CHAPTER II – Literature review

The role of the family in the Indian setting is paramount considering the availability of palliative care services. The caregiver can be seen as holding a unique position of both providing and needing support. The World Health Organization promotes the importance of families receiving input from palliative care services, identifying the patient and family as the unit of care. Clinicians need to recognize that patients and their caregivers react to cancer as a unit and, as a result, they both have legitimate needs for help from health care professionals. When caregivers’ needs are not addressed, their mental and physical health is at risk, and patients are denied the opportunity to obtain optimal care from a well-prepared family caregiver. Programs of care directed only toward patients are seldom sufficient to meet patients’ needs because so much of the patient’s care depends on family caregivers. Therefore, the psychological and social issues need to be investigated to promote the quality of life of both the patient and the caregiver.

The present chapter comprises of review of literature on psychological and social factors that contributes to quality of life of caregivers of cancer patients.

Quality of Life

Several studies has been conducted in the recent past on the quality of life of cancer survivors and their family caregivers. For instance Mellon.S. Northouse.L. Weiss. L. (2006) conducted a study on Population-based study of the Quality of Life of cancer survivors and their family caregivers. It was found that the cancer survivors report significantly higher quality of life, less fear of cancer recurrence, and more support than their family caregivers. The strongest predictors for cancer survivors’ quality of life were
family stressors, social support, meaning of the illness, and employment status, whereas the strongest predictors for family caregivers' quality of life were fear of recurrence and social support. Both the survivor's and family caregiver's quality of life independently contributed to the other's quality of life.

The impact of caregiver burden of a patient-focused palliative care for patients in advanced cancer stage was examined by O'Hara RE, Hull JG, Lyons KD, Bakitas M, Hegel MT, Li Z, Ahles TA (2010). The researchers found no significant differences in caregiver burden between intervention and usual care conditions. It was seen that higher caregiver objective burden and stress burden are related to lower patient quality of life, higher symptom intensity, and higher depressed mood which the follow-up analysis indicated. Caregivers who perceived that patients had unmet needs at end of life reported higher objective burden, and those who perceived that patients were not treated with respect reported higher demand burden. Successful patient-focused intervention does have a similar beneficial effect on caregiver burden.

Moody L., McMillan., (2003), found mastery to be an important predictor of the patient's quality of life. In their study on Dyspnea and quality of life indicators in hospice patients and their caregivers found that caregivers can obtain ratings of dyspnea that are congruent with the patient's perceived symptoms. This is especially important in hospice care as patients may become so debilitated that they need to rely on proxy ratings from their caregivers to assess and attend to their symptom management. Caregiver perceived quality of life was related to four variables, perceived mastery, symptom distress, age, and years of education, with mastery being the strongest predictor. Overall
symptom distress and education were found to be the best predictors of the patient's quality of life.

The purpose of investigation by Ferrell.B., Grant.M., Borneman.T., Juarez.G., Veer.A., (2005), on Family Caregiving in Cancer Pain Management was to describe the experience of pain management from the perspective of family caregivers of patients with cancer amidst the current healthcare environment. The investigation reveals disruption to family caregiver quality of life in the areas of physical, psychological, social, and spiritual well-being. There is a continued need for education regarding cancer pain management. Comparison between patients and family caregivers demonstrates that pain impacts both the patient experiencing it and their caregivers.

In Taiwan Yeh.P., Wierenga.M., Yuan.S., (2009), studied the influences of Psychological Well-being, Quality of Caregiver-Patient Relationship, and Family Support on the Health of Family caregivers for cancer patients. The study showed that the Psychological well-being and the quality of the caregiver-patient relationship of family caregivers are found to be significantly positively correlated with caregiver’s health. The lack of family support was found to be significantly negatively correlated with caregivers’ health. Psychological well-being, quality of caregiver-patient relationship, and family support accounted for 59% of the variance in caregiver’s health.

difficulties in coping with the demands of role. The need for support, education, and self-care through the lung cancer illness trajectory is discussed.

Awadalla A., Ohaeri J., Gholoum J., Khalid A., Hamad H., and Jacob J. (2007), who made a controlled study on factors associated with quality of life of outpatient with breast cancer and gynecologic cancers and their family caregivers, found that the cancer groups had similar QOL domain scores, which were significantly lower than those of their caregivers, but higher than the control group as well as those of psychiatric and diabetic patients studied. Patients who were married, with higher education, better employment, and with longer duration of illness had higher QOL. Patients on radiotherapy and their caregivers had higher QOL scores. Higher correlations between patient’s ratings and caregiver impression of patient’s QOL were found. Caregiver impression was a significant predictor of patient's and caregiver's QOL. Other predictors for the patient were: currently feeling sick and duration of illness; for the caregiver: feeling sick, relationship to patient, and age.

Nihan Turkoglu*, Dilek Kılıç 2013, in their research article found that there was a negative relationship between caring burdens and the quality of life (p<0.001); descriptive characteristics, caring-related properties, and caring burden variables are all significant predictors of the quality of life.

