Chapter 2

*Literature Review*

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LITERATURE REVIEW

INTRODUCTION

Previous research studies were abstracted and the more significant works of authors relevant to this research were reviewed. This chapter provides an appropriate background for the development of the present study since every research is a leap from the known to the unknown. This section will bear testimony to the laborious effort the investigator has put in and the pains endured to probe authenticity and findings well-founded. A brief summary of the various areas of agreement and disagreement in findings was made and the gaps in existing knowledge were filled through a more elaborate enquiry and a systematic review of literature. This has greatly helped the researcher to justify the present findings and to project some new worthwhile elements for further investigation.

This chapter has been logically structured objective-wise and consolidates the results of the existing research. It shows how the studies are related, points out the areas of agreement and disagreement and indicates where the gaps or inadequacies exist, which make the present study relevant and useful. The significance of the problem, the need for conducting the investigation, and the logic that justifies the study are explained in this review of past studies.

The worldwide incidence of cancer is formidable, and growing. In the year 2000, there were well over ten million people
newly diagnosed with cancer, worldwide. More than six million people died from the disease in that year alone. Although most psychosocial oncology research stems from developed countries, there is clearly a need to consider the impact of psychosocial care on patients in less developed countries. Psychosocial care not only improves the quality of life, but can considerably lighten the overall burden caused to the health care system. This is clearly an important goal in health care management in both the developed and developing countries.

Survival rates have improved with advances in medical care and by giving importance to psychiatric interventions designed to assist cancer patients in dealing with diagnosis and treatment. Fawzy, I.F et al, (1990)1. According to Holland, the goals of these interventions are to decrease feeling of alienation by talking with others in a similar situation, to reduce anxiety about the treatments, to assist in clarifying misperceptions and misinformation, and to lessen feelings of isolation, helplessness and being neglected by others. Interventions that are designed to help the person feel less helpless and hopeless, have added to the benefit of encouraging more responsibility to get well and better compliance with medical regimens Holland, J C. (1993)2. Being aware of the benefits of these psychosocial therapeutic interventions, today’s patient often specifically request such services.

A number of research has shown that psychosocial interventions can contribute significantly to both psychosocial and physical health outcome in patients with cancer Fawzy et al.
Many studies done in the area of psycho-oncology suggest that psychosocial and behavioural factors play an important role in the onset, course and sequel of cancer.

Three areas are suggested by Cunningham (1985), that research in these areas has given substantial credibility to the link between psychological factors and the onset and progress of cancer. They are Psycho-physiological studies with experimental animals that relate stress and mental states to cancer growth and functions of the immune system. The investigation relates psychosocial events and personality traits to the incidence and progression of cancer. Clinical studies suggest that various psychosocial interventions may increase the longevity of cancer patients.

Considerable research has been done in the area of psychosocial problems of cancer patients. This makes it necessary to review the literature so that one can understand the problems to improve upon it and get a better insight into the problem.

This chapter deals with a review of literature of the past studies, which are pertinent to the objectives of the study undertaken. This review has helped the researcher in collecting information on the subject, various methodologies used and conclusions drawn from past studies. The review is of both Western and Indian studies and based mainly on the following seven aspects:

- Socio-demographic background.
- Family burden and cancer
SOCIO – DEMOGRAPHIC BACKGROUND

Over 1 in a 1000 patients were diagnosed as cancer cases in 1941; since then there has been a steady increase in patients’ attendance and at present over 25,000 new patients get registered and over 15,000 patients are diagnosed for cancer annually. (Tata Memmorial Hospital Based Cancer Registry, Mumbai, 1999-2000) The Hospital Based Cancer Registry (HBCR), at the Regional Cancer Centre (RCC) Thiruvananthapuram provided the data of cancer patients reporting to the Regional Cancer Centre, for the year 1999-2000. Annually more than 10,000 new patients, with 95,000 follow up visits and more than 2,00,000 non cancer patients reported to the centre for various investigation and treatment. During the last five years, there has been 25% increase in the registration of both cancer and non-cancer cases. Rajan, B etal(2003)\textsuperscript{5}.

The total number of cancer diagnosed at five different hospital based cancer registries (HBCRs), over a period of two years from 1\textsuperscript{st} January 1999 to 31\textsuperscript{st} December 2000 is as follows. A total of 74938 cancers (38,794 males and 36,144 females) were diagnosed at the five HBCRS. Among these the proportion of cancers diagnosed at different HBCR hospitals were 42% at Mumbai, 18% at Bangalore and Chennai, 20% at Dibrugarh.
Bangalore and Chennai 100 female patients and 81 to 87 male patients were reported, where as in Mumbai (129), Thiruvananthapuram (108) and Dibrugah (186) more males were reported. The trend in the actual total number of cancer registered from 1984-2000 in the different HBCRS. Mumbai, Chennai and Thiruvananthapuram have shown a significant increase in numbers over the year. Dibrugarth has shown a decline. At Thiruvananthapuram for males lung (13%) was the leading site followed by mouth (9%), tongue 6% NHL 5% and larynx 5%. The proportion percentage of cancer for females at Thiruvananthapuram was thyroid gland (9%) which was the third leading site after breast 28% and cervix 13%. Thyroid gland was followed by cancer of ovary 8% and mouth 5%.

The number and relative proportions of cancer in the broad age group 0-14, 15-34, 35-64 and 65 and above years of age, for both series across the registry show that proportion of young adults (15-34, years) varied from 7 to 14% in all registries and both sexes. Proportion of patients in the age group 35-64 years varied from 57% in males at Thiruvananthapuram to 75% of cancer in females in Chennai and Dibrugargh. The mean age of female patients was 48.2 while that of male patients was 50.4. (Two year report of the HBCRS:1999-2000)⁶.

