Review of Literature

It is a well-established fact that a diagnosis of cancer affects not only the patient, but the family as well. The family caregiver, a family member most responsible for meeting the caregiving needs of the patient, is suddenly faced with the challenge of fulfilling unfamiliar care tasks, working through the emotional toll of the diagnosis and trying to maintain a sense of normalcy for the rest of the family. The process of meeting these challenges results in a significant amount of health problems, psychological distress and disturbances in the caregiver’s occupational, familial and social routines. Consequently, programs that help caregivers meet the caregiving demands adequately and minimize the degree of distress they experience are essential.

The current review of literature is focused on understanding the caregiving experience in the context of cancer-affected families. The review will focus on the nature of cancer as a chronic illness with far-reaching effects on the caregiver. It will primarily highlight the consequences of providing care to a cancer patient on the caregivers’ health, quality of life and coping processes. The review will also examine the current scenario with regard to interventions given to cancer caregivers. The review of literature has been organized under the following dimensions.

- Prevalence of cancer in India and the world
- Facets of caregiver burden in the context of cancer
- Impact of caregiving on the caregivers’ health, quality of life (QOL) and coping processes
- Interventions for cancer caregivers
Prevalence of cancer in India and the world

The mortality and morbidity associated with cancer is rising steeply. The International Agency for Research on Cancer (2012) estimated that the year 2012 witnessed 14.1 million new cancer patients, while 8.2 million succumbed to the illness in that year. At least 1.2 million individuals are being diagnosed with cancer annually since 2012 with the incidence rate continuing to rise (American Cancer Society, 2012). A recent American study estimated that 15.5 million people were living with cancer and that another 5 million new patients would be registered by 2026; it also identified prostate, breast, uterus and colorectal cancers to be the most prevalent (Miller et al., 2016). However, an Institute of Medicine Report (Denlinger et al., 2014) reported that for almost all cancers, the 5-year survival rate had increased to 64% for patients of both genders.

Jemal et al. (2011) showed the global burden of cancer to be on the rise, especially in people of developing countries who are switching to numerous cancer-causing behaviours. Lung and breast cancers were the most common malignancies reported by these studies for males and females, respectively. In the Indian setting, Takiar, Nadayil, and Nandakumar (2010) estimated an increase in cases of cancer from 9.79 lakhs in 2010 to 11.48 lakhs by the year 2020. About 50 children succumb to pediatric cancers every day in India (Dey, 2016) with leukemia, lymphomas and CNS malignancies being the biggest killers in this age group (Arora, Eden, & Kapoor, 2009).
Facets of caregiver burden in the context of cancer

Caregiving outcomes are impacted by various socio-demographic correlates of the patients and caregivers like age, gender, socio-economic strata, among others. Within the field of caregiving research, various other variables related to illness and the caregiving situation has also been implicated in how caregivers appraise their challenges. This section summarizes some of the most important socio-demographic and situational variables in cancer caregiving as these variables form the backdrop against which the stresses and rewards of caregiving are experienced. Kim and Schulz (2008) investigated caregiver strain in cancer caregivers in comparison to that of caregivers looking after the frail elderly or patients with diabetes or dementia. The researchers selected 606 caregivers from a nationally representative sample of caregivers from the mentioned categories and surveys were conducted to obtain data on socio-demographic variables, illness categories, caregiving variables and caregiving outcome variables. While the four groups of caregivers had no significant differences in their socio-demographic characteristics, cancer and dementia caregivers provided greater assistance in terms of both activities of daily living (ADLs) and instrumental activities of daily living (IADLs) and the group that reported the greatest caregiving burden was that of the cancer caregivers (67.3%), closely followed by the dementia caregivers (64.4%).

To predict caregiving outcomes, multivariate linear regression analysis was computed and it was found that caregiver’s physical strain was affected by illness category. Cancer and dementia caregivers reported the highest levels of physical strain and emotional stress.
**Gender and caregiving.** Rhee et al. (2008) investigated the prevalence and correlates of depression among cancer caregivers. A sample of 310 patient-caregiver dyads was selected. Demographic data was collected from both patients and caregivers, while caregivers had to complete the Beck Depression Inventory, Caregiver Quality of Life-Cancer (CQOL-C) and the Family Impact Questionnaire. The results showed a high prevalence of depression in the sample with approximately 70% caregivers reporting high depression scores and 35% reporting very high scores. The logistic regression analyses revealed women caregivers, spousal caregivers and those caregivers who reported poorer health, greater caregiver burden and an inability to adapt and function normally as being more likely to experience depression. Caring for a patient with a poorer health status was also linked to depression in caregivers. The heightened vulnerability of cancer caregivers who were female, parents of the patient, less educated, unemployed or generally in poor health has been well-documented (Alpetkin et al., 2007; Quesada, Madrigal, Luna, & Perez-Carceles, 2015).

Li and Loke (2014) conducted a literature review to examine the role of gender differences in the experience of providing informal cancer care to spouses diagnosed with cancer. Using a systematic search process, 19 studies (published between January 2000 and July 2012) meeting the inclusion criteria were reviewed. The review reinforced prior research findings about female spousal caregivers being at a greater risk for mental, physical and social morbidity than their male counterparts. They were more likely to report greater levels of common mental disorders, poorer physical health, bodily strength and physical functioning along with experiencing less than desired levels of marital satisfaction and social support. The caregiving literature is replete with evidence of women caregivers being more
burdened in the caregiving role (Baghi et al., 2007; Li, Mak, & Loke, 2013). Conversely, Srinivasagopalan, Nappinnai, and Solayappan (2015) reported that the male gender being one of the factors predicting poor outcomes for cancer caregivers, while Leeuw et al. (2007) found that gender played no role in caregiving outcomes.

Moser, Kunzler, Nussbeck, Bargetzi, and Znoj (2013) investigated the dyadic interdependence between ratings of psychological distress between cancer patients and their spousal caregivers. A sample of 154 dyads was assessed at four different points of time using the Hospital Anxiety and Depression Scale (HADS), Symptom Checklist - Short Version and Short Form Health Survey. The data was analyzed using linear mixed models and actor-partner interdependence models. The findings of the study showed a high prevalence of common mental disorders and low quality of life in 40% of the sample. The results of the mixed model analyses showed that the risk for significant psychological morbidity was greater for female patients and female partners. Of greater significance was the finding that female partners faced an elevated risk of distress even after psychological strain from caregiving had decreased and that there was a transmission of distress from male cancer patients to their female partners making female spousal caregivers a vulnerable group. Psycho-oncological research has documented that women experience greater distress when confronting cancer, both as patients and caregivers to partners due to gender-based patterns of emotional expression, communication and roles (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Hagedoorn, Kreicbergs, & Appel, 2011; Zwahlen, Hagenbuch, Jenewein, Carley, & Buchi, 2011).
Age and caregiving. Spillers, Wellisch, Kim, Matthews, and Baker (2008) probed into the experience of guilt and psychological distress in cancer caregivers. They selected a combination of demographic and care-related variables and examined the impact of these variables on the feelings of caregiver guilt and adjustment outcomes. A sample of 635 caregivers provided data that was collected through selected subscales of the Caregiver Reaction Assessment Scale (CRA), Caregiving Competence subscale of the Pearlin Stress Scale and the Medical Outcomes Study Short Form-36. They also assessed the physical and mental functioning through composite scores on a generic health index which was measured against norms to evaluate those aspects of stress that were less related to caregiving. The Caregiver Guilt Scale was developed by the authors of the study and the Profile of Mood States (Short Form) was used to assess psychological distress. The results of the study revealed that younger, adult-offspring and employed caregivers were three categories who reported greater guilt. Younger caregiver and women caregivers also reported significantly greater psychological distress. Almost all care-related factors like caregiving at the time of the study, lower familial support, greater caregiving demands, lower perceived self-efficacy and poorer health status of the patient were linked to significantly higher psychological distress. Sherwood et al. (2007) stressed that younger caregivers, being more likely to be employed, suffer more due to caregiving-related work disruptions because the loss of productivity at this early stage may be detrimental to their careers in the long run. Effendy et al. (2015) and Kier et al. (2006) have also supported the finding that younger age of caregivers is allied with poor outcomes. Harden et al. (2013) found younger age to be the sole predictor of negative caregiving appraisals in couples coping with cancer. However, Cormio et
al. (2014) found that older caregivers showed significantly reduced functioning in areas like physical activity, social functioning, vitality, and mental health when compared to their younger counterparts.

**Socio-economic factors in caregiving.** Gorji et al. (2012) conducted a cross-sectional study with 63 caregivers of women with breast cancer in Iran. The study aimed at examining the relationship between depression and quality of life among caregivers. Depression was assessed using Beck Depression Inventory while Caregiver Quality-of-Life-Cancer Scale was used to measure the quality of life of caregivers. A strong negative correlation was found between depression and quality of life of caregivers ($r = -0.67; p<0.01$) and lower levels of income and education had a moderate negative impact on caregivers’ quality of life. Monthly income has repeatedly been implicated in the manner in which cancer caregivers perceive their quality of life to be affected by the illness (Lkhoyaali et al., 2015; Zhu et al., 2013).