**Burden of caregivers**

Study by Williams, A. L, McCorkle. R, (2011), on cancer family caregivers during the palliative, hospice, and bereavement phases found that the as a direct consequence of assuming the caregiver role, cancer family caregivers in the palliative, hospice, and bereavement phases are at increased risk for physical and mental morbidity.
Often, the psychological burden of the caregiver exceeds that of the critically ill patient. The distressed caregivers have a deleterious influence on patient well-being. It can be noticed that the need to develop research standards, especially regarding measurement instruments, so that caregiver research can mature and interventions can be developed to support family caregivers.

Grunfeld E., Coyle E, Whelan T, Clinch J, Reyno L, Earle C, Willian A., Viola R., Coristine M., Janz T., Glossop R. (2004) in their longitudinal study on Family caregiver burden of breast cancer patients and their principal caregivers had a sample where half of the caregivers were male (55%) and the patient's spouse or partner (52%), with a mean age of 53 years. It was found that at the start of the palliative period, the caregivers' mean physical functioning score was better than the patients' (51.3 v. 35.1, 95% confidence interval [CI] 13.3\(\pm\) 20.0); there were similar mean mental functioning scores (46.6 and 47.1 respectively); similar proportions were depressed (11% and 12%); and significantly more caregivers than patients were anxious (35% v. 19%, \(p = 0.009\)). More caregivers were depressed (30% v. 9%, \(p = 0.02\)) and had a higher level of perceived burden (26.2 v. 19.4, \(p = 0.02\)) at the start of the terminal period than at the start of the palliative period. Researchers concluded that burden was the most important predictor of both anxiety and depression. Of employed caregivers, 69% reported some form of adverse impact on work. In the terminal period 77% reported missing work because of caregiving responsibilities. Prescription drugs were the most important component of financial burden. They concluded that caregivers' depression and perceived burden increase as patients' functional status declines.
Studies have been done on caregivers of adult cancer patients. Bevans.M., Sternbeg.E.M. (2012) did a case study on the effect of care giving burden, stress, and health effects among family caregivers of adult cancer patients. The case study was on the experience of a 53-year-old woman who is the sole caregiver for her husband, who has acute myelogenous leukemia and was undergoing allogeneic hematopoietic stem cell transplantation. During this intense and unpredictable course, the caregiver's burden is complex and complicated by multiple competing priorities. Because caregivers are often faced with multiple concurrent stressful events and extended, unrelenting stress, they may experience negative health effects, mediated in part by immune and autonomic dysregulation. Physicians and their interdisciplinary teams are presented daily with individuals providing such care and have opportunity to intervene. The case study report describes a case that exemplifies caregiving burden and discusses the importance of identifying caregivers at risk of negative health outcomes and intervening to attenuate.

The relationship between the caregivers and family members is also an important determiner of caregiver experiences of burden. In their study Francis.L.M., Kypriotakis.G., Lewis.S., Rose.J., (2010) examined the Relationship quality and burden among caregivers for late-stage cancer patients. Their study results showed that higher quality relationship with family was associated with lower burden in family, caregiver abandonment, health, scheduling, and finances. Higher quality relationship with patients' health care providers was associated with lower burden in Family Caregiver abandonment health and finances. More discordant communication in patient relationship was associated with lower financial burden. Relationship quality was not associated with caregiver self-esteem.
Kim Y. Schulz., (2008), made a comparative analysis of cancer caregiving with dementia, Diabetes and Frail Elderly care giving. The study result showed that although the four different types of caregivers were comparable in most socio demographic characteristics, caregiving involvement and caregiving outcomes differed among the caregiving groups. Both cancer and dementia caregivers reported greater levels of physical burden and psychological distress than other caregivers, after controlling for socio demographic and caregiving involvement (i.e., level of burden and caregiving duration) factors. Their comparative analysis provided a systematic review of cancer caregiving in the context of three other types of caregiving.

Grov K E, 2006, in the study on primary caregivers of cancer patients in the palliative phase examined the association of theory-driven variables with the caregivers' burden by means of path analysis. Testing of the models suggested that caregivers' depression was the main factor associated with caregiver burden, but also an important mediator of indirect association, caregivers' anxiety and physical health.

Wang L C, (2011), examined the caregiving burden and associated factors among caregivers of terminally ill gastrointestinal cancer patients. The caregiving burden of caregivers of terminally ill gastrointestinal cancer patients in hospice homecare was significantly higher than that of those recruited from outpatient departments. Caregiving burden for liver and pancreatic cancer patients was significantly higher than for colorectal cancer patients. The caregiving burden of spousal caregivers was significantly higher than that of lineal blood relatives. The caregiving burden of caregivers with worse self-perceived health status was significantly higher than that of those with better self-perceived health status. The most important explanatory factors of caregiving burden
among primary caregivers terminally ill gastrointestinal cancer patients were (in descending order) social support, self-perceived symptom distress in patient, self-perceived health status, location of study subject recruitment, fear of death, and relationship with patient. Social support was the most important explanatory factor.