Demography is a risk factor for virtually all-chronic disease, including Cancer. The low socio-economic background from which people hail is the root cause for many of the serious and chronic illness. The most common cancer among the poor are lung, esophageal, oral, cervical and prostate American Cancer
According to recent national statistics, the incidence of cancer increases as family income decreases. Five years cancer survival rates are lower for the economically and medically disadvantaged, and cancer mortality among the poor is significantly higher than among people with income above the poverty line Public Health Services, (1990). Contributing to these are a multitude of economically related risk factors, individual high-risk behaviour, and diagnosis and treatment limitations. Many of these risk factors are present among the middle-income people who at one time were classified as economically disadvantaged. Economic disadvantages and medical disadvantages have a significant bearing on an individual’s ability to have access to and effectively use the health care system Leffall L. et al (1992).

According to the data available with the Thiruvananthapuram Cancer Registry, reported in the Hindu, May 17th 2006, the prevalence rate of cancer in rural areas is 19.8 per 100,000, while in urban areas 30.5 per 100,000. This statistical data was sent out by M.C. Kalavathy of the department of Clinical Epidemiology, Regional Cancer Centre.

Researches have found out that indicators of low socioeconomic states are related to caregiver reactions. In Mor, Guadagnoli and Wool’s study (1987), unemployed wives revealed more problems during their husband’s final illness than did the wives who worked. It was found that family members with lower income and less education were more likely to quit their jobs when caring for home hospice patients; it was also
found that the younger family members had financial problems. More recently, Oberst et al (1989) found that caregivers in families with low socio-economic status and those with less education felt more threatened by the patients’ illness. (Goldberg and Tull (1983) and Vachon et al (1982). It was also found that younger spouses had more adjustment problems at both immediate and subsequent follow-up periods and it was found that at earlier stages of illness and for patients younger than 50 revealed greater role difficulties and impaired marital relationship than did spouses of older patients.

David B Callan (1989) studied hope and coping in 120 men and women with cancer ranging in age from 21 to 85. She found no significant relationship between hope and age, but a positive relationship was noticed with religious faith. Victims who reported no interference in performing family role responsibility had higher levels of hope than those who reported interference.

Nowootny, E. et al (1989) asked 156 medically healthy subjects and 150 subjects with cancer to respond to her hope scale in relation to stressful events that they had experienced. She found a wide range of scores in both group but no significant difference between the two groups.

Vess, Moreland and Schewebel (1985) undertook a longitudinal study of 54 couples. The couples were interviewed as soon as the spouses were discharged from the hospital. The author found that families which were adaptable regarding role assignments, exhibited greater cohesiveness and competence in
new illness induced roles than did families which adhered to traditional gender roles.

Studies prove that survival rates have improved with advances in medical care and giving importance to psychiatric intervention to assist cancer patients in dealing with diagnosis and treatment. Most of the researches have shown that psychosocial intervention can contribute significantly to both psychosocial and physical health outcome in patients with cancer. Some studies prove the substantial credibility to the link between psychological factors and the onset and progress of cancer.

**FAMILY BURDEN AND CANCER**

Mary E. Morris, James C. Lynch, et al. (2007) conducted studies on Family distress among long-term cancer survivors—five studies, two at the University of Nebraska Medical Center and three based on the nursing literature. Single item scores were compared among the participants regarding “How distressing has your illness been to your family”. All the five studies reported significant level of family distress as a result of treatment and disease. Cassileth et al. (1985) found that the family of patients receiving active treatment reported significantly more anxiety and mood disturbance than family members of the patients receiving follow-up care. The family members of patients receiving palliative care reported the highest level of distress.

The level of stress can be assessed on the basis of the position of the patient in the family. Acosta et al. (1983)
compared 99 families with either one of the members as a cancer patient with equal number of families where no one had cancer. The analysis revealed that the highest level of anxiety was found in families where the mother had cancer, followed by those in which the father was a patient. The least amount of distress was reported where the child was affected by cancer.

Wellisch et al (1978) in their studies on the impact of cancer of family members found that husband of breast cancer patients reported significant psychosomatic concern and psychological difficulties at the time of their wives’ surgery and until the time the patient was discharged.

Northhouse and Swain (1987) in their study on the magnitude and duration of family member’s stress, reported that husbands were found to have much more distress than their wives during the hospitalization period and 30 days after the patient had returned home.

Oberst and James (1985) in a study on the spouses of newly diagnosed patients found that life style disruption was a matter of concern for most spouses. Over 50% of the spouses reported that their employment and household schedules were altered, arrangement for childcare changed and social activities curtailed.

Christ (1987) studied a heterogeneous sample of ambulatory cancer patients and found that the commonly reported unmet need were for information Houts et al, (1984) and Schag et al (1994) have supported these findings.
Any family that must deal with a family member who has cancer, undergoes severe, unusual and prolonged stress *Rait and Lederberg* (1990)\(^{24}\). Although the patient is obviously the primary victim of the disease, family members, especially the spouse, are the ones who must assume responsibility for meeting virtually all the patients’ medical, nursing, financial and practical needs. Thus, family members have been referred to as second order patients or hidden victims. Highly malignant gliomas are associated with a poor prognosis *Salzman et al* (1994)\(^{25}\); few patients survive more than two years after the diagnosis. Since the disease attacks the area of the brain that control mobility, perception, cognition and emotion, it often leads to physical or mental handicaps or both, with an implication not only for the patient but also for their spouses and families as well (*Amato*, 1991), *Falloufield* (1996) *et al*\(^ {26}\).

In a study by *Patricia T. Kelly*, (1987)\(^ {27}\) on Risk counselling for relatives of cancer patients – a new approach it was found that cancer risk analysis is a relatively new service that is used increasingly in clinical practice since more precise information about cancer risk becomes available and as the importance of an informed public is more widely appreciated.