Pagano et al. (2014) focused on the economic aspect of caregiver burden among parents of children with cancer. They used administrative data in order to overcome the problems of recall and selection bias associated with using the questionnaire method in this context. They identified 912 cases of pediatric cancers registered with the Piedmont Childhood Cancer Registry and all cases of hospital administration for these patients in the three years following the diagnosis were collated. The total opportunity cost of informal caregiving in this study was assessed through the number of days spent by a parent with the child during inpatient treatment along with radiation and chemotherapy on an outpatient basis too. The results showed that the financial impact of cancer was most pronounced
when the patients were younger or required treatment of a greater complexity. Treatment for leukemia emerged to be the most burdensome financially. Longo, Fitch, Deber, and Williams (2006) extended the understanding of financial costs linked to cancer caregiving by making an assessment of various out-of-pocket costs estimating them to be anywhere between $300-500 per month. They also ascertained that the hours of work lost due to caregiving demands had an impact on perception of burden for these caregivers.

Papastavrou, Charalambous, and Tsangari (2009) conducted a study to understand the caregiver outcomes in family members of cancer patients and identify factors that predict burden and depression among them. A sample of 130 family caregivers was assessed through the Greek versions of the Burden Interview, Center for Epidemiology Scale – Depression (CES-D) and the Ways of Coping Questionnaire (WOCQ). The findings of the study revealed that over 66% of the sample had clinically significant levels of depressive symptoms. The ANOVA computed for the demographic variables of caregiver education and caregiver income revealed these factors to be significantly predictive of high caregiver burden. There was a highly significant relationship between greater levels of burden and differences in coping strategies. Some recent studies, however, reported no effect of caregiver education upon the perception of quality of life (Effendy et al., 2015) and mental health (Zhu et al., 2013). Lukhmana, Bhasin, Chhabra, and Bhatia (2015), from their survey of 200 Indian family caregivers, identified education, employment, marital status, family type of the caregivers along with the type of treatment facility as significant predictors of burden.
Houtven, Ramsey, Hornbrook, Atienza, and Ryn (2010) assessed the economic component of caregiver burden among cancer caregivers. They surveyed caregivers of lung and colorectal cancer patients to obtain data on the number of hours of care they provided per week, their hourly wage and cancer-related expenditure. Combining this information with the number of weeks since diagnosis, they were able to estimate the total economic burden of cancer to approximately equal $14,060 annually for each diagnosed case of cancer.

Campbell and Ramsey (2009) estimated the lifetime cost of medical management of breast cancer to range between 20,000 to 100,000 dollars. Yusuf, Adamu, and Nuhu (2011) studied the burdensome effect of poverty on family members of cancer patients from an African setting and underscored the connection between high psychological morbidity and the lack of finances to cope with the challenge of treatment and caregiving. Bevans and Sternberg (2012) estimated that cancer caregivers spend over 40 hours weekly in fulfilling their care-tasks.

**Multiple roles.** Ryn et al. (2011) studied the various tasks and needs associated with cancer caregiving. A sample of 677 cancer caregivers of lung and colorectal cancer patients were recruited for the study from seven sites. Caregiving variables were obtained from hospital data and ratings based on the extent of caregiving needed while social support and caregiver health was measured using the MOS (Medical Outcomes Study) Social Support Scale and the General Health subscale of Short Form – 12. Almost 70% of the caregivers were providing cancer-specific care and about 50% were helping manage the side-effects of treatment like nausea, pain and fatigue. A significant proportion of caregivers were also involved in functions relating to medication, wound management and emergency care. Half
of these caregivers also had paid jobs to attend to in addition to caregiving and about 20% each reported having poor health and other family members to look after as well. Dahlrup, Ekstrom, Nordell, and Emstahl (2015) and Gonzalez et al. (2016) reported significantly elevated levels of stress, depression, burden of housework, poor health and life satisfaction among informal caregivers in Sweden.

Wadhwa et al. (2013) described the various factors affecting QOL and mental health among cancer caregivers. A sample of 191 caregivers was recruited from 24 oncology centers and data was collected from them using a socio-demographic tool as well as the Caregiver Quality of Life Index-Cancer and the Medical Outcomes Study SF. A majority of caregivers were partners living with the patients and caregiving demands had necessitated a quarter of them to alter their work situation. The results of the multiple regression analysis revealed that better caregiver QOL was linked to a better functional status of the patient, better caregiver mental health and a lack of other dependents. Women caregivers and caregivers who spent greater hours in providing care or had to accommodate caregiving by cutting down or changing their work situation reported greater QOL deficits. Sherwood et al. (2007) and Duxbury, Higgins, and Smart (2011) also emphasized the theme of disturbances in occupational functioning and productivity specifying that any reduction, change in work or withdrawal from the work force was detrimental.

Kim, Carver, Shaffer, Gansler, and Cannady (2015) explored the impact that early caregiving stress had on development of subsequent health impairments among a sample of cancer caregivers who were studied 2, 5 and 8 years after the diagnosis of their patients. The caregivers were divided into two groups based on
whether the person they were looking after during the initial assessment was alive or deceased. The researchers looked for the presence of three health impairments, namely, arthritis, chronic back pain and cardiovascular illnesses during the course of the assessment points. From the analysis, it was evident that initial caregiving stress and later health impairment were concurrent. This tendency of caregivers who were distressed initially to develop one of the three identified illnesses was most prominent for spousal caregivers who experienced these impairments as late as 5 to 8 years after the cancer diagnosis of their patient. Psychological distress in caregivers is the result of complex interplay of patient’s illness characteristics and the personal characteristics and resources of the caregiver (Sherwood et al., 2008).

Ryn et al. (2011) identified some consequences like health deterioration, role conflict, social restrictions, symptom management and medical monitoring as being associated with poor adjustment in caregivers. Park et al. (2012) identified the determinants that help caregivers identify both positive and negative consequences of caregiving and showed that caregivers were more likely to report positivity in this experience if they were male, spiritually inclined, perceived fewer schedule disruptions from caregiving and received adequate social support.

**Duration of illness.** Kim, Shaffer, Carver, and Cannady (2014) used a prospective longitudinal design to understand the factors that predict depression in cancer caregivers two years and five years post-diagnosis. The demographic variables, caregiving variables and depression (using the CES-D) was assessed for 416 cancer caregivers at 2 years post diagnosis. The second round of assessment of depressive symptomatology was conducted 3 years after the initial assessment. The caregivers were then categorized as former, current and bereaved caregivers. The
findings of the study revealed that after controlling for the initial level of depressive symptoms, the level of caregiving stress and poor levels of social support were the strongest predictors of depression five years down the illness trajectory. Current caregivers reported the largest increase in depressive symptoms over the three-year interval between the two assessment points. The prevalence of psychological distress of proportions justifying formal psychological support has been reported in one in five cancer caregivers in a study by Merckaert et al. (2013). Likewise, Janda et al. (2007) conveyed that caregivers in their study were more anxious and depressed than their patients and were seeking psychological support to cope effectively with their stress and health problems.

Klassen et al. (2010) identified factors that influence the health-related quality of life (HRQOL) of caregivers in the context of paediatric cancers in Canada. They developed a model using the stress process paradigm and collected data from 411 parental caregivers. The components of the model included socio-demographic background, patient characteristics, family-centred service delivery, caregiver strain, intrapsychic factors, coping/supportive factors and caregiver HRQOL. The Functional Status II was used to assess the patient characteristics and My Child with Cancer Questionnaire was used to assess caregiver strain. Measures of Process of Care and the Life Orientation Test-Revised (LOT-R) were used to assess medical services delivery and dispositional factors like optimism in the caregivers. Family Assessment Device, Medical Outcomes Survey Study Scale, Coping Health Inventory were used to evaluate the coping and supporting factors. The SF-36 was used for assessing HRQOL of parents. Data was partitioned based on time since diagnosis into two groups: less than a year since diagnosis and over a
year since diagnosis. In the first year of treatment, caregiver strain and social support accounted for 50% of the variation in physical health, while family-centred service delivery, caregiver strain and self-perception accounted for almost 60% of the variation in psychosocial health. For caregivers who had been providing care for over a year, caregiver strain alone explained 66% and 55% of the variation in psychosocial and physical health, respectively. Caregiver burden is perhaps the most potent predictor of the most common caregiving outcomes: health and quality of life (Akpan-Idiok & Anarado, 2014; Rha, Park, Song, Lee, & Lee, 2015).

**Positive factors in caregiving.** Nam et al. (2016) assessed the multifactorial nature of caregiver distress in the context of pediatric oncology. They assessed various socio-demographic and patient/clinical parameters involved in the experience of caring for a child with cancer in a sample of 366 pediatric cancer caregivers. The Impact of Event Scale was the primary outcome measure with two subscales to assess avoidance and intrusion. Analysis of the data revealed caregivers with a family income of below $40,000 dollars experienced significantly more distress. Weak religious affiliation as assessed by infrequent attendance at religious services and younger patient age were related to higher levels of intrusion in these caregivers.