**Psychosocial distress of caregivers**

Mosher C., Jaynes H, Hanna N, Ostroff J, (2013) examined the psychosocial and practical challenges of distress family caregivers of lung cancer patients. The Caregivers of lung cancer patients described three key challenges in coping with their family member’s lung cancer. The most common challenge, identified by 38% of caregivers, was a profound sense of uncertainty regarding the future as they attempted to understand the patient’s prognosis and potential for functional decline. Another key challenge, identified by 33% of caregivers, involved time-consuming efforts to manage the patient’s emotional reactions to the illness. Other caregivers (14%) characterized practical tasks, such as coordinating the patient’s medical care, as their greatest challenge.

Mosher CE, Champion VL, Azzoli CG, Hanna N, Jalal SI, Fakiris AJ, (2013) conducted a study on Economic and social change among distressed family caregivers of lung cancer patients. Seventy-four percent of distressed caregivers experienced one or more adverse economic or social changes since the patient's illness. They found that the common changes included caregivers' disengagement from most social and leisure activities and, among employed caregivers reduced hours of work. In few of the cases, a family member quit work or made another major lifestyle change due to care giving. The caregivers also reported losing the main source of family income, losing most, or all of
the family savings. Loss of the main source of family income and disengagement from most social and leisure activities predicted greater caregiver distress. The concluded that distressed caregivers of lung cancer patients experience high rates of adverse economic and social changes that warrant clinical and research attention.

Murray SA, Kendall M, Boyd K, Grant L, Highet G, Sheikh A (2010) made a qualitative analysis of interviews which studied the Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family caregivers of patients with lung cancer. The results showed that carers followed clear patterns of social, psychological, and spiritual wellbeing and distress that mirrored the experiences of those for whom they were caring, with some carers also experiencing deterioration in physical health that impacted on their ability to care. In the study it was found that Psychological and spiritual distresses were particularly dynamic and commonly experienced. The study suggests in addition to the "Why us?" response, witnessing suffering triggered personal reflections in carers on the meaning and purpose of life. Certain key time points in the illness tended to be particularly problematic for both carers and patients: at diagnosis, at home after initial retreatment, at recurrence, and during the terminal stage.

Sugiura K, Ito M, Mikami H (2004) in their study of Evaluation of gender differences of family caregivers with reference to the mode of caregiving at home and caregiver distress in Japan found that there were no significant gender differences in the level of nursing needs of recipients. However, cognitive disorders of care recipients of female caregivers were more severe. The study showed that female caregivers spent more time providing care, and performed a greater number of care activities and in particular, assisted their care recipients in taking medications, dressing, bathing, eating, meal
preparation, shopping, laundry, and money management more often to a significant degree. The burden and depression were higher in female than in male caregivers. Concerning the usage of Long-term care insurance services, males used a Home-helper service more often. Female caregivers used types of Informal support seeking and Positive acceptance of caregiving role as coping strategies more often than the men. The study concluded that that caregiver’s subjective burden and types of informal support seeking, as well as acceptance of the caregiving role were significantly higher in female caregivers.

In a study on Barriers and facilitators of family experience to caring for individuals with stroke by White CL, Korner-Bitensky.N, Rosmus.C, Sourial.R., Lambert.S, Wood-Dauphinee.S. (2007), found the primary barriers to undertake and maintain the caregiving role were: lack of collaboration with the health care team, the intensity of the caregiving role, the negative impact on the caregiver, and the lack of community support for the caregiving role. The facilitative factors were: coordination of care, progress of the patient towards normalcy, mastery of the caregiving role, supportive social environment, and accessible community resources.

In a study by Pellegrino. R., Formica.V., Portarena I., Mariotti.S., Grenga.I., Monte.G., (2010), on Caregiver Distress in the early Phases of Cancer found that most of the caregivers (52%) spent more than 8 hrs daily caring for the patient, they also frequently reported the occurrence of new psychosomatic disorders, with the most reported symptoms being sleep disruption (24%), headaches (20%) and asthenia (16%). High levels of anxiety and depression were demonstrated in nearly a quarter of the study subjects. Researchers also found a substantial increase in monthly family expenses and
restriction of recreation activities among fifty percent of the sample under study. The overall gravity of the medical situation was perceived as severe by 86% of the Primary Caregivers.

The Direct and Meditational Effects of Psychosocial Resources and its negative outcome of cancer caregiving was studied by Gaugler.J., Linder.J., Given.W., Kataria.R., Tucker.G., Regine.W. (2009). The study found that primary subjective stressors were the strongest predictors of depression and negative health impact. A path analysis indicated that mastery mediated the relationship between role captivity and negative health impact. These results emphasize the importance of multidimensional assessment in cancer caregiving. The concluded by suggesting refinements to the stress process model when examining family cancer care.