**SOCIAL SUPPORT AND CANCER**

In family issues in cancer care; Current Dilemmas and future directions by *Deborah* (1988)\(^ {28}\) he presents a clinician’s views on the current status of family –focused cancer care on future directions for supportive interventions to help families cope with cancer. Developmental consideration, special or high-
risk groups, and a family assessment framework were discussed. Finally, recommendation on future care opportunities was proposed. The family is perhaps the most important social context within which illness occurs and is resolved (Litchman R.R., S E Taylor, J V Wood, Ryan C.S. and K Ryan et al, (1987) in their book, *A Private Battle*, said: “Cancer is no respecter of the immediate family. It strikes and scars them all and the scars remain for years”. Patients do not cope with cancer in a vacuum; regardless of family size or the presence of formal or informal support networks, patients cope with cancer within the context of the family unit. Hence, all health professionals providing cancer treatment must perceive cancer as a family disease. In addressing the status of supportive care for families of adult cancer patients, current dilemma must be reviewed and future direction must be defined. As the disease progresses, profound personality and behavioural changes take place over time, the person who existed before gradually vanishes, leaving some one who often is unable to communicate and may be agitated, combative or demented. Most patients lose the capacity to carry out the activities of daily living and require demanding round-the-clock care and place the whole burden on the family members.

The framework most applicable to the study of social support derives from the theory of social network. It is a set of people with whom one maintains contacts and has some form of social bond. Social contacts and relationships are important ways for an individual to influence the environment. They
provide pathways through which the environment influences the individual.

Social support explains why some people are better than others when exposed to similar stressful situations. The structure of the recipient network is also an important contextual aspect. Family joints are among these social support network sizes, density and relationship that can influence a recipients’ satisfaction with support. Social support mainly plays a buffering role in reducing the stress caused by the disease itself. One of the factors i.e. the patients’ ability to deal with the stress of cancer is the availability and presence of emotionally supportive persons in the environment Holland (1994).30

Faced with a life-threatening disease such as cancer, patients desperately seek help and support from family members and health professionals. However, they may not receive the help they seek and may not be satisfied with the kind of support rendered. Studies have shown that social support is a coping resource that enhances cancer patient’s quality of life Boardhead, Wortman and Kaplan, (1991).31 Apart from the global impact of social support on patients’ adjustment, the patients’ adjustment was related to specific type of support received from specific sources at different phases of the illness such as patient’s self-esteem when it was enhanced by the surgeon’s support at the time of surgery.

Family, friends and health professionals have been identified as the most important sources of support for patients with serious illnesses. Among these three sources of support,
adolescent patients perceived their family as most helpful, followed by the surgeon; friends were perceived as less helpful. Several authors found that cancer patients wished to receive emotional support from family, health professionals and friends. Rose et al. (1990)\textsuperscript{32} found that cancer patients’ need for support may vary from one phase of illness to another, depending on the adaptive task they required.

According to Cohen and Wills (1985)\textsuperscript{33}, the study of social support involves structural and functional perspectives. The structural aspect is the size of social net working frequency of interaction and membership in formal organization. Studies found that social support buffers the negative impact of stress on adjustment when it is conceptualized from a functional perspective, which focuses on a person’s perception of the overall quality of social relationship. Revenson, Wollman and Felton (1983)\textsuperscript{34} found that socially supportive behaviour had little impact on the psychological adjustment of cancer patients. A study by Robert et al. (1994)\textsuperscript{35} demonstrated that the linkage of perceived social support and psychological adjustment was confounded by a personality variable social desirability.

Social support is a certain factor in the quality of life for cancer patients. The changes in the patients body functions, the alterations in his or her appearance and the aura of dread which cancer evokes can create severe obstacles to the maintenance of consistent and meaningful contact between the patients and significant others.
Although lack of support experienced by spouses of cancer patients was noted decades ago, during recent investigation, it was recognized that the ill person’s ability to provide support to his or her spouse is likely to be altered as a result of the disease process and the result is that unmet relationship becomes important.

Marital satisfaction, support networks and stress of events may explain a significant amount of variance in husbands’ perceptions of their own health. Several studies show that social support predicts adjustment to disease. Spiegel et al (1989) reported that survival was significantly longer for patients who had been in a support group.

The efficacy of different types of support, say informational aid, instrumental aid and emotional aid, change over the course of the disease. It is also clear that potential providers of support may not be equivalent to those who share similar perception of or similar emotional responses to the patient’s situation that provide the most effective support regarding coping.

Bloom and Spiegel’s (1987) study results indicate that emotional support strongly influenced related to the patient’s outlook and that greater opportunities for social activity affected both self-perceptions and social functioning and outlook on life. They concluded that both aspects of social support – emotional support and level of social activity affect patient’s perception of well-being.

The quality of communication within the marriage revealed that marital satisfaction was positively related to both
the partners open discussions of their concerns about disease and death. They suggest that the ability to cope with cancer related problems was associated with the quality of the marital relationship before the diagnosis.

Cassileth et al (1985)\(^{37}\) studied a heterogeneous sample of cancer patients and their relatives to determine the compatibility of psychological distress. Despite large individual variations the psychological status of patients and their matched relatives were closely correlated. The patients’ treatment status affected both patients and their next of kin. Increased understanding of the interrelationship between the family’s and patient’s response to illness is of fundamental importance to the care of the patient with cancer.

Faller, Shilling, Otteni & Lang (1995)\(^{38}\) explored the connection between social support and emotional distress in cancer patients and in their support providers and found a correlation between support efforts and emotional distress. Studies of patient’s satisfaction showed that many patients were dissatisfied with the amount of information and support they received Ali Khalil (1989) \& Ganz (1995)\(^{39}\).

Descriptive studies suggest that emotional support has the strongest association with better adjustment Halverson \& Cohen (1996)\(^{40}\). It can be concluded that in social support the emphasis should be laid on interaction process between the providers and the recipient Blanchard et al, (1995)\(^{41}\) in his longitudinal studies has assessed the impact of disease stage on interaction and relationship between social support and quality
of life. An empirical study of 330 cancer patients was made in Kerala, on the quality of life experienced by cancer patients and the social support received by them. The findings show that the cancer patients had a moderate level of quality of life and they received a relatively high level of social support from family, relatives and friends. Joseph I. Injody (2005).

**COPING AND CANCER**

The conceptualization of coping process is a central aspect of contemporary theories of stress. Coping is viewed as a stabilizing factor that may help individuals maintain psychosocial adaptation during stressful periods. Prior research on coping skills falls into two general categories - efforts to develop a typology of coping processes and studies of the influence of coping processes on adjustment.