Teixeira and Pereira (2013) evaluated the psychological morbidity, burden and social support in a sample of 214 adult offspring caregivers looking after their parents with cancer. The tools used for the study were Depression Anxiety and Stress Scales (DASS), Impact of Event Scale-Revised, Satisfaction with Social Support Scale and Burden Assessment Scale (BAS). Hierarchical regression analyses identified female caregivers, caregiving duration, parental dependency,
greater caregiver distress and poor social support as important predictors of
caregiver burden in this sample. Butow et al. (2014) studied caregivers of advanced
ovarian cancer patients to find that both emotional distress and quality of life were
lower than population norms, worsened with illness progression and were predicted
by health and unmet needs and non-support.

**Impact of caregiving on the caregiver’s health**

The health-related consequences of cancer caregivers are enormous. Cancer
caregiving affects every domain of function and the chronic stress inherent in
cancer caregiving results in the caregivers’ functioning being affected in the most
elemental of ways. The impact of cancer caregiving on health is examined in this
section through a few broad divisions like overall health, cardiovascular
functioning, immunological functioning, distress and sleep.

**Overall health.** Goren, Gilloteau, Lees, and DiBonaventura (2014)
conducted an exploratory study to examine different facets of caregiver burden in
the cancer-affected populations in Europe. A sample of 1713 cancer caregivers and
103868 non-caregivers was contacted through the Internet and asked to provide
self-rating assessments of their socio-demographic background, health status and
behaviours, work productivity and activity impairment, healthcare resource usage
and diagnosed stress-related comorbidities. Multivariate regression analysis
revealed that cancer caregivers reported significant deficits on all health outcomes
even after adjusting for a wide range of confounding factors. The detrimental
impact of cancer caregiving on general health has been a consistent finding
(Glajchen, 2012; Gupta & Sharma, 2013; Rhee et al., 2008). Beesley, Price, and
Webb (2010) highlighted that this detrimental effect of caregiving on health
extended to a point where caregivers found themselves unable to maintain a personal health regimen.

Heins, Korevaar Rijken, & Schellevis (2013) explored the degree to which partners of cancer patients meet their general physicians in the two years following the cancer diagnosis through a cohort study. They selected 3071 partners of patients diagnosed with breast, prostate, colorectal and lung cancer and tracked the general physician (GP) visits and health complaints of the caregivers six months before diagnosis and two years after diagnosis. While there were no changes in the first six months following diagnosis, in the time period between 6 and 24 months after diagnosis, partners of breast, prostate and colorectal cancer registered a significantly higher frequency of visits to their GPs Partners of lung cancer patients reported greater psychological symptoms, while those of prostate cancer patients reported more somatic complaints. Partners of breast and colorectal cancer patients reported both psychological and somatic symptoms and across all categories, the partners’ cancer diagnosis was a frequently reported reason for contacting the GP. Literature exists to attest the higher health service usage among cancer caregivers for mental health difficulties (Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005) and for a steep increase in the same in the first two years following diagnosis of the patient (Sjovall et al., 2009).

Sjolander et al. (2012) used a prospective study design to evaluate the health-related quality of life (HRQOL) of caregivers of cancer patients, three months post-diagnosis. A sample of 36 caregivers was assessed five times using the Short Form Health Survey (SF-36) and the EuroQol (EQ-5D). The results of the study indicated that compared to norms, caregivers scored significantly lower
on mental HRQOL and EQ-5D Visual Analogue Scale throughout the one-period of assessments. The study highlighted that the greater deficits in physical health were reported by older and spousal caregivers, while younger caregivers tended to experience lower levels of mental health as a result of caregiving.

Mosher, Bakas, and Champion (2013) studied the physical and mental health of caregivers of lung cancer patients and their associations with life changes. A total of 91 family caregivers were contacted at four different oncology centres and clinics in Indianapolis and asked to provide responses to medical, socio-demographic and standardized tools to evaluate health and life changes. The results demonstrated that caregivers reported poorer mental and physical health when compared to the general population. Over half the caregivers experienced negative emotional consequences from caregiving, while one-third of the sample reported that their health deteriorated too. However, 40% of the caregivers in this study did report positive changes in their relationship with the patient as well as with other family members following the experience of coping with cancer. Mental health emerged to be more strongly associated with life changes when compared to physical health. Mental health has emerged as a variable of interventional interest among caregivers due to its role in affecting all other domains of functioning, especially physical health and quality of life (Zhu et al., 2013).

Psychological distress. Feiten et al. (2013) interviewed a sample of 137 family caregivers of cancer patients with a metastatic solid tumor in Germany. They were assessed to obtain a picture of their levels of distress (through the Distress Thermometer) and their caregiving-related problems (through the Hospital Anxiety and Depression Scale). Over half the caregivers in the study scored over
the cut-off of 5 on the Distress Thermometer (mean=4.8). Clinically, about 20% of the caregivers were anxious and another 15% were depressed as assessed by the HADS. While women did report greater psychological distress, gender was found to not be a predictor variable in the ratings of distress provided by the caregivers. Manjeet, Jyoti, and Sainath (2014) found that one-third of the 100 cancer caregivers in their study in India reported moderate to severe anxiety and depression, while over half the caregivers reported elevated levels of emotional distress, when compared to the high HADS cut off (>15). Yusuf, Adamu, and Nuhu (2010) reported very high burden [(95% CI 39.9–59.1%)] and psychological morbidity [(95% CI 37.0–56.2%)] in over half the African cancer caregivers who participated in their study.

Gadiraju, Vanlalhrualii, Rana, Nandinee, and Hariharan (2016) studied the psychological distress and somatization inherent to the cancer caregiving experience. They selected a sample of 100 cancer patients and caregivers each and administered the Four-Dimensional Symptom Questionnaire. The results revealed significant interrelationships between the psychological functioning of patients and caregivers. The four symptoms – depression, anxiety, distress and somatization – in caregivers explained 17% of the anxiety experienced by patients. Brinda, Rajkumar, Enemark, Atterman, and Jacob (2014) also documented the presence of substantial levels of depression in their study of rural Indian family caregivers. This elevated psychological distress maybe attributed to various factors. Illness-related uncertainty and the consequent disruption in normal functioning significantly predicted depressed mood in caregivers (Lewis, Fletcher, Cochrane, & Fann, 2008). Similarly, fear of recurrence is described to be a very potent form
of anxiety among cancer caregivers, affecting them more intensely than general anxiety (Kim, Carver, Spillers, Love-Ghaffari, & Kaw, 2012).

Yang et al. (2012) aimed to assess the prevalence and predictive factors of depression among cancer caregivers in China. They conducted personal interviews with 312 cancer caregivers and obtained data on demographic variables, caregiving variables and depression, as measured by the CES-D. The results of a multivariate hierarchical regression showed that demographic variables pertaining to the caregiver and subjective caregiver burden accounted for most of the variance in the model and the latter was positively related to depressive symptoms. The study ascertained the prevalence of depressive symptoms in caregivers to be about 63.5% in this sample. High rates of depression in cancer caregivers, as measured by the CES-D cut-off (>16), have been reported by Kessler et al. (2014), Kim, Shaffer, Carver, and Cannady (2014), and Sternberg, Cvancarova, Ekstedt, Olsson, and Ruland (2014).

**Cardiovascular functioning.** Cora, Partinico, Munafo, and Palomba (2012) examined the linkages between long-term caregiving and allied health risks in caregivers. The researchers selected 20 family caregivers of terminally ill cancer patients and compared them to 20 control samples, who were matched for both age and gender. They evaluated the psychological impact of caregiving through interviews. They also collected blood pressure readings and heart rate readings along with other measures to assess cardiovascular risk at four different points of time. The findings revealed greater levels of depression, state anxiety and sleep disruption as evidence of psychological impact. The caregivers had elevated blood pressure readings and the elevation noted in heart rates was linked to the duration
of caregiving. However, cancer caregivers in a similar study reported no
differences when compared to healthy controls for adjusted rates of different
cardiovascular conditions and diabetes (Shaffer, 2013). The same study reported
that older age, subjective caregiver burden and depressive symptoms were
associated with elevated cardiovascular risks.

Ji, Zoller, Sundquist, and Sundquist (2012) assessed the health risks posed
by caregiving. A total of 122,683 husbands and 161,287 wives who provided care
to their spouses with cancer were identified from the Swedish Cancer Registry. The
spousal caregivers were followed up starting from diagnosis (between 2000 and
2002) till 2008. The computed standardized incidence ratios of the caregivers were
compared to non-caregiving spouses. The results showed that the risk of husbands
developing coronary heart disease, ischemic stroke and haemorrhagic stroke
(following cancer diagnosis for their wives) increased by hazard ratios of 1.13,
1.24 and 1.25, respectively; the corresponding rise in hazard ratios experienced by
wives looking after husbands with cancer increased by 1.19, 1.29 and 1.27.
Additionally, these risks remained consistent and were higher for caregivers who
were providing care to a spouse who had a poorer prognosis. Spousal caregivers
were found to be at an elevated risk for morbidity in terms of an elevated hazard
ratio (1.39) for mood disorders (Nakaya et al., 2010) and mortality one year post-
diagnosis of their spouses (Christakis & Allison, 2006).