Sjovall.K., Attner.B., Lithman., Noreen., Gunnars., Thome.B., Olsson.H., (2009) examined the free influence on the Health of the partner affected by tumour Disease in the Wife or Husband based on a Population-based Register Study of Cancer in Sweden. Results showed that health care use for partners increased in terms of in-patient care after the cancer diagnosis. A significant increase was seen the second year for partners of patients with colon cancer and lung cancer. Psychiatric diagnoses increased after the cancer diagnosis in the total sample, with a significant increase for partners of colon, lung, and prostate cancer patients. Costs of care increased more than the consumer price index the two years after the cancer diagnosis. Costs of care increased most for male partners and especially for younger male partners (age 25 to 64 years) of patients with colon, rectal, and lung cancers. The conclusion of the study was there is a increase in
health care cost and psychiatric diagnosis after the diagnosis of cancer among partners of cancer patients.

A case study on Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure by Murray SA, Kendall M, Grant E, Boyd K, Barclay S, Sheikh A. (2007) sought to identify and compare changes in the psychological, social, and spiritual needs of people with end-stage disease during their last year of life by synthesizing data from two longitudinal, qualitative, in-depth interview studies investigating the experiences and needs of people with advanced illnesses by case study method. Characteristic social, psychological, and spiritual end-of-life trajectories were discernible. The conclusion of the study was in lung cancer, the social trajectory mirrored physical decline, while psychological and spiritual well-being decreased together at four key transitions: diagnosis, discharge after treatment, disease progression, and the terminal stage. In advanced heart failure, social and psychological decline both tended to track the physical decline, while spiritual distress exhibited background fluctuations.

Varying degrees of interrelated cognitive, physical, and psychological impact were experienced by male caregivers of patients with breast and gynecologic cancer which extended to twelve months. The researchers Lopez.V. opp.G, Molassiotsi.A. (2012), found in their study varying degrees of interrelated cognitive, physical and psychological impact of caregiving which extended for a period of 12 months. Gender-specific attitudes prevented male caregivers from supporting their own self. Male caregivers dealt with problems that arose in the caregiving congruent with their masculinity, such as minimizing disruptions, focusing on tasks, and keeping their own
stress to themselves. The researcher concluded that male caregivers as a separate group with their own needs have not received much attention in the cancer literature, and their concerns and challenges may differ from those of female caregivers.

Tatsuo Akechi 2006, in their study on Psychological Distress Experienced by Families of Cancer Patients in psychiatric consultation of cancer center hospital, found that of a total of 1469 psychiatric consultation, 47 (3.2%) family members were referred, and 85% of them were spouses. The most common patient cancer site was the lung. Approximately one-half of the referred family encountered patients’ end-of-life issues. The most common psychiatric diagnoses were adjustment disorders, followed by major depression.

The results of a study by Kenneth R Meehan, (2006) titled prospective evaluation of the time commitment and financial requirements of caregivers of autologous stem cell recipients during the period of inpatient hospitalization found that each caregiver traveled a median of 829 miles over 17.8 hours. Out-of-pocket expenses varied greatly depending on whether a caregiver stayed in local accommodations (cohort 1; n = 11) or in the patient’s hospital room (cohort 2; n = 29). Total expenses (median) for each caregiver in cohort 1 were $849.35, including accommodations ($560), gasoline ($87.35), and food ($202). Total expenses (median) for each caregiver in cohort 2 were $181.15, including gasoline ($70) and food ($111.15). Each caregiver in cohort 1 lost a median of 43.5 hours of work compared with 8 hours for each caregiver in cohort 2. The findings of this study demonstrate that there is a significant financial and time requirement on the part of the caregiver when a family member or significant other is hospitalized for an autologous stem cell transplant.
The well-being of family caregivers of older memory-impaired adults was examined in four dimensions: physical health, mental health, financial resources, and social participation. (Linda.K.George, 1986) Results indicated that, relative to random community samples, caregivers are most likely to experience problems with mental health and social participation. In addition, characteristics of the caregiving situation were more closely associated with caregiver well-being than were illness characteristics of the patients.

The relationship between psychological distress and intrapersonal, family, and socioecological variables was examined in 77 caregivers of adults actively receiving cancer treatment by James.R.Rodrique, 1994. Results indicated that a sizable minority (29%) of caregivers were experiencing clinically significant psychological distress. Furthermore, family disturbances and maladaptive coping strategies were most predictive of psychological distress in this sample.

Stefan Feiten, 2013, in a study on Psychosocial Distress in Caregivers of Patients with a Metastatic Solid interviewed 200 patients. According to HADS-D 20% were anxious (cut-off ≥11) and 15% depressed (cut-off≥9) in a clinical sense. The results showed with regard to the distress level of caregivers and patients, gender was not found to be a confounding variable although female patients showed higher distress levels than male patients.