The importance of spirituality as a central component of psychological well-being is increasingly recognized by doctors and mental health professionals. Among the medically and terminally ill in particular, patients struggle with the question their mortality, the meaning and purpose of life, and whether a great power exists, forcing them to grapple with issues they had previously ignored.

*Bianchard, et. al. (1995)* states that spiritual issues which “lie at the spirituality is perhaps best defined as the way in which people understand their lives in view of their ultimate meaning and value”. Many people turn to religion for answer to this difficult question, but others seek support through their spiritual beliefs outside the context of organized religion.
Growing data have provided empirical support for the hypothesis that spiritual well-being might help to bolster psychological functioning and adjustment to illness. Results of several studies of medically-ill patients show a strong inverse relation between spiritual well-being and a sense of meaning and purpose in life, faith and comfort with existential concerns and depression. Coward, (1988)\(^4^4\) noted that her self-transcendence intervention provided important benefits for a group of women with breast cancer. In various studies made on physically healthy individuals, similar results have been reported, suggesting that spiritual well-being is a central component of psychological health.

The reason why some individuals become depressed during the terminal stage of an illness has become an increasingly important focus of palliative care and mental health research in recent years. This attention has targeted recently to spirituality, a potentially important variable in understanding how patients cope with terminal illness. It holds importance because many physical, psychological and social stressors often accompany life threatening diseases. In addition, the unpredictable nature of such illnesses may limit the effectiveness of traditional coping strategies.

Sandy Hutchison (2006)\(^4^5\) a clinical psychologist and manager with many years of experience in helping people cope with the challenges related to cancer focuses on the role of improved communication which can result in reducing level of distress for women with cancer and those close to her.
A study on the impact of spirituality, and religion on depression in the terminally ill by Christian, Rosenfeld et al (2002)\textsuperscript{46} confirms the impact of spirituality and religiosity on the severity of depressive symptoms in a sample of terminally ill patients with cancer and AIDS. These results suggest that the beneficial aspects of religion may be primarily those that related to spiritual well-being rather than to religious practices.

Linda E and Baner S.M. (2003)\textsuperscript{47} conducted a study on the psycho-spiritual well-being in patients with advanced cancer. This study is an integrative literature review of 43 primary research studies. It was found that patients with an enhanced sense of psycho spiritual well-being are able to cope more effectively with the process of terminal illness and final meaning in the experience. Prognostic awareness, family and social support, autonomy, hope and meaning in life—all contributed to positive psycho spiritual well-being. The research indicates that health professionals can play an important role in enhancing psycho-spiritual well-being, but further research is needed to understand specific interventions that are effective and contribute to positive patient outcomes.

Mathew J. Cordova, Janine, Mitch et al (2003)\textsuperscript{48} conducted a cross-sectional study to test whether the coping styles of emotional suppression and fighting spirit were associated with mood disturbance in cancer patients. It was found that lower emotional suppression and greater adoption of a fighting spirit, in addition to older age and higher income, were associated with lower mood disturbance. Expression of negative affect and an
attitude of realistic optimism may enhance adjustment and reduce distress for cancer patients in support groups.

A study on the effect of spiritual well-being on end-of-life despair in terminally ill cancer patients was conducted by Colleen S. MC Clain et al (2003)\(^49\). Significant correlations were seen between spiritual well-being and desire for hastened death, hopelessness and suicidal ideation. Spiritual well-being was the strongest predictor of each outcome variable and provided a unique significant contribution beyond that of depression and relevant covariates. Depression was highly correlated with desire for hastened death in participants low in spiritual well-being but not in high spiritual well-being. Controlled research assessing the effect of spirituality based intervention is needed to establish what methods can help engender a sense of peace and meaning.

Linda E Carlson, Barry D.Bultz et al (2003)\(^50\) analysed the impact, adjustment and coping across the illness trajectory in partners of cancer patients and it was found that partners have become the target of studies more extensively in recent years. It also is apparent that partners often suffer more psychological distress from the impact of the diagnosis than patients do.

A study on cancer patient’s coping style and doctors-patient communication was conducted by Lucille M.L, et al, (1999) \(^51\). The study highlights monitoring and blunting style have become relevant concepts regarding their potential impact on patients and doctors behaviours. It was found that cancer patients coping styles are not related to other personal and disease characteristics. Further a monitoring style seems to have
an impact on patients’ question-asking and dominance during the oncological consultation.

*Baider et al (1999)* examined the possible relationship between a newly developed instrument, the spiritual beliefs inventory and the coping style of a group of cancer patients. The results revealed a significant positive correlation between the spiritual beliefs inventory and the active cognitive coping style.


A study by *Mark Petticrew, Ruth Bell, Duccan Hunter et al* (2002) on the influence of psychological coping on survival and recurrence in people with cancer, summarized the evidence on the effect for psychological coping styles on survival and recurrence in patients with cancer. There is little consistent evidence that psychological coping styles play an important part in survival from or recurrence of cancer. People with cancer should not feel pressured into adopting particular coping styles to improve survival or reduce the risk of recurrence.

**PSYCHO-SOCIAL PROBLEMS AND CANCER**

For most people, the diagnosis of cancer denotes a catastrophic threat paramount to a death sentence. Clinical observations of newly diagnosed patients with cancer indicate an apparently common sequence of emotional reaction, such as shock, disbelief, anxiety, anger, guilt and depression. The two major reasons of continuing emotional distress are fear of
recurrence of disease and a sense of lack of personal control over the situation.

*(Diane Lauver, Kiran Connolly-Nelson, Pa Vang (2007)*) 55 in a content analysis on Health Related Goals in Female Cancer Survivors After Treatment found out that the most common goals were improving physical activity, performing meaningful activity, losing weight and eating better diet.

*Mumbai Mirror (2007)* 56 report an inspiring tale of how love, faith and courage won against the dreadful disease cancer. Seven years ago, Winnie was stricken with Wilms Tumour. Her kidney removal surgery was followed by two weeks of radio therapy that involved the use of x-rays to destroy cancer cells in the affected areas. Further the last leg of the treatment involved 52 weeks of chemotherapy that gave the family some measures of relief as the doses came only once in every three weeks. At the end of the programme, all forms of tests were done to see if there were signs of cancer. To everyone’s surprise Winnie was all clear. Even when the doctors gave up the patient her parents were confident that God would see her through. There was never a doubt in their minds. Faith along with systematic medication healed Winnie from the most dreadful disease.