Physiological and immune functioning. Gregorio et al. (2012) examined
the impact of cancer recurrence and subjective impact of cancer-specific stress on
physical health and immune function of spousal caregivers of breast cancer
patients. A matched-control design was used with 16 participants each in the
experimental and control group. To evaluate cancer-specific stress, the Impact of Events Scale was used while physical health was measured by the Total Disruption Scale of the Fatigue Symptom Inventory – Revised. To assess immunological function, a profile of the T-cell blastogenic response pattern was obtained for all caregivers. In addition various socio-demographic variables and details on health behaviours and health status were obtained. The results of the study revealed that cancer recurrence was not a significant predictor of poorer health status and lower immune functioning but greater cancer-specific stress was associated with both these variables. The study reinforces the finding that the burden of caregiving has a pronounced impact on caregiver health and immunity and that the subjective assessment of cancer-related distress is a major determinant of caregiving outcomes. In a classic study by Cohen and Pollack (2005), distressed adult daughters of breast cancer patients experienced disrupted immune functioning in the form of decreased in vitro interleukin secretion that was mediated by norepinephrine and cortisol; similar reports of immunological changes due to HPA axis disruption have been reported recently as well (Bevans et al., 2016).

Lucini et al. (2008) investigated the role of the autonomic nervous system in responding to the chronic stress of caregiving. They recruited 58 cancer caregivers and 60 controls and obtained measures of their stress levels, hormonal activity and autonomic reactivity. To evaluate stress levels, a semi-structured interview was used by a clinical psychologist who eliminated cases that could have a psychiatric component. Further, the Overall Stress and Tiredness Scale, Control Perception Scale, Subjective Stress-Related Somatic Symptoms Questionnaire and the Satisfaction Profile were used as self-report measures of stress, health and
quality of life. The hormonal assessments included the ELISA test and a cortisol assessment through saliva. As a part of the autonomic assessment, blood pressure, ECG and respiratory activity were recorded after a rest period. The collected data was subjected to autoregressive spectral analysis and revealed high levels of stress and poor quality of life. Of greater significance was the result that there existed a palpable autonomic imbalance without the evidence of organ malfunction. This lead the researchers to link caregiving-related stress as a precipitator of cardiovascular changes in the caregivers. Bevans and Sternberg (2012) have highlighted the role of psychological stress in the emergence of physical impairments in cancer caregivers, while Miller et al. (2014) reported evidence of greater inflammatory gene expression among chronically stressed caregivers which could undermine their immunity.

Ratnakar et al. (2008) examined the relationship between psychological stress experienced by caregivers with their levels of oxidative stress and elevated glomerular permeability to proteins. The biological markers of the stress response were obtained by monitoring the levels of urinary malondialdehyde:creatinine ratio (UMDA:Cr), urinary protein:creatinine ratio (UP:Cr) and SDS polyacrylamide gel electrophoresis in the urinary protein profiles of a sample of 31 cancer caregivers. In comparison to the matched controls, the level of anxiety and depression (as assessed by HADS) as well as the urinary malondialdehyde:creatinine ratio and urinary protein:creatinine ratio (UP:Cr) were significantly elevated in the experimental group reflecting an increased glomerular permeability. This relationship between oxidative stress and increased glomerular permeability in the
kidneys has been reported in Indian caregivers of patients with mental illnesses (Dalui, Guha, De, Chakraborty, & Chakraborty, 2014).

Rohleder, Marin, Ma, and Miller (2009) examined the specific biological impact of caregiving on family members of cancer patients. They collected samples of some key biological markers from 18 caregivers and 19 control samples at four different points of time in a year. Salivary biomarkers assessing HPA functioning and SNS activity were collected in addition to systemic inflammatory marker in the blood. The results indicated that while cortisol output was the same in both groups, caregivers had marked changes in their production of diurnal salivary amylase—a measure of sympathetic nervous system activity. The caregivers also registered a drastic linear increment in their level of C-reactive protein, highlighting the systemic inflammation experienced by caregivers. In addition, the caregivers were also noted to have lower levels of mRNA related to anti-inflammatory signalling molecules and poorer glucocorticoid sensitivity. The role of chronic-stress related inflammation in the development of various physical and mental health conditions has been reported by Currier and Nemeroff (2014), Libby, Ridker, and Hanson (2011) and Scrivo, Vasile, Bartosiewicz, and Valesini (2011). Interestingly, Laudenslager et al. (2015) reported no differences in salivary cortisol awakening response between cancer caregivers and controls.

Sleep disruption. Kontronoulas, Wengstrom, and Kearney (2016) engaged in a longitudinal examination of patterns of sleep-wake parameters in patient-caregiver dyads coping with breast cancer. In this repeated-measures study, 48 breast cancer patients and their caregivers were assessed using the Pittsburgh Sleep Quality Index before, during and upon completion of adjuvant chemotherapy...
cycles. The findings of this study revealed that in each of the patient-caregiver dyads, at least one person had poor sleep quality and in about a third of the cases, both the patient and the caregiver reported deficits in the sleep-wake parameters assessed. Strong evidence emerged for the interrelatedness between patients and caregivers with regard to sleep onset latency, total sleep time and general sleep impairment. Cancer caregivers experience significant sleep disruption related to physical and emotional tasks involved (Brummett et al., 2006). Patient’s medical status and caregiver’s financial distress predicted greater sleep disruption, while positive coping was related to fewer disturbances in sleep patterns (Zhang, Yao, Wang, & Zhou, 2014). Such sleep disruption in cancer caregivers is associated with elevated allostatic load (Roepke et al., 2010), cognitive deficits (Bonnet, 2011), as well as depressive symptoms (Hamilton, Nelson, Stevens, & Kitzman, 2007).

Pawl, Lee, Clark, and Sherwood (2011) conducted a study to examine the degree of sleep loss experience by caregivers of patients with primary malignant brain tumors and its impact on their health. From a sample of 133 caregivers, data was collected using standardized questionnaires, serum blood samples and sleep profiles of caregivers for a 3-day period using an accelerometer. The statistical analysis revealed that caregivers had a sleep latency period of 35 minutes, total sleep time of 357 minutes and more frequent awakenings (15.1%). These measures significantly differed from the parameters recommended by the American Academy of Sleep Medicine which stipulates a sleep latency of less than 15 minutes, sleep duration of more than 7 hours and a sleep efficiency of 85%. Those caregivers who experienced poorer sleep quality and high degrees of anxiety had
small but significant differences in their quality of life ratings. Pawl, Lee, Clark, and Sherwood (2013) assessed the sleep patterns of caregivers looking after patients with primary brain malignancies to report substantially compromised sleep hygiene.

**Impact of caregiving on the caregiver’s quality of life (QOL)**

The adverse effects of caregiving transcend beyond the immediate health and functioning of cancer caregivers. They disrupt their functioning at home, in the workplace and in their relationships thus undermining their overall quality of life. These outcomes are produced directly due to the cancer (financial burden due to cost of medical care) or indirectly as in the case of proliferative or secondary stressors like relational deprivation, recreational handicap or lifestyle interference. The multi-dimensional impact of cancer on the caregivers’ life is reviewed in this section.

**Psychological functioning.** Escobar-Ciro (2012) studied the manner in which a group of Spanish cancer caregivers perceived their quality of life. A sample of 2009 cancer caregivers who were providing care for a minimum duration of three months was selected through convenience sampling. These caregivers were then asked to provide basic socio-demographic details and information about their patient’s functional status. They also responded to the Quality of Life Scale – Family Version which assesses psychological, social, physical and spiritual domains of quality of life. The results of the study indicated that the caregivers reported greatest disruption in their physical quality of life, closely followed by psychological and social quality of life. In sharp contrast, studies by Bergelt, Koch, and Peterson (2008) and Grov, Dahl, Moum, and Fossa (2005) described cancer
caregivers’ psychological quality of life being more affected than physical functioning.

Fujinami et al. (2015) examined the manner in which caregiver distress, caregiver QOL, burden and preparedness interact to identify unique challenges faced by caregivers of cancer patients. A sample of 163 caregivers of patients with non-small cell lung cancer was recruited and data was collected from them through a battery of tests: socio-demographic questionnaire, City of Hope QOL Scale (Family), Distress Thermometer, Caregiver Burden Scale and others. A moderate level of distress was reported and this was attributed to three components vis-a-vis self-care, caregiver role and caregiver stress which accounted for 49% of the reported distress. This perception of the self as a caregiver and knowledge of what caregiving entails is implicated in another study assessing preparedness (Herriksson & Arestedt, 2013) wherein female gender of the caregiver, living close to the patient, low anxiety and a sense of hope and rewards in the caregiving process emerged as predictors of caregiver quality of life.