In an article by Coleman.M.P. (2001), on socioeconomic inequalities in cancer survival in England and Wales said survival rose steadily for most cancers over 25 years to 1995 in England and Wales, but inequalities in survival between patients living in rich
and poor areas were geographically widespread and persistent over this period of time. These patterns existed for 44 of 47 adult cancers examined but not for 11 childhood cancers. These inequalities in survival presented more than 2500 deaths that would have been avoided each year if all cancer patients had the same chance of surviving up to 5 years after diagnosis as patients in the most affluent group. The largest national cancer survival study has provided strong evidence of systematic disadvantage in outcome among patients who lived in poorer districts compared with those who lived in wealthier districts.

Saskia Mostert, (2006), in their investigation on Influence of Socioeconomic Status on Childhood Acute Lymphoblastic Leukemia Treatment in Indonesia found that of all patients, 35% refused or abandoned treatment, 23% experienced treatment-related death, 22% had progressive or relapsed leukemia, and 20% had an overall event-free survival. Treatment results differed significantly between patients with different socioeconomic status; 47% of poor and 2% of prosperous patients refused or abandoned treatment. Although poor and prosperous patients used the same protocol, the provided treatment differed. The study indicated that poor patients received less individualized attention from oncologists and less structured parental education. Strong social hierarchical structures hindered communication with doctors, resulting in a lack of parental understanding of the necessity to continue treatment. Most poor patients could not afford treatment. Access to donated chemotherapy also was inadequate. Treatment refusal or abandonment frequently resulted. There was no follow-up system to detect and contact dropouts. Health care providers were not fully aware that their own attitude and communication skills were important for ensuring compliance of patients and parents.
Self-Efficacy of Caregivers

Keefe FJ, Ahles TA, Porter LS, Sutton LM, McBride CM, Pope MS, Mckinstry ET, Furstenberg CP, Dalton J, Baucom D. H., (2003) in their preliminary study examined the self-efficacy of family caregivers with regard to helping cancer patients manage pain at end of life. Analyses revealed that caregivers who rated their self-efficacy as high reported much lower levels of caregiver strain as well as decreased negative mood and increased positive mood. Caregiver self-efficacy in managing the patient's pain was related to the patient's physical well-being. In dyads where the caregiver reported high self-efficacy, the patient reported having more energy, feeling less ill, and spending less time in bed. Considered overall, the results of this study suggest that caregiver self-efficacy in pain management is important in understanding how caregivers adjust to the demands of caring for cancer patients who have pain at the end of life.

In a study titled Perceptions of patients' self-efficacy for managing pain and lung cancer symptoms: correspondence between patients and family caregivers, Laura S Porter (2002) found that although patients and their caregivers showed a moderate degree of agreement in their perceptions of the patient's self-efficacy for managing pain and other symptoms, there was considerable variability in the degree of congruence. Factors that contributed to lower levels of congruence included low patient-rated self-efficacy, female gender of the patient, high patient psychological distress, and high caregiver strain. Caregivers were about evenly split in their tendency to overestimate versus underestimate the patient's self-efficacy. The results indicated that poorer quality of relationship between the caregiver and the patient (as rated by the patient), high levels of patient-rated
symptoms, and high levels of caregiver strain were associated with caregivers overestimating patient self-efficacy.

Study titled Improving patients' symptom management by engaging informal caregivers by Maria J Silveria, 2011 found that Patients undergoing chemotherapy experience many symptoms that they may be able to manage with the support of an activated caregiver. The intervention of the study used readily available technology to improve patient caregiver communication about symptoms and caregiver knowledge of symptom management. The study concluded that if the technology used is successful, it could substantially improve the quality of life of veterans and their families during the stresses of chemotherapy without substantially increasing the cost of care.

Laura S Porter (2008), examined self-efficacy for managing pain, symptoms, and function in patients with lung cancer and their caregivers, and associations between self-efficacy and patient and caregiver adjustment. Analyses indicated that, overall, patients, and caregivers were relatively low in self-efficacy for managing pain, symptoms, and function, and that there were significant associations between self-efficacy and adjustment. Patients low in self-efficacy reported significantly higher levels of pain, fatigue, lung cancer symptoms, depression, and anxiety, and significantly worse physical and functional well being, as did patients whose caregivers were low in self-efficacy. The finding of the study was when patients and caregivers both had low self-efficacy, patients reported higher levels of anxiety and poorer quality of life than when both were high in self-efficacy. Significant associations were found between patient and caregiver self-efficacy and caregiver adjustment, with lower levels of self-efficacy associated with higher levels of caregiver strain and psychological distress.
Stressors of caregivers

A meta analysis study of Associations of Stressors and Uplifts of Care giving With Caregiver Burden and Depressive Mood done by Pinquart.M, Sorensen.S. (2002) showed that Care recipients' behaviour problems showed stronger associations with caregiver outcomes than other stressors did. The size of the relationships varied by sample characteristics. Amount of care provided and care receivers' physical impairments were less strongly related to burden and depression for dementia caregivers than for caregivers of nondemented older adults. For spouse caregivers, physical impairments and care recipients' behaviour problems had a stronger relationship to burden than for adult children. Evidence was found that the association of caregiver burden with the number of caregiving tasks, perceived uplifts of caregiving, and the level of physical impairment of the care receiver were stronger in probability samples than in convenience samples.