A newer branch in psychiatry called psycho-oncology is emerging. In recent years there are a number of research publications conducted in this area are available now. There is an independent psycho-oncology clinic in Manipal. *Alexander et al (1999)* 57 studied psychological morbidity in cancer patients & revealed 82.5% patients had psychiatric morbidity, 44% had
depression in, and 32% had adjustment disorder in Singh et al (1999) 56 reviewed features of depression in cancer patients. Behere (1983)58 in a study of psychological complications of breast cancer found that there were more psychological complications in malignant than in cases of benign lumps in the breast.

The role of psycho-social factors in cancer has been recognized as important since a long time by Indian clinicians. However, active research and other activities have been pursued only during the last decade or so. Chadurvedi and Vyas (1993)59 are the most memorable names in this field of study. In the Indian setting, 38% if cancer patients were found to have identifiable DSM-III-R anxiety or depressive disorders Chadurvedi, (1994).60 Psychiatric morbidity has been assessed in various studies. Cancer pain, which becomes severe in the advanced stage of disease makes the patient is usually aware of the progressive and irreversible nature of the cancer. Fear is a common reaction during this stage. Patients are caught with fear of, abandonment by doctors, fear of loss of composure, bodily function and dignity, and above all fear of death Chadurvedi (1985)61. Depression, anxiety, and disturbances in familial and social relationships have been noted as main problems in laryngectomy patients Chadurvedi (1994)62. In a comparative study made on son of preoperative and post operative laryngeal and oral cancers in India, concerns about speech and communication were reported in 76% laryngectomies following surgery Chaturvedi,(1994)63. Physicians are concerned about the
adverse drug reaction due to the use of antidepressants in cancer, but a recent study disclaims this apprehension and indicates that anti depressants given to cancer patients do more benefit than harm. Psychotropic medications can also be safely and effectively used in palliative care of terminally ill cancer patients Chadurvedi, (1996)\textsuperscript{64}.

The frequency of the occurrence of depression in cancer patients has been the subject of a number of studies Koenig et al, Derogalis et al and Evans et al (1986)\textsuperscript{65}, which depended on clinician’s reports of depressive symptoms with the absence of defined diagnostic criteria for depression. The study covered patients with advanced stages of disease and patients with more severe level of illness.

Oberst and Scott (1988)\textsuperscript{66} who analyzed the psychosocial impact of cancer and the meaning that patients assigned to the cancer experience. Barkwell, and O’ Conner et al (1991)\textsuperscript{67} underscored the importance of understanding the patient’s interpretation of illness experience, contending that the meaning ascribed to illness had a significant impact on how the individual coped with the illness.

O’Conner, Wicker, and Germino (1990)\textsuperscript{68} identified six themes reflecting the process searching for meaning after a diagnosis of Cancer. Faith and social support proved to be the major factors facilitating the search for meaning. Although the study provided valuable insight into the process that newly diagnosed cancer patients used as they struggled to understand their illness and incorporated it into their life experiences, it did not illuminate
the actual meanings that participants ascribed to the illness experience.

In a study conducted by (Lipowski (1970)\textsuperscript{69} he outlined eight categories of meaning that an illness or disability might have for an individual challenge, enmity, punishment, weakness, relief, strategy, irreparable loss and value. Barkwell (1991)\textsuperscript{70} used Lipowski’s framework to examine how patients suffering from cancer related pain and classified the meaning of their pain. The patients with their pain as a challenge had significantly lower depression than those identified pain as enmity or punishment. The study proves that the most important determinant of effective coping with cancer related pain was the perceived meaning of pain.

(Babbara et al (1992)\textsuperscript{71} studied the relationship between emotional distress and psychosocial cancer among newly diagnosed cancer patients. The data analysis focused on how these measures of psychosocial concern were related to the stage of cancer, type of treatment and level of mood disturbance and psychosocial concern. The study proved that the stage of disease did not correlate with the level and type of psychosocial concerns whereas treatment modality and mood disturbance did. The result indicated the specific screening and inquiry into types of concerns and emotional distress, including distinctions between somatic non-somatic concerns.

For adults, the diagnosis and treatment of cancer can be a highly stressful and isolating experience Friedman et al (1989)\textsuperscript{72}, his studies show that youthful patients experience more frequent
psychosocial and treatment related problems and express higher negative emotions than do older age groups. (Ell et al 1989)

Younger patients also seem to want greater involvement in medical decision-making.

Cassileth et al (1985) current observations about middle-aged cancer patients suggest that their priorities and perception of emotional support may be distinct from those of other age groups. His studies indicate that during the middle age the patient has been able to build up greater stability in family life and support networks. It is important to note that the incidence of cancer rises steadily with the onset of middle age.

Cancer treatment during young adulthood is extremely stressful for most patients. A number of studies have found that younger cancer patients suffer greater psychosocial morbidity than their older counterparts do. (Cassileth et al (1984); Edlund and Sneed (1989); Mor Allen and Matin (1994).)

Roberts et al (1994) studied the life changes and specific problems among female cancer patients. It was found that they all related angrily about their health and the recurrence of their disease as their most stressful problems because almost everyone in the group was worried about his children’s future and risk of cancer.

Mastectomy has a profound psychological impact on women Austin et al (1990) it has defined as an “emotional operation” indicating that it is impossible for a woman to escape serious emotional trauma in connection with mastectomy. The social role change and body image disturbance noted with
mastectomy contributed to poor adjustment. It was documented that mastectomy is followed by psychological upheaval ranging from mild anxiety to major depression.

Reence Royak (1991)\textsuperscript{78} in his study on women, having breast cancer points out that breast cancer is a process that has profound psychological depression in women. Successful adjustment was found in women who believed that they could control the dysfunction.