Ferrell, Koczywas, Grannis, and Harrington (2011) followed up the quality of life of family caregivers of lung cancer. They examined the QOL concerns for family caregivers of patients with advanced lung cancer for 6 months. In cases of caregivers coping with an early stage illness, the follow up was conducted over a 12-month period. A battery of tools was used to evaluate quality of life, caregiver burden, psychological distress, self-care assessment and preparedness for caregiving. From a study of 161 such caregivers, it emerged that a majority of caregivers were women, aged over 55 and had a chronic illnesses themselves. The most frequently reported QOL concerns by the caregivers involved distress relating
to the initial diagnosis, recurrence, treatment and dealing with the uncertain prognosis. With regard to caregiver burden, caregivers reported that the time required in providing care, the overall stress associated with the experience and navigating the healthcare system as the most pressing concerns. Only a quarter of the caregivers surveyed in the study by Ryn et al. (2011) reported feeling confident in their ability to provide care. Cancer caregiving is replete with cancer-specific caregiving tasks that caregivers have to perform with little preparation, limited resources and in conjunction with additional demands – a process that is highly burdensome (Rha, Park, Song, Lee, & Lee, 2015).

Grant et al. (2013) studied the degree of burden, skill preparedness and QOL among caregivers of patients with non-small cell lung cancer. The study was cross-sectional and used the longitudinal design. A sample of 163 family caregivers was recruited and assessed at baseline and at 7, 12, 18 and 24 weeks from baseline. The researchers used the Caregiver Burden Scale to assess both objective and subjective burden. Skill preparedness was measured through the Preparedness for Caregiving subscale of the Family Caregiving Inventory, while the Psychological Distress Thermometer was used to evaluate emotional distress. Although the caregivers in the sample reported high skill preparedness and only moderate distress at the start, skill preparedness reduced over time and psychological distress rose. The subjective component of burden increased with time. The overall QOL registered a significant decrease and this drop was most pronounced in the dimension of psychological well-being. Grant et al. (2013), Mosher, Bakas and Champion (2013), and Siminoff, Wilson-Genderson, and Baker (2010) reinforced the finding that within the construct of quality of life, the
psychological domain is particularly vulnerable to the adverse consequences of cancer caregiving.

Soleimani, Lehto, Negarandeh, Bahrami, and Chan (2016) investigated the role of a unique facet – death anxiety – in quality of life appraisals of cancer caregivers in Iran. Death anxiety can affect functioning of the caregiver, family communication as well as impede the process of delivering quality care to a loved one with cancer. A sample of 130 cancer caregivers was given the Templer Scale for death anxiety and the family version of a standard quality of life tool. The findings reflected the existence of a moderate level of death anxiety and quality of life deficits among the caregivers surveyed. As a class of caregivers, daughters reported greater death anxiety.

Financial functioning. Denzen et al. (2016) conducted a multi-centre study to assess the financial burden inherent to hematopoietic cell transplantation. They studied a group of 16 patient-caregiver dyads at baseline and at 6, 12, 18 and 24 months after the procedure. The cumulative impact of the treatment was significant even two years after treatment with half of the sample reporting that the family income reduced due to the patient being unable to regain employment. A substantial majority (80%) of the families admitted that the procedure and its costs had affected their household income in a moderate to severe extent. Many patients and caregivers reported finding it difficult to fulfil medical care costs in the two years following the diagnosis. The financial impact of cancer on the caregiver’s quality of life is expressed through various facets like unexpected hospitalization and employment disruption (Warner, Kirchhoff, Nam, & Fluchel, 2014),
heightened risk for bankruptcy (Ramsey et al., 2013) and time costs (Yabroff and Kim, 2009).

Park et al. (2012) compared the quality of life of caregivers of advanced cancer patients with the general population. Using the propensity-matching technique, a sample of 137 caregivers and 137 control subjects were selected. They were asked to respond to the EuroQOL-5D and its EQ Visual Analog Scale, along with the Caregiver Reaction Assessment tool. The caregivers reported significantly lower health-related quality of life and experienced more depressive episodes in the year prior to the study. Facets of caregiver burden such as impact on health and finances as well as lack of family support had adverse effects on both health-related quality of life and mental health of the caregivers. Parallel findings were reported by Abbasnezhad et al. (2015) in the Iranian context wherein cancer caregivers stating financial and psychological distress had reduced physical quality of life in domains like pain and physical activity, while Bužgová, Jarošová, and Hajnová (2015) documented the multidimensional QOL impairments and common mental disorders in this population. Cancer Caregivers in a recent study (Rha, Park, Song, Lee, & Lee, 2015) showed a decline in physical activity, while engaging in other health-promoting behaviours (responsible alcohol consumption and adherence to cancer screenings) indicating a possible consequence of caregiver fatigue on physical activity alone.

**Interpersonal and familial functioning.** Harden et al. (2013) showed how QOL deficits arising from cancer caregiving continue to affect the spousal caregivers even after 36 months post-treatment. The current study was conducted through telephonic interviews with 95 female spouses of prostate cancer patients at
36 months after initial treatment. Quality of life was assessed using the Medical Outcomes Study –SF 12 and the Caregiver Quality of Life Index – Cancer. Satisfaction in marital and sexual functioning was assessed through the Dyadic Adjustment Scale and the Sexual Satisfaction Scale. The Appraisal of Caregiving Scale, Omega Screening Questionnaire and Spouse Expanded Prostate Cancer Index Composite were used too. The findings indicated that poorer cancer-specific QOL and lower sexual satisfaction was related to perceptions of threat and stressfulness as appraised by greater perceptions of bother over urinary irritation, sexual and hormonal disturbances in the patients.

Wagner, Bigatti, and Storniolo (2006) compared the quality of life of husbands of patients with breast cancer to a control group of husbands of healthy wives. The study assessed 158 husbands (79 participants each in the experimental and control groups) on parameters like quality of life, activities of daily living and coping processes through the Medical Outcomes Study SF, Illness Impact Form and Ways of Coping Questionnaire, respectively. The findings revealed a low quality of life among spouses of breast cancer patients in the domains of general health, mental health, vitality and role-emotional daily activities. These factors, in turn, were associated with higher illness impact reported by the spousal caregivers in the study. Given, Given, and Sherwood (2012), in a review, linked the burden of caregiving to the physical, physiological and psychological deterioration of cancer caregivers. The continuation of this tendency manifests in impaired quality of life.

Lee et al. (2013) examined the degree to which caregivers of advanced lung cancer patients experienced anxiety and depression just after diagnosis and before starting treatment. They also explored factors that predicted the psychological
distress experienced by the caregivers. A sample of 106 patient-caregiver dyads were recruited from a hospital in Taiwan and the Hospital Anxiety and Depression Scale and the Self-Efficacy in Symptom Management Scale were administered. The results revealed that approximately 50% of the patients and 30% of the caregivers were at significant risk for anxiety and depression before treatment started. The results also showed that when caregivers were younger and had lower self-efficacy, they reported greater psychological distress. Psychological distress was also linked to having to look after another ailing family member and symptoms of pain in the cancer patient. Valeberg and Grov (2013) identified pain, fatigue, constipation and sleeplessness in the patient as determinants of caregiver quality of life and mental health, with these associations being more pronounced in the case of female and younger caregivers. Pain in cancer patients, in turn, causes fatigue, loss of appetite and sleep disturbances which the caregiver must manage. For caregivers, pain is the starting of other problems like costs associated with pain management and its effect on occupational and household functioning (Ovayolu, Ovayolu, Aytac, Serce, & Servinc, 2014).

Murray et al. (2010) studied the degree to which domain-specific distress experienced by lung cancer patients and their caregivers are concordant. They selected 19 patient-caregiver dyads and conducted a total of 88 interviews with them. The secondary analysis of the collected data revealed that caregivers clearly followed a pattern of domain-specific distress that was similar to that experienced by the patients. Psychological and spiritual distress was more pronounced among these caregivers. This distress peaked at certain points of the illness trajectory: diagnosis, adjusting to home after treatment, recurrence and towards the end of the
patient’s life. The variable impact of illness trajectory has been reported consistently. Janda et al. (2007) found high-grade malignancy to be the key predictor of caregiver quality of life in their study. Sherman, McGuire, Free and Cheon (2014), in their qualitative analysis of pancreatic cancer caregivers, uncovered transitional themes that paralleled the critical points mentioned in literature like the appearance of sentinel symptoms, diagnosis and acceptance of the eventual outcome of the process.