Greater caregiving stress and lack of social support were significant predictors of greater depressive symptoms among caregivers of colorectal cancer patients during the first year since diagnosis: a longitudinal investigation Kim 2013. The adverse effect of caregiving stress was more pronounced among African American caregivers, whereas the beneficial effect of social support was more pronounced among White caregivers.

Chan C W. 1999 investigated the relationships between perceived difficulty in managing caregiver tasks and the experience of stress symptoms among 26 family caregivers of terminally ill patients with cancer in Hong Kong. The findings revealed that more stress symptoms were experienced by caregivers who had reported increased difficulty in managing caregiver tasks. The psychological stress symptoms, rather than physical symptoms, overwhelmed most of the caregivers. There were significantly more
negative responses to stress by caregivers who had a shorter duration of experience in providing care. In addition, caregivers who had less education were at higher risk of developing stress.

A study by Raynuha Mahadevan, 2013, on the cross-sectional study aimed to determine the proportion of the family caregivers who experienced stress while caring for the breast cancer patients who were on oncologic treatment, and factors which predict the stress among these caregivers. Results showed that about 1 in 4 (24.6%; n=32) caregivers of breast cancer patients were stressed. It was found that the duration of caregiving, sharing of caregiving burden, patients’ age and patients’ functionality were significantly associated with stress. This study found that a high proportion of the family caregivers experienced stress.

Alice cora, 2010, investigated Health Risk Factors in Caregivers of Terminal Cancer Patients and found that the caregiving stressor is associated with considerable psychological vulnerability, sleep disorders, and risk of alterations in the cardiovascular system, which seem to be modulated by caregiving characteristics.

Sherwood, et.al, 2008, in their study on new approach to oncology caregiving on mind-body model to study family caregivers of brain-tumour suggest ways in which emotional reactions to caregiving may be manifested as changes in physical health.

**Anxiety and Depression among Caregivers**

E. K. Grov, A. A. Dahl*, T. Moum and S. D. Fossa.,(2005) examined the Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. Results of the study showed that Physical QOL was significantly higher than norm in both genders, while mental QOL was significantly lower in male PCs. The level of
anxiety was significantly higher than norm in both genders. The results of the study did not find significant difference for level of depression in either gender, while depression was significantly more prevalent in female primary caregivers compared with norm. The study concluded that primary Caregivers of both genders had significantly more anxiety than norm samples.

Associations between Caregiver-Perceived Delirium in Patients with Cancer and Generalized Anxiety in their Caregivers was investigated by Buss.M., Vanderewerker.L., Inouye.S., Zhang.B., Block.S., Prigerson.H., (2007). The results of the study showed that of the 200 caregivers who completed the SCARED, 38 (19.0%) reported seeing the patient “confused, delirious” at least once per week in the month prior to study enrollment and 7 (3.5%) met criteria for generalized anxiety. Caregivers of patients with caregiver perceived delirium were 12 times more likely to have generalized anxiety. The relationship between caregiver-perceived delirium and caregiver generalized anxiety persisted after adjusting for caregiver burden and exposure to other stressful patient experiences.

The study by Youngmee Kim (2003) on Mediational Role of Spouses’ Motives for Caregiving examined the prediction of caregiver well-being from the relationship qualities specified by attachment theory and from motives specified by self-determination. Results showed that the investigating security (assessed with respect to the spouse) related positively to autonomous motives for and finding benefit in caregiving; attachment anxiety related to introjected motives for caregiving and more depression. Among husbands (but not wives), autonomous motives also related to less depression, and introjected motives related to less life satisfaction and more depression.
Among wives (but not husbands), autonomous motives related to greater benefit finding. Three measures were included as indicators of the caregiver’s psychological adjustment:

1. Benefit finding in cancer caregiving experience,
2. Life satisfaction and
3. Depressive symptoms.

Study by Karin Oechsle (2013) on anxiety and depression in caregivers of terminally ill cancer patients showed that fifty-five percent of male caregivers and 36% of female caregivers showed moderate or severe anxiety; 36% of male caregivers compared to 14% of female caregivers had moderate or severe depression. Caregivers' anxiety was associated with a discrepancy in the patients' symptom evaluation for shortness of breath, nausea, and frequency, intensity, and distress due to anxiety. Depression was associated with a discrepancy in the patients' evaluation of distress due to constipation, as well as intensity and distress due to anxiety. Findings of the study suggest both the caregivers' anxiety and depression were not significantly associated with an underestimation of symptoms. There was a trend towards a higher risk of overestimation in caregivers with higher levels of anxiety and depression.