Eakes et al (1996)\textsuperscript{79} investigated the meaning of the cancer experience of individuals receiving outpatient radiotherapy. The studies revealed that the health care professionals needed to recognize the emotional as well as physical ramifications of the treatment experience and help patients cope with these stresses.

Minagawa et al (1996)\textsuperscript{80} in his study on psychiatric morbidity in terminally ill cancer patients reported that delirium was the most common psychiatric disturbance. He also emphasized the prevalence and importance of depression in these patients. It was found that out of 22 patients with Mediterranean lymphoma two committed suicide.

M Barrers et al (2003)\textsuperscript{81} in a study on the role of emotional social support in the psychological adjustment of siblings of children with cancer found that high level of social support appeared to play a protective role in psychological adjustment with age and gender as modifying factors.

Schon, Ekeberg et al (2003)\textsuperscript{82} in a study on breast cancer patients newly diagnosed administered hospital anxiety and depression scale (HAD) one year following surgery with special
focus on dispositional optimism/pessimism. It was found that prevalence of emotional morbidity was significantly higher among pessimists at all assessment. Health care professionals should therefore provide intervention for pessimists, as well as for patients with high anxiety score at the time of diagnosis.

*Sophie Lebel et al (2003)*\(^83\) in a study on the psychosocial consequence and coping strategies adopted by patients waiting for a breast biopsy found that distress level was high in this sample. Using cognitive avoidance coping strategies, cases having history of previous biopsies and family history of breast cancer were associated with greater distress. It was found that waiting period between suspicious mammogram and breast biopsy may be a time of high distress for many women and it would be good enough if social work intervention be imparted during this phase of anxiety and tension.

*Lea Baider, Pnina Ever –Hadani et al (2003)*\(^84\) in a pilot study identified the variable that characterized couples in whom one of the partners is a cancer patient. 118 men with prostate cancer and 169 women with breast cancer were compared. Gender difference was observed in the psychological distress of the spouses. The husbands were significantly more distressed than the wives and their distress was as high as that of patients of both genders. These groups reported more or less similar level of psychological distress. These findings prompt us to suggest that high psychological distress of the spouse affect male more than females.
Timothy Pearman (2003) in a review on the quality of life and psychosocial adjustment in gynecologic cancer survivors found that gynecologic malignancies occurred one in twenty women in the United States. Recently a comparison was made between the QOL of women with gynecologic cancer with other types of cancer. It was noted that risk factor for poor adjustment was stronger among gynecologic cancer patients.

Jon G Reichelt, Ketil et al, Oslo, (2004) in a study on short-term psychological impact of receiving definite results concerning BRCAI mutation status in a clinical setting found that women with cancer were significantly more distressed than those without cancer as measured by hospital anxiety and depression scale (HADS).

The sample had a low level of psychological distress at baseline. Receiving a definite positive or negative result on the BRCAI test had minimal effect on short-term psychological distress. These findings indicate that establishing a special psychological service in relation to predictive BACAI testing could be unproductive.

In a study by Richard L Heinrich Cyndic et al (1988) on the psychological impact of cancer on cancer patients and healthy control it was observed that cancer patient had higher level of psychological distress, impaired physical abilities, poorer quality of life and marital distress than the healthy controls because of the deleterious effects of cancer. The patient’s ongoing experience with cancer developed in them a great fund of information about cancer than the healthy control. The results
indicate considerable support for this hypothesis. The patients appeared to be less distressed and more active than anticipated.

Harry R Kranzler, Maner et al (1987) in a study on psychological issues concerning a pregnant adolescent with Hodgkin’s disease highlights the following findings. Serious physical illness and pregnancy are both major psycho social stressors. The frequency distribution of Hodgkin’s disease is bimodal, with one peak occurring among people 15 to 34 years old. Even though among males this illness is found mostly among males a substantial number of women of reproductive age too are at risk.

Jennifer M Jonel et al (2003) in a study on 224 inpatients on desire for hastened death (DHD) in hospitalized cancer patients it was found that there was significant physical and psychological distress in the sample. Findings suggest that desire for hastened death is significantly related to hopelessness and advancing disease.

**DEPRESSION AND CANCER**

The incidence of depression in Palliative care patients varies from study to study depending on the population and the diagnostic criteria employed Breathart et al, (1995), but it is believed to be about 25%. Barraclough (1994) Psychiatric disorders in terminally ill patients are under diagnosed. It is often difficult to distinguish between when can be called appropriate sadness at the end of life and a depressive illness. Another factor is that patients with advanced cancer under-report their psychological and psychiatric symptoms Maguire
often believing that they are ‘weak’ or ‘bad’ patients or that they will impose a burden on their doctor. Untreated depression leads to difficulty with physical symptoms control, social withdrawal, prevents patients from completing ‘unfinished business and generally reduce the quality of life of patients.

*Lees N and Lloyd William M* (1999)\(^9^3\) in a study on assessing depression in palliative care patients using visual analogue scale[VAS] found that depression is not detected and therefore not treated in patients who are terminally ill. It is difficult to distinguish depression from sadness at the end of life and many of the criteria for diagnosing depression are not appropriate in the terminally ill patients. The findings suggest that VAS may be useful as a screening tool for depression in patients with advanced metastatic disease and that more intensive studies comparing VAS to clinical psychiatric interviews should be undertaken.

A study was conducted on the relationship between depression and reinforcing events in cancer patients by *Betsy Bisno et al* (1987)\(^9^4\) which was aimed at understanding the depressive symptoms of newly diagnosed cancer patients receiving radiation therapy and the relationship of these symptoms to Lewinsohon’s behavioural model of depression. Depressive symptoms were measured using the Beck Depression Inventory (BDI). Investigation revealed that subscales of unpleasant events most strongly correlated with depression were perception that others were dissatisfied with them, perception that others were intriguing on them and concerns over poor work
performance. The subscales of pleasant events that inversely correlated most strongly with depression were feelings of good health and leisure time activities.

In a study on suicides in terminally ill Japanese patients with cancer by the Division of Psycho Oncology, Institute (2004), it was found that the risk of suicide is higher in patients with cancer than in the general population. The important risk factor is advanced disease. Suicidality can change even in terminally ill patients. The end of life care that focuses on the psychological distress of dying individuals may be effective in preventing suicide.

