life. This proves that the emphasis on psychosocial intervention in cancer care is justified even when it does not significantly promote survival.

Sheinfeld’s (1993) survey of 211 survivors of breast cancer suggests that the more frequent the contacts with friends, neighbors, and the relatives, the more the length of time between initial diagnosis and first recurrence. More specific assistance yields less recurrence and both frequency of contacts and increased assistance influence the quality of life. These findings go along with the view that social support of the patient’s environment may influence prognosis and rehabilitation. However, there is a corollary to this finding which was explored by Roberts et al (1994). They studied the effects of perceived social support from friends, family, and spouses of 135 newly diagnosed breast cancer patients and found that the characteristics of the person rather than of the situation underlie the apparent relationship between social support and adjustment to illness.

The crucial factor affecting tumor growth is the interaction among stress, an individual’s personality, and available psychosocial support, and the effect of this interaction on an individual’s ability to cope with stress (Hilakivi et al, 1994).

Though a patient expects support from all sources including the above mentioned peer groups, the most important source of support is still the family. A patient’s received or perceived support from the family depends a great deal upon the
quality of communication he or she has with the family. Gotcher (1991) examined the relationship between patient-family communication and psychosocial adjustment to cancer. It was found that interactions with immediate family members, especially spouses were important factors in determining psychosocial adjustment. Independently, emotional support was the most important predictor affecting global adjustment as well as domains of health care orientation, domestic adjustment and psychological distress. Thus family members are very important means of social support. Well-adjusted patients indicated that interpersonal interactions with the family members facilitated adjustment through emotional support, interest, reassurance, positive feedback, and encouragement. Delay (1992) also reported similar findings.

This also brings into discussion the strategies used by the individual to mobilize family support. Aymanns et al (1995) studied the interrelationships between the coping behaviors of 169 cancer patients and perceived amount and adequacy of family support, as well as the role of these factors in predicting psychosocial adjustment to cancer. Survey data suggested that cognitive strategies of coping may be more effective in mobilizing family support than behavioral strategies. Moreover, the perceived adequacy of various support is influenced by cognitive coping preferences independent of perceived amount of support. Their cluster analysis point to a coping-support pattern identified as "highly risky", characterized by perceived low levels of support, strong tendencies to ruminate, and weak tendencies to minimize disease-related threat.

Klein (1994) explored the relationship of daily hassles demand of illness, and social support to the psychosocial adjustment of people with newly diagnosed, primary lung cancer. It was found that the participants report relatively high social support, low hassles, moderately low demand of illness, and positive adjustment.

The present study assesses the phenomenon of social support as experienced by the patient. The various possible emotional and behavioral reactions that the patient attributes to the significant others in his/her social environment in their interactions with him/her are measured. It also measures how the person feels about himself/herself in relation to others in the social context. The researcher also tries to explore the bearing this phenomenon has on the other factors under scrutiny. An effort
is also made to find out how other factors mediate and influence one's perception of social support appraisal.

**Conclusion**

The above review of the available research on the variables explored in the present study, it is obvious that they have a great impact on the treatment and survival in cancer. It is essential for the professional involved in the management of patients and families to be sufficiently aware of these factors and their impact on each other. For the successful management of these issues, the professional has to be well-equipped and well-versed in these dynamic interrelationships. There is an obvious dearth of literature on these aspects in cancer in Indian setting. The present study hopes to add to the existing knowledge that we have.