An investigation by Ioannis Vrettos, 2012, indicates that female patients more frequently experience anxiety and depression than male patients. Male and higher-education caregivers had higher anxiety scores, while demographic factors did not seem to influence patients' health-related quality of life. Anxiety and depression of caregivers are correlated with patients' problems in self-care and usual activities.

Ambigga Devi (2005), in the study on Depression and Anxiety among Family Caregivers of Cancer Patients in an Oncology Clinic found that the prevalence of
probable anxiety and probable depression among the family caregivers were 48.6 % and 29.4 % respectively. Probable depression was significantly associated with education level, and duration of illness. Where as probable anxiety was significantly associated with age. The study concluded by identifying that the educational level, age of caregivers and duration of illness in the patient were factors that should be looked into when caregiving of cancer patient was done.

In a nationwide survey of patient-family caregiver dyad in Korea on prevalence and predictors of anxiety and depression among family caregivers of cancer patients by Park B, 2013 found that the prevalence of anxiety in family caregivers was 38.1 %; 20.3 % reported mild anxiety, 13.3 % reported moderate anxiety, and 4.6 % reported severe anxiety. The prevalence of depression was 82.2 %; 40.4 % reported mild depression, 25.5 % reported moderate depression, and 16.3 % reported severe depression. Family caregivers, who were younger, were caring for male patients, or had a low quality of life (QOL) in relation to three of the variables measured i.e, burden, disturbance, and financial concerns reported increased anxiety. The findings of the study revealed that 1. becoming unemployed during care giving, 2. being the spouse of a patient and having low QOL in relation to burden, 3. Disturbance and positive adaptation were associated with depression among family caregivers.

Clinical Factors Associated with Suicidality in Cancer Patients was studied by Tatsuo Akechi, 2002. The study found that of 1713 psychiatric referrals, 62 (3.6%) were related to suicidality, including 44 cases with suicidal ideation, 10 suicide attempts and eight cases who had requested euthanasia and/or continuous sedation. Most of the patients suffered from physical distress and/or psychiatric disorders. The results of a
multivariate analysis comparing cancer patients with a psychiatric referral related to suicidality and those referred for other reasons indicated that impaired physical functioning and major depression were significant associated factors. The findings suggest that early detection and appropriate management of major depression and comprehensive care improving physical functioning may help to prevent suicide and manage suicidality in Japanese cancer patients.

Mohammad Ali Heidari, 2012 in their study on Quality of life and depression in caregivers of patients with breast cancer found depression has strong negative correlation with QOL and participants with depression were more likely to have a poorer overall QOL.

In a nationwide survey in Korea by Boyoung Park, 2013, in their study on Suicidal Ideation and Suicide Attempts in Anxious or Depressed family caregivers patients with cancer, found a total of 17.7% family caregivers reported suicidal ideation, and 2.8% had attempted suicide during the previous year. Among family caregivers with anxiety, 31.9% had suicidal ideation and 4.7% attempted suicide. Compared with family caregivers without anxiety and depression, family caregivers with anxiety or depression showed higher adjusted odds ratios for suicidal ideation and attempts. Among family caregivers with anxiety or depression, being female, unmarried, unemployed during caregiving, and having a low QOL were associated with increased odds of suicidal ideation. The survey indicated that family caregivers with anxiety who became unemployed during caregiving constituted a high-risk group for suicide. Being unmarried and having a low QOL with respect to financial matters were associated with increased suicide attempts among family caregivers with depression.
Laura A. Siminoff A. L., 2010, study investigated depressive symptomatology in lung cancer patients and their family caregivers and the influence of family environment. More than half of patients (55%) were male but 74% of caregivers were female. The majority (57.4%) were spouses, followed by offspring and other family or friends. The baseline model with covariates showed that younger caregivers, spouse caregivers, and caregivers who blamed the patient for the cancer had higher depressive symptom scores. Patient and caregiver reports of lower familial cohesion and expressiveness and higher conflict were associated with higher depression scores for patient and caregiver respectively. The cross-partner effects indicated, patient reports of lower cohesion, lower expressiveness, and greater conflict were associated with higher caregiver depression scores. Offspring caregivers reported less depression than non-offspring caregivers. The family environment and blaming the patient during times of illness can affect both patient and caregiver depression. Findings suggest that quality of the family dynamic is important for patients but may be particularly influential for caregivers.

Given B, 2004, examines the patient and family caregiver variables that predicted caregiver burden and depression for family caregivers of patients with cancer at the end of life. Caregivers aged 45-54 reported the highest levels of depressive symptoms, and caregivers aged 35-44 reported the highest levels of depressive symptoms, and caregivers aged 35-44 reported the strongest sense of abandonment. Caregivers who were the adult children of patients with cancer and those who were employed reported high levels of depressive symptoms. Feeling abandoned (A portion of caregiver burden) was more prevalent in female, nonspouse, and adult children caregivers of patients with early-stage cancer and patients with multiple symptoms reported a high perception of disruption in
their schedule because of providing care. Caregivers whose patients died early following diagnosis reported the highest depressive symptoms, burden, and impact on schedule.