Molassiotis, Wilson, Blair, Howe, and Cavet (2011) explored the experience of living with a diagnosis of multiple myeloma in a family member. In a rare qualitative study on the quality of life of patients with multiple myeloma and their caregivers, the researchers conducted semi-structured interviews with 20 patients and 16 caregivers. The data was collected using a grounded theory approach, analyzed through a content analysis and independent raters were used to arrive at a consensus about the final coding procedure. The major findings pertaining to quality of life of caregivers were grouped under themes like current and future concerns (fears about the treatment outcome), effects of myeloma on daily life (changes in daily, social and occupational functioning), coping (need for information about prognosis, need to engage in protective buffering), unmet needs (limited expressed need and support) and caregiver burden (cost of staying positive, lack of free communication about illness). On the whole, the quality of life of the caregivers was affected adversely as they sought to provide practical and emotional support to the patients at the cost of their own needs and concerns. Bergelt, Koch, and Peterson (2008) and Rigoni, Bruhn, DeCicco, Kanda, and Matos (2016) identified a similar multidimensional impact of cancer caregiving on various elements of quality of life like health, daily activities, and social
functioning. Lee et al. (2015) identified 29 themes and 59 sub-themes of quality of life disruptions in various domains like health, finances, spirituality and daily functioning that are relevant to cancer caregivers.

Nightingale, Curbow, Wingard, Pereira, and Carnaby (2016) assessed caregivers of patients undergoing radiotherapy for head and neck cancers (HNCs). They assessed the perceived burden, quality of life and perceived social support for these caregivers at the start of radiotherapy, five weeks into radiotherapy and a month after radiotherapy was completed. The results revealed that caregivers experienced greater burden and disruption in quality of life once radiotherapy was well underway. Various facets of quality of life like lifestyle disruption and overall health showed a persistent downward trend with each assessment point. In another study of caregivers of HNCs, adaptation to the “new normal” and feelings of vigilance, fear, sympathy and guilt were prominent (Fronzeck, 2015). Some aspects of HNCs that make the caregiving process more burdensome are complicated wound management, altered appearance, persistent communication and feeding difficulties (Baehring & McCrorckle, 2012).

Tamayo, Broxson, Munsell, and Cohen (2010) examined the quality of life and well-being of a sample of 194 family caregivers of patients with leukemia who were receiving outpatient chemotherapy. The Caregiver Quality-of-Life-Cancer Scale, the Caregiver Well-Being Scale and a Learning Needs Questionnaire developed for the study were utilized as tools in the study. The collected data was subjected to descriptive analysis and an exploratory factor analysis to identify the key factors affecting the quality of life and well-being of the caregivers. The findings revealed caregiver burden as being the most important factor affecting
quality of life; communication, positive attitudes, support and the level of education of the caregivers also had a bearing on their quality of life.

Tang et al. (2013) examined the psychological well-being of cancer caregivers over the course of the illness trajectory. The CES-D, MOS Social Support Survey, Caregiver Reaction Assessment and Symptom Distress Scale were administered to 193 cancer caregivers in this prospective longitudinal study. The results obtained from the generalized estimating equation modelling identified terminal illness, lack of social support and younger patient age as some predictors of greater symptom distress. Various forms of quality of life deficits like greater burden, more pronounced disruption in schedules, higher deterioration in caregiver health and low family cohesiveness in the face of the illness were some factors that heightened the vulnerability to depression among the participating caregivers. Disrupted schedules and financial challenges are often related to heightened caregiver burden (Harnett, Thom, & Kline, 2016) as are the physical, social, and emotional challenges precipitated by caregiving (Sternberg, Ruland, & Miaskowski, 2010).

Turkoglu and Kilic (2012) conducted a study with 190 family caregivers of cancer patients who were providing care to a family member diagnosed with cancer in East Turkey. The aim of the study was to assess the effect of care burdens on the quality of life of the caregivers and the researchers used the Burden Interview and the Caregiver Quality-of-Life-Cancer Scale to assess the main variables. The findings indicated that there was a negative relationship between care burden and caregivers’ quality of life with the care burden accounting for 60% of the variance in quality of life of caregivers. Gender, age, income, caregivers’
relationship with the patient and the patient’s perception of their health status were some demographic variables that emerged to have an important effect on quality of life of the caregiver in this study. Grant et al. (2013) provided evidence for a similar relationship between caregiver burden and quality of life in their study; preparedness and skills buffered this decline in burden and quality of life but only to a limited extent.

**Impact of cancer caregiving on the caregiver’s coping processes**

Coping processes among cancer caregivers have been studied in depth only to reveal that no watertight divisions exist. Cancer caregiving being an abrupt and persistent challenge elicits a vast range of coping responses among individuals and some broad strokes point to problem-focused strategies being desirable and coping through substance abuse or self-blame (dysfunctional strategies) being counterproductive. Some elements of emotion-focused coping like acceptance are helpful, while others like denial or venting are not. In this section, the various ways in which family members cope with cancer caregiving are reviewed.

Aydogan et al. (2016) examined the relationship between coping processes of cancer patients and caregivers and their association with caregiver quality of life. A sample consisting of 74 cancer patients, (46 cancer caregivers and 46 control group participants) was recruited. The COPE and SF-36 were utilized to assess coping attitudes and quality of life, respectively. When compared to cancer patients and normal controls, cancer caregivers reported statistically significant elevations in their use of problem-focused coping strategies (active coping and planning) and the emotion-focused strategy of acceptance. Women caregivers reported significantly greater usage of mental disengagement and dysfunctional
coping strategies and experienced the greatest disruptions in some domains of quality of life like pain, vitality and emotional role strain. Ellis et al. (2016) demonstrated that meaning-focused coping mediated pathways between patient functioning and caregiver health and quality of life. Garcia-Alberca et al. (2012) demonstrated that disengagement coping mediated the relationship between caregiver burden and psychological distress among dementia caregivers.

Fife, Monahan, Abonour, Wood, and Stump (2009) examined the adaptational process in caregivers of patients undergoing bone marrow transplant across the acute phase of the transplant trajectory. The data was collected through self-report questionnaires from 193 caregivers before, during and after the period of acute hospitalization and transplant. To assess adaptation, the Positive and Negative Affect Scale was used for emotional response and Bakas Caregiving Outcome Scale was used for perceived caregiver burden. To assess the mediating variables of coping, personal control and spirituality, the Ways of Coping Checklist, the Mastery Scale and the FACIT – Spiritual Well-Being Scale was used, respectively. To study the contextual factors, the Perceived Health-Care Provider Support Scale, the Dyadic Adjustment Scale and the Symptomatology Checklist were used. The main findings of the study were a decline in distress as caregivers moved through the illness trajectory and that higher levels of distress were significantly associated with lower personal control, lower sense of spiritual connectedness, greater disruption in caregiver’s life and the use of avoidant coping. Lack of personal control, as reflected in helpless, hopeless, and submissive approach partially align to emotion-focused coping strategies and have been
associated to ineffective coping in cancer caregivers (Tokem, Ozcelik, & Cicik, 2015) and cancer patients (Tan, 2007).

Fitzell and Pakenham (2010) applied the stress and coping model to understand positive and negative adjustment outcomes in caregivers of colorectal cancer patients. A sample of 622 caregivers was assessed to obtain measures of their caregiving parameters, levels of social support, appraisal of caregiving and coping strategies. Results of a regression analyses revealed that after controlling the effect of the caregiving parameters, better caregiving outcomes were linked to higher social support, higher challenge appraisals and lower usage of avoidant and substance use as coping strategies. This is in accordance to the hypothesis that avoidant coping is less adaptive in the context of caregiving. Teschendorf et al. (2007) have described how caregivers who cope by repressing unwanted feelings (rather than accepting the illness and understanding its implications) were likely to experience feelings of deprivation, non-support, and lack of pleasure. Caregivers who cope by accepting the challenge and looking for meaning and value, tend to experience moderate levels of health and stress, but possess a relatively positive perception of cancer and caregiving (Kulkarni et al., 2014; Yiengprugsawan, Seunsman, & Sleigh, 2012).

Goldzweig et al. (2013) looked into the issue of how caregiving is more complex for aged cancer patients. A sample of 216 family caregivers of cancer patients older than sixty years was selected and compared with 76 family caregivers of elderly patients without a life-threatening illness. The Brief Symptom Inventory, the Brief COPE and the Cancer Perceived Agents of Social Support were administered. The caregivers in the criterion group were highly distressed and
received low levels of social support. With regard to coping, it was seen that those strategies that correlate negatively with distress (self-distraction, active coping, instrumental support, emotional support, positive reframing, planning and acceptance) were used to a lesser extent. Patient age and coping (assessed through the mean of strategies listed above) accounted for 25% of the distress in the regression model.