A case-control study was conducted by David Protheros, Kim Turvey et al, (1999) on stressful life events and difficulties and onset of breast cancer at NHS breast clinic serving West Leeds. The findings of the study do not support the hypothesis that severe life events or difficulties are associated with onset of breast cancer.

In a study conducted by the American Cancer Society, (2004) on the prognostic values of depression and coping and depression in survival of lung cancer patients was aimed at investigate whether there was any co-relation between depression, coping and survival. It was found that depression coping was associated with shorter survival and depression was not linked with survival. To conclude, the prognostic value of depressive coping was only partially confirmed, warranting further probe into the robustness of this relationship.
Akechi Tastsuo et al (2004) conducted a study on the major depression, adjustment disorder and post traumatic stress disorder among terminally ill cancer patients. It was diagnosed that the terminally ill patients showed lower performance status, concern about being a burden to others and lower satisfaction with social support as significant associates with adjustment disorder and major depression. The reasons underlying psychological distress are multi-factoral. Early intervention to treat sub clinical anxiety and depression may prevent subsequent psychological distress.

Derogatis et al, (2001) found that almost half of the cancer patients had been diagnosed with a psychiatric disorder. Maladjustments and major depression are common psychiatric disorder among cancer patients and are more common in patients with advanced cancer or in cancer patients who are terminally ill.

Marilloyd William Trevoz Friedman et al, (2001) in a study on an analysis of the validity of the Hospital anxiety and depression scale as a screening tool in patients with advanced metastatic cancer found that depression was difficult to diagnose in terminally ill patients. This had an adverse effect on the quality of life and made the palliation of physical symptoms more difficult. They recommended that if HAD is used as a screening tool in palliative care, it should be as a combined scale, but low sensitivity and specificity may lead to poor efficacy as a screening tool.
Harvey Max Chochinov, Keith G Wilson et al (1997) conducted a screening for depression in the terminally ill cancer patients. They compared the performance of four brief screening measures for depression in a group of terminally ill patients. It was found that depression was a common problem in older adults and medically ill patients that often went unnoticed by treating clinicians. Efforts have been made to develop self-report screening inventories that would improve the accuracy of detection of depressive symptoms are yet to be brief enough for routine administration to the medically ill.

A screening for Depression in Head and Neck cancer was done by Mark R. Katz, Neil Kopek et al (2003). The objective of the study was to identify the prevalence of depression and the accuracy of depression screening instruments in ambulatory head and neck cancer patients who have received radiation. This segment is at risk for depression because of the life–threatening nature of the illness, and treatment induced oral morbidity. The prevalence of major and minor depression was 20%. All of the screening instruments tested were found to be highly accurate. Hospital anxiety and depression scale demonstrated the highest absolute level of sensitivity, specificity and positive predictive value. These results suggest that a significant minority of head & neck cancer patients are depressed during the post radiation period and that accurate screening for clinically significant depression is possible using any of the three instruments i.e. Beck Depression Inventory (BDI), the Hospital Anxiety and
Depression Scale (HADS) and the centre for Epidemiological studies-Depression. (CES–D scale)

Depression is thought to be one of the most common psychosocial squeals of cancer and the most likely reason for being referred to a mental health professional Mermelstein and Lesko, (1992); Massic et al, (1994); Ciaramella and Poli, (2001) while transient states of dysphoria are part of the expected response to a life threatening illness (Masse and Popkin, 1998) found that prevalence rates of clinically significant depression have varied widely, with reported rates between 1-53% in published studies. Zabora et al, (2001). The most commonly cited estimate is that between 20-30% of cancer patients will experience clinically significant depressive symptoms at one time or the other.

**FINDINGS OF THE PAST STUDIES**

A brief summary of the results of the studies done by researchers discussed in the review of the past studies is given below: Socio-demographic background studies show that the incidence of cancer increases as family income decreases. The individual high risk behaviour, diagnosis and its limitations are seen as high risk factors present among the middle-income group. The economic and medical disadvantages have significant impact on the individual’s ability to access and effectively use the health care system. It is found that the unemployed wives have more problem than the employed wives. The persons with limited resources and with less education quit their jobs to take care of the spouses at the time of home hospice. The younger spouses...
had more adjustment problems at both immediate and subsequent follow-up period. It was noticed that younger patients had role conflict and impaired marital relationship. No relationship between hope and age was noticed but relationship between hope and religious faith was noticed. Similarly, no special relation with stressful events and cancer was noted but a wide range score was found in both categories. It was observed that families, which adhered to traditional gender role, had adjustment problem in having to accept a change of role due to illness.

The findings of the studies on psychosocial problems highlight fear of recurrence of disease and lack of personal control over the situation as two main factors aggravating the problem. Even the meaning ascribed to cancer had a significant relationship to coping with the illness. It was found that faith and social support are the two factors facilitating the search for the meaning of cancer. The eight dimensions of meaning, the patient ascribed to cancer are challenge, enmity, punishment, weakness, relief, strategy irreparable loss and value.

It was noted that patients who took pain, as a challenge had significantly lower depression and those patients who identified pain as punishment and enmity had high depression. The most important determinant of effective coping to cancer related pain was the perceived meaning of pain. The study proved that the stage of disease did not co-relate with the level and type of psychosocial concern whereas it showed correlation with treatment modality and mood disturbances.
It was also observed that adult suffered more psychological problem than others and the diagnosis and treatment of cancer was a highly stressful and isolatory experience. The middle aged patient has been able to build up greater stability in family life. It was also noted that incidence of cancer rose steadily with the onset of middle age.

Younger cancer patients suffer greater psychosocial morbidity than their older counterparts and the most stressful problems that the patients faced are recurrence of the disease, worry about children’s future, social role change, body image disturbances which led to mild depression, sometimes to major depression.

It was noticed that depression was less in women who believed that control of disease is possible through life-style change and through support from family, friends, and doctors. Women with lung cancer had greater physical distress difficulty in communicating with health care team and greater marital dysfunction.