**Spousal Caregivers**

Studies suggest that spouses of cancer patients are at increased risk for several chronic diseases. Bishop.M. (2007), investigated mortality in relation to cancer morbidity in the stable female partner. The findings of the study indicated that the risk for death was only slightly elevated among men whose partner had cancer than for men whose partner remained free of cancer (hazard ratio = 1.03; 95% confidence interval = 1.01-1.05). The findings indicated that although a cancer diagnosis in a spouse might be associated with considerable distress, the risk for death differs only slightly between men living with a partner with cancer and those living with a partner without cancer.


**INDIAN STUDIES**

Anjum S Khan Joad (2011), in a study on the needs of informal Caregiver of a Terminally Ill Cancer report that most of the caregivers who were in middle age had no prior experience of care giving. The caregivers were satisfied by the information and medical support provided to them by their treatment team. Most had an “emergency plan”. The unmet needs of the caregivers were homecare, psychological support, and financial help.
Sharma, Sagar, and Monica Sharma (2007), deals with research on preventing illness and promoting of health and well-being from the stress perspective, while staying focused on the socio-cultural and economic contexts of people’s lives. Two broad research areas that were examined are: (I) The role of coping and social support or psychosocial care and battle against stress in various life domains in general, and in the case of chronic/acute stress of terminal/chronic illness (e.g., cancer, HIV/AIDS) or that of events of mass destruction in particular, and the health and wellbeing consequences that are manifested in suffering, adaptation, recovery and quality of life; and (ii) individual and community based illness prevention and health-promotion initiatives, including facilitating health communication, fostering behaviour change, reducing barriers to health care provision, developing disaster mental health intervention package and promotion of positive health and well being.

Tandon, Sweta and Seema Mehrotra (2007) in their study on Encounter with Cancer illustrating the process of psychological adaptation, articulates the process of psychological adaptation to cancer, using three case illustrations. A sense of uncertainty, distress related to interference with family tasks and individual goals, attempts at maintaining a sense of control characterized the initial adaptation process following cancer diagnosis. Religious/ spiritual beliefs played an important role in shaping appraisals and coping. Availability of support was also facilitated coping. However, social interactions at times also tended to enhance a sense of vulnerability. The narrative indicated that experiences of distress and positive changes can co-exist and that even during the initial phase post cancer-diagnosis, while people are on active treatment they
may be aware of positive personal changes occurring in their lives, in the midst of
struggles to cope with illness-demands.

P. Sharan, (1995), in their investigation on Coping and adaptation in parents of
children suffering from acute lymphoblastic leukemia using Thematic Apperception Test
(TAT-Indian modification) found that emotional distress was evident in the stories of
83%, only 37% maintained an expectation of a positive outcome. Parents’ psychiatric
morbidity was found to be associated with the gender of the parent, employment status,
and on the TAT-with the expectation of an unfavorable outcome, feelings of lack of self
efficacy and emotional distress, particularly depression. A significant association
between the presence of psychiatric disturbance in the children and the parents was also
found.

Rao, G P. (1992), in their investigation on psychosocial study of leukemic
children and their parents found that Psychological dysfunction existed more frequently
in parents of leukemic children. Depression as an initial reaction on being conveyed the
diagnosis was seen in 85.8% while anger was observed in 42.8%. Majority (89.7%)
entertained doubts about whether a correct diagnosis has been established. Understanding
of the disease, its possible course and the need for prolonged treatment, was appreciated
by about 65.7% of parents. The disease imposed serious social, financial, and
occupational burdens on the family. Measures used to cope with such stresses included
meeting close friends and relatives and finding solace in religious activities. When
comparing psychopathology in leukemic children with that in chronically ill non-
leukemic counterparts, significant differences were observed in certain specific syndrome
scores. Conduct disorder, anxiety, depression, and psychotic symptoms were more prevalent in leukemic children.

Since it is increasingly recognized that psychological, social and behavioural variables influence treatment outcome, attention will likely to continue to increase. The field must meet the challenges of the 1990's in psychosocial care and availability of services, support for training clinicians and investigators in psycho-oncology, and implementation of an exciting research agenda. The focus of new research will encourage collaborative investigations combining biological and psychosocial variables, quality of life research in clinical trials, controlled studies of psychotherapeutic, behavioural and psychopharmacologic research, and cross-cultural studies that will examine differences in prevention and detection, health care systems, alternative therapies and meta analyses.

In this chapter, review of literature on psychological factors of caregivers has been provided. Review of literature revealed several facts that have been so far researched into, as far as caregivers are concerned, namely burden, quality of life, symptoms of stressors, self-efficacy, anxiety and depression.

Based on review of literature, the objectives and hypotheses for the present study have been framed. The methodology with which the study has been carried out is provided in the next chapter.