Patient’s illness stage emerged to be an important predictor of coping styles in the two recent Indian studies. Bhattacharjee et al. (2015) found that caregivers at stage II reflected preponderance towards problem-focused strategies (although they did use other strategies), while caregivers at the terminal phase (stage IV) used acceptance to manage their psychological distress. Caregivers looking after patients in stage III seemed to use a combination of problem-focused and emotion-focused strategies. Similarly, Gupta and Sharma (2013) identified the areas of financial and physical functioning in cancer caregivers as being most affected by caregiving duties. These caregivers also resorted to problem-focused coping techniques and utilized their social support networks to manage caregiving demands. In contrast, caregivers of psychiatrically-ill patients experienced tremendous disruptions in family functioning and resorted to avoidance, coercion and collusion as coping strategies owing to the nature of the illness. Cancer caregivers also displayed a tendency to have less information about the illness and to view the situation as inherently negative.

Han et al. (2014) examined the relationship between depression, social support and coping styles in caregivers of oesopharyngeal cancers in the Chinese setting. A sample of 300 cancer caregivers was selected using the convenience
sampling approach. The CES-D, Brief COPE and Multidimensional Scale of Perceived Social Support were used along with a socio-demographic questionnaire. The analysis of data revealed that male and female caregivers used maladaptive coping styles equally, while male caregivers used problem-focussed coping strategies to a greater extent.

Karabulutlu (2014) examined how caregivers cope with the experience of looking after a loved one with cancer in the Turkish setting. A sample of 127 caregivers was selected at a clinic in Turkey and the personal information form and Attitude of Coping with Stress Inventory was used. Overall, the results depicted that caregivers most often resorted to using active planning as a way to manage the challenges of caregiving. Biochemical avoidance-isolation behaviours like smoking, alcohol consumption and drug use/abuse were the least used means of coping. The socio-demographic factors in the study had no effect on the type of coping strategy used. Comparably, Kohlsdorf and Costa Junior (2011) studied the impact of various coping strategies on the level of anxiety of parents looking after their children with leukemia to show that problem-focused coping correlated highly with religion and social support and other more adaptive forms of coping. Williams, Dixon, Feinn, and McCorkle (2015) found attendance at religious services to possess an inverse linear trend with depression as assessed by the CES-D.

Bigatti, Wagner, Lydon-Lam, Steiner, and Miller (2011) compared the prevalence and correlates of depression (social support and coping) in husbands of patients with breast cancer and a comparison group. A set of 78 matched pairs of caregivers-comparison group participants were asked to complete the CES-D,
Ways of Coping Questionnaire and Interpersonal Support Evaluation List. The analysis of data reflected that 30% of the caregivers were clinically depressed, as opposed to 11% of the comparison group and this difference was statistically significant. Male caregivers who enjoyed high social support reported lower depression, while those who used escape-avoidance, distancing, acceptance and confrontative coping experienced more depressive symptomatology. Comparable levels of depression and anxiety were noted in a study by Gotze, Brahler, Gansera, Polze, and Kohler (2014) with high financial burden, low social support and lineal blood relationships (rather than spousal) relationships predicting fewer depressive symptoms.

Mukwato, Mweemba, Makukula, and Makoleka (2010) through their study on stress and coping in the Zambian setting added to the existing cancer caregiving literature which is predominantly Western. They reviewed all published articles in the area until 2010 to identify the essence of the cancer caregiving experience in the African setting. The analysis of 22 articles fulfilling the inclusion criteria revealed four key themes. According to the authors, social support, reliance on God, positive reinterpretation and information gathering were the main themes that encapsulated the experience of cancer caregivers in Zambia. In a mixed-methods study of husbands of breast cancer patients, better caregiving appraisal and adjustment was related to the use of social support and religion in the Arabian setting (Alblowi, 2014). Butow et al. (2014), Kim, Carver, Rocha-Lima, and, Shaffer, (2013), Teixeira, and Pereira (2013) identified social support to be a robust indicator of good adjustment among cancer caregivers.
Perez-Sanchez, Rascon-Gasca, and Villafana-Tello (2014) examined the role of different coping strategies in eliciting emotional discomfort in cancer caregivers of patients in both curative and terminal phases. A total sample of 133 cancer caregivers was surveyed using the Zarit Burden Interview, Hospital Anxiety and Depression Scale, and Carers Assessment of Managing Index. The results of the survey reflected that caregivers of patients in the terminal phase experienced more psychological distress and burden than caregivers of patients receiving treatment with curative intent. A high prevalence of dysfunctional coping strategies like venting, crying and substance abuse was noted with such coping behaviours being associated with a heightened perception of depression and caregiver burden. Use of active coping strategies was linked to instrumental and informational social support. Perez-Ordonez, Frias-Osuna, Romero-Rodriquez, and Del-Pino-Casado (2016) examined the coping processes of cancer caregivers at the end of illness trajectory and found that emotion-focused coping was inversely related to anxiety, while dysfunctional coping strategies went hand in hand with anxiety.

Leeuw et al. (2007) examined the experience of distress in spouses and patients of head and neck cancers. A sample of 41 patient-spouse dyads was included in the study; various socio-demographic and caregiving-related variables along with psychological distress (assessed by the Hospital Anxiety and Depression Scale) were measured. The results revealed that caregivers who used a passive coping style, displayed less vitality, and experienced greater disruptions owing to caregiving reported greater distress.

**Interventions for cancer caregivers: Needs and strategies**

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Our knowledge of cancer caregiving is ultimately necessary to design evidence-based and feasible intervention programs to alleviate caregiver distress and foster effective coping among them. The literature in this regard is being developed robustly but there is no single proven effective way to intervene in this population. Instead, literature in the field has shown that a handful of strategies, when used individually or in combination, have been effective in promoting positive caregiving outcomes to varying degrees. In this section, the unmet needs reported most often by cancer caregivers are described and the related intervention studies are summarized.

**Unmet needs.** Chen et al. (2009) conducted a needs assessment for patients-caregiver dyads coping with oral cancer. They studied 122 patient-caregiver dyads using the following tools: Cancer Needs Questionnaire Survey, Karnofsky’s Performance Status Index along with other tools to measures specific site-related needs for cancer and Caregiver Reaction Assessment, among others. The unmet needs reported were relatively high with the domain of health system and information being the most prominent unmet needs. This unmet need in terms of health system and information, along with patients’ physical and medical needs and caregivers’ social support were significantly related to caregiver burden in this sample. There is a need to fulfil this lacuna by providing standard and usable information about cancer, its symptoms, treatment and side-effects to patients and caregivers coping with the illness. Patients with unmet needs in the domains of physical, psychological and spiritual functioning scored substantially lower on Karnofsky’s Performance Status Index (Buzgova, Hajnova, Sikorova, & Jarosova, 2014). Unmet needs pertaining to health information, physical and psychological
functioning and daily life have been persistently reported by cancer survivors, making these needs relevant to cancer caregivers as well (Harrison, Young, Price, Butow, & Solomon, 2009; McDowell, Occhipinti, Ferguson, & Chambers, 2010).

Yousafzai et al. (2013) made an assessment of the informational needs experienced by mothers of children who had recently undergone hematopoietic stem cell transplantation – a procedure often used for haematological cancers. The procedure involves acute risks to the health and integrity of the patient, requires patients to stay in isolation to prevent infections (like graft versus host disease) and involves a significant monetary expenditure. A sample of 74 maternal caregivers was recruited and the Child Information Form and Informational Needs Form were administered. The participants reported a high need for information, on an average. Moderate to high levels of unmet informational needs was reported especially for dealing with the physical side-effects of the procedure like pain, nausea, fatigue, diarrhoea and sleep disruptions. Problems related to patients’ symptom management and care coordination were also prominent in a study by Osse, Vernooij-Dassen, Schade, and Grol (2006), while challenges related to inadequate information exchange were highlighted in a systematic review by Bee, Barnes and Luker (2009) and in an Indian study by Gupta and Sharma (2013). The detrimental effect of unmet needs relating to information, patient symptoms and support expressed by caregivers is associated to greater QOL deficits, especially for caregivers who are younger, less-educated and unemployed (Buzgova, Spatenkova, Fukasova-Hajnova, & Felti, 2016; O’Hara et al., 2010).

**Interventional strategies.** Hudson et al. (2015) examined the impact of a brief psycho-educational intervention in reducing caregiver distress in the longer
run. In this randomized controlled trial, 298 caregivers of cancer patients in palliative care were studied at three assessment points spread out between 2 and 8 weeks. The intervention was delivered through a standard guidebook used to develop a tailored management or care plan. A family caregiver support nurse assisted the caregivers in the process. The intervention was offered in two visits to one intervention group and through a single visit to another intervention group. The third group received standard care alone. Although caregiver distress did not drop between baseline and the T2, there was a significant improvement in GHQ scores at T3 for the one visit intervention group. In a manner consistent with this study, Hudson, Thomas, Quinn, Cockayne, and Braithwaite (2009) and Hudson et al. (2013) successfully used psycho-education to buffer the sense of preparedness and competence among cancer caregivers. In both these studies, preparedness for caregiving was enhanced in caregivers even though other outcome measures like psychological well-being or unmet needs did not reduce substantially.