Patients undergoing out patient treatment needed the co-operation and assistance of health care professionals to cope with their stress. The Psychosocial problems of patients were identified as delirium, depression and suicidal tendency. Emotional disturbance was found high among pessimist and patients who have a family history of cancer. High psychological distress of the spouse affects males more than females. Risk factor for poor adjustment was stronger among gynecological cancer patients than any other type.
It was also observed that cancer patients were more vulnerable to psychological problems than the normal individuals were well informed of the effects of cancer. Women at reproductive age had greater risk of cancer and desire for hastened death, which was significantly related to hopelessness and advancing disease.

Studies on depression highlight difficulty in distinguishing between the natural sadness experienced at senility depressive illness. Advanced cancer patients underreported their psychological and psychiatric symptoms. Consequently depression went undetected and therefore untreated. The reason assigned for depression was the feeling that others were dissatisfied with them; others were intriguing on them and their own poor work performance.

Suicide rate was higher, among cancer patients than normal people. End of life care that focuses on alleviating psychological distress of dying, would help in preventing suicide and making earlier intervention to treat sub clinical anxiety and depression, which would prevent psychological distress.

Half of the terminally ill cancer patients have reported psychiatric disorder, adjustment problem and major depression are common problems. It was found that depression was a common problem among older adults and medically ill patients and this was not noticed by clinicians. Most common ailment noticed among cancer patients was depression and 1-53% suffered from dysphoria (breathing difficulty), 20-30% manifested clinically significant depressive symptoms.
Families of patients receiving active treatment reported greater anxiety and mood disturbances than family members of patients receiving follow up care. The stress on the family was dependent on the position of the patient in the family. Highest distress was reported when mother was fallen ill, father coming second and third in order the child. The husbands of breast-cancer patients reported significant psychosomatic concern and psychological difficulty.

Moreover husbands were found to experience greater stress when the wives were hospitalized than vice versa. A study of the spouse revealed life style disruption to 50%. Household and employment schedule were altered, arrangements for child care changed and social activity curtailed.

The patients were dissatisfied with the amount of information and social support received. Lack of adequate information was a major reason for depression, stress and tension in cancer patients. Disability of the patient to carry out his/her daily personal routine was considered to be burdensome to the family members.

Social support plays an important role. Emotional supportive persons within easy reach are needed to reduce stress. Social support is a coping resource that enhances the quality of life. Family, friends and health professionals are important sources of support for patients. In the descending order of efficiency firstly stand family, doctors, and friends. Social support includes structural perspective, functional perspective social relationship and membership in organizations.
Survival was significantly longer in patients who were in a support group. Both aspects of social support that is emotional support and level of social activity, affect patient’s perception of well-being. The ability to cope with cancer related problems was associated with the quality of marital relationship before the diagnosis.

The psychological status of patients and their matched relatives were closely correlated. There was correlation between social support and emotional distress, social support and better adjustment and social support and quality of life.

It is important to know whether psychological factors have an influence on survival because psychological interventions have been developed to enhance the use of certain coping styles to prolong survival, and there is strong professional support for such therapies.

The medically-ill patients show a strong inverse co-relation between spiritual well being and depression. The result of studies on the impact of religion on depression in the terminally ill suggests that the beneficial aspect of religion may be primarily those that related to spiritual well-being rather than to religious observances.

Patients with an enhanced sense of psycho spiritual well-being are able to cope more effectively with the problems of terminal illness. Contributory factors of positive psycho spiritual well-being are prognostic awareness, family and social support, authority, hope, meaning in life.
It was noted that medical professionals could play an important role in contributing to positive patient outcome. Expression of negative effects and an attitude of optimism might enhance adjustment and reduce the distress of cancer patients in support group. Individuals with high spiritual well-being had low depression and patients with low spiritual well-being had a desire for hastened death. Moreover, it was found that partners suffered more psychological problem than patients.

There was significant positive correlation between spiritual belief inventory and active cognitive coping style. Study on coping strategies and emotional well-being revealed that coping did improve psychological well-being.

High-risk behaviour and delayed diagnosis because of poor accessibility to effective health care delivery system and change in social role have created adjustment problems for family members, as well as patients. The male counterpart faced more problems than the female. Fear of recurrence of disease and lack of personal control over the situation gave rise to psycho social problems. Those patients who took pain as punishment and enmity had more depression. Middle age was a period when people became more vulnerable with dreadful diseases like cancer, delirium, depression and suicidal tendency. Emotional disturbance was found high among pessimists. Desire for hastened death was significantly related to hopelessness and advanced disease. End of life care could alleviate psychological distress. Adequate amount of information on the illness and good social support from family members were considered most
valuable for patients, their relatives and friends. Importance of spirituality was a central component of psychological well-being in patients and it was also reported that higher the spiritual well-being lesser the depression. It was also noted that patients who experienced depression and did not find meaning in life supported the concept of euthanasia.

CONCLUSION

It is a shocking revelation that there are about 1500 cancer patients for every one million of the population. Nearly 80% of them have been found to have incurable cancers at the time of diagnosis itself. The conventional medical establishment is much too inadequate to address the problems faced by these patients.

Findings of the above given studies have shed light into the nature and extend of prior research in the field and have greatly helped the researcher to identify the untouched areas which provide ample scope for conducting research which might prove beneficial to the terminally ill cancer patients and the support mechanism that is being developed to alleviate their suffering. These unfortunate patients are aware of the painful truth that they are going to bid final farewell to all the kith and kin and the dear earth in a few days or months. They have given up all hopes and stopped planning for their future which is heading towards a dead end.

The contributions of above studies may be linked in part to the continued refinement of creative, feasible and reliable or valid assessment methods. It is necessary to realize that the task
a head to tackle the problem is laborious and calls for long persistent effort, indomitable will and unfailing optimism. The general over all success lies in the best use of the existing system of detection of cancer and treatment and venturing on further research aimed at discovering all the implications of this fatal malady so as to enable us to evolve an effective mechanism to tame it and, if possible, to subdue it to the relief of mankind as a whole.
References