Lapid et al. (2015) examined the feasibility of an intervention program for caregivers of patients with a recent diagnosis of advanced cancer. Caregivers attended four sessions covering information on physical, social, communicative, mental health and spiritual aspects of cancer and caregiving. The Caregiver Quality of Life –Cancer Scale, Profile of Mood States-Brief and Linear Analogue Self-Assessment scales were administered to the sample of 131 caregivers at baseline and later assessment points (4th, 27th and 52nd weeks). The results of the intervention with 116 cancer caregivers (after accounting for attrition) revealed that the caregivers showed better spiritual well-being, mood and activity levels a month
after the baseline. Additional improvements were noted in two dimensions of CQOLC at the end of follow-up.

Leow, Chan, and Chan (2015) pilot tested an intervention titled “Caring for the Caregiver Programme” through a randomized controlled trial (RCT). They selected 80 caregivers and randomly assigned them to the experimental and control groups. The control group participants received standard care, while the experimental group participants were provided a psycho-educational intervention consisting of a one-time face to face interaction, a video clipping, follow-up calls and online interaction with peers. The Caregiver Quality of Life-Cancer Scale, Social Support Questionnaire, Depression Anxiety Stress Scales, Self Efficacy in Self Care Scale and the Rewards in Caregiving Scale were used in addition to a socio-demographic questionnaire. Caregivers receiving the intervention registered significant improvements in all the outcome measures of the study according to the two-way repeated measures analysis of variance. Interventions targeted at building the self-efficacy of the caregiver have become popular in recent times (Hendrix & Ray, 2006; Hendrix, Landerman, & Abnerthyr, 2011).

McMillan et al. (2006) conducted a comparative design study using repeated measures. Three groups consisting of approximately 110 patient-caregiver dyads in each were used. The first group received standard care, while the second received three supportive visits in addition to standard care. The third group received standard care plus the COPE intervention. The COPE intervention is an offshoot of the Problem Solving Therapy (Nezu & D’Zurilla, 2006) and involves a brief problem-solving presentation followed by three sessions of applying an active problem-solving approach to symptom management issues using a detailed home
care guide. The caregivers were evaluated along the following variables: quality of life, caregiver burden from cancer symptoms and mastery. The findings of the study indicated that caregivers reported less distress from the patient’s symptoms and less caregiving burden. Gregory (2014) applied an intervention derived from the Problem-Solving Therapy perspective to family caregivers in a hospice setting and found consistent results for quality of life improvements.

Shum (2013) developed and tested the feasibility of a nurse-led psycho-educational module for colorectal cancer caregivers. Derived from the transactional approach to stress and coping, this intervention involved three telephonic sessions with a nurse interventionist. During these calls, any unmet needs regarding symptom management concerns of the patient were discussed and each call was followed by an assessment of the main outcome measure, depression, using the Depression Anxiety Stress Scales along with certain other outcomes. Psycho-education did reduce the levels of depression, stress and anxiety in two weeks. However, Holm et al. (2015) informed that psycho-education solely improved caregiver preparedness without alleviating caregiver burden, depression, anxiety or health. Nurse-led interventions involving psycho-education have proven effective with cancer patients (Mahendran et al., 2015).

Northouse, Katapodi, Song, Zhang, & Mood (2010) conducted meta-analytic review of the various RCTs conducted to improve caregiver outcomes between 1989 and 2009. They selected 29 intervention studies where the primary family caregiver was the focus of a psychosocial, cognitive or behavioural intervention program incorporating the principle of random assignment. Three different theoretical frameworks guided the process of scrutiny of the articles. The
scrutinized studies were categorized based on three domains (illness appraisal factors, coping resources and quality of life) and three time frames. The analysis revealed psycho-education to be the most common intervention strategy followed by skills training and therapeutic counselling with caregivers consistently reporting improvements in multiple domains. Small to moderate effect sizes were obtained for the impact of interventions for caregivers in this meta-analysis. Naaman, Radwan, Fergusson and Johnson (2009) and Tatrow and Montogomery (2006) estimated fairly similar small to medium effect sizes, while Sorensen, Pinquart, Gill, and Duberstein (2002) reported larger effect sizes with regard to improvement in knowledge and ability of cancer caregivers. Although psycho-education and skills training emerge as the predominant intervention strategies, emotional support provided to caregiver also alleviates psychological distress consistently (Candy, Jones, Drake, Leurent, & King, 2011).

Waldron, Janke, Bechtel, Ramirez, and Cohen (2013) conducted a systematic review to understand the state of the field with regard to psychosocial interventions for cancer caregivers. All relevant articles published from 1947 to 2011 were reviewed using the PEDro coding scale and collated through a narrative approach. From their review, they identified small effect sizes for most interventions. However, effect sizes were larger when establishing the feasibility of problem-solving or communication skills training as intervention strategies. There has been a marked development in the field of psychosocial interventions for cancer caregivers since then. Harding, List, Epiphaniou, and Jones (2012) also conducted a meta-analytic review of 33 intervention studies for cancer caregivers as a follow-up to previous assessment made in 2003 and found a marked increase
in both the number and rigor of interventions. In the Indian setting, psycho-
educational interventions have been executed successfully for colorectal cancer
caregivers (Kadam & Shinde, 2014) and caregivers of patients with head and neck
cancers (Nympha, Joseph, & Thomas, 2014).

Vainboim et al. (2014) examined the efficacy of psycho-educational
program designed for caregivers of glioblastoma patients. Glioblastoma is a
challenging cancer site to deal with due to intensity of treatment and the multiple
functional deficits that the patients may experience executive functions and
language. The researchers compared a control group of ten caregivers with an
experimental group of 20 caregivers on their quality of life. Quality of life was
assessed using the WHOQOL-BREF. The results from inferential tests like ‘t’ and
Wilcoxon’s revealed that caregivers in the experimental group experienced
increments in quality of life, especially in the area of psychological functioning.
Caregivers in the control group registered a drop on all parameters of quality of
life. However, in another study utilizing a similar approach with caregivers of
pediatric cancer patients, no significant reductions were found in caregiver stress or
posttraumatic symptoms (Lamanna, 2012). Poor consent rates, good pre-
intervention functioning and varying time lapses between diagnosis and
intervention were some reasons to which the non-effect of the intervention was
attributed. Schildmann and Higginson (2011) have explained that the impact of
psycho-education as an intervention strategy for cancer caregivers in both curative
and palliative settings maybe affected by the different study designs involved.
RCTs are linked to low generalizability, while pre-test/post-test studies are
susceptible to selection bias. Before and after studies are inherently weaker than both RCTs and pre-test/post-test designs.

Northouse et al. (2014) examined the feasibility of a psycho-educational intervention delivered in an online format to patients and caregivers. A set of 38 patient-caregiver dyads were provided support and information based on their specific illness-related needs through an online format. The intervention was provided three fortnightly sessions and patient-caregiver dyads had to attend these sessions together. Emotional distress and quality of life were assessed through the Profile of Mood States and FACT-G, respectively. Results of the repeated measures analysis showed statistically significant reductions in distress and elevations in quality of life along with increments in self-efficacy. However, interventions based on specific symptom management needs have sometimes not proven effective in reducing depressive symptoms (Kurtz, Kurtz, Given, & Given, 2005) and alleviating caregiver distress (Given et al., 2006).

Tang, Chan, So, and Leung (2014) examined the feasibility of using the Internet as a medium of interventions for cancer caregivers. Web-based interventions transcend many of the frequently cited barriers to participation among caregivers like time constraints and commuting to the intervention site. Although gaining popularity as an alternative strategy, Web-based interventions present a mixed picture when it comes to their feasibility. The researchers thus examined all published articles on online intervention programs in 2012 and selected a set of six which met their inclusion criteria. These interventions indicated that standalone online support or online support combined with a psycho-educational website was typically found to enhance caregiver coping and promote
significant reductions in distress, burden and anxiety in cancer caregivers. Similarly, DuBenske et al. (2014) utilized a Web-based psycho-educational package for lung cancer caregivers, abbreviated as CHESS, to bring about significant reductions in burden and mood. Further, Namkoong et al. (2010) were able to foster a socially charged learning environment in which CHESS was delivered resulting in a salutatory effect in caregivers’ uptake of problem-solving strategies and appraisal of the situation.

The field of caregiving research has consistently provided evidence of the all-pervading nature of the experience. Caregiving, as a role and as a challenge, affects all domains of the life of a caregiver. This impact of caregiving is most evident in the health and quality of life of the caregiver. The various domains of health and well-being described in the review of literature are important components of functioning and must be studied to facilitate better adjustment among caregivers. Caregivers’ coping is another important area of research interest due to its role in mediating caregiving outcomes. Together, health, quality of life and coping comprise a very relevant triumvirate of caregiving-related variables that would allow for sufficient understanding of the caregiving experience and were selected to form the basis of the survey. Interventions for cancer caregivers are an imperative need and this study identified a perceptible knowledge gap in this regard in the Indian setting. The intervention combining elements of psycho-education and emotional support was designed to contribute a step towards fulfilling that lacuna.