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CHAPTER 2

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The previous chapter provided some insight into the concepts of caregiving and caregivers’ stress which results when the demands of providing care for the ill person do not match with the resources available. Individuals and families who face a diagnosis of some chronic illness experience varying levels of stress and emotional turmoil. Just as patients require ongoing evaluation throughout their course of treatment, so do family caregivers. Both male and female caregivers experience significantly more anxiety, depression and burden than normal subjects. Sadness and grief are normal reactions to the crises faced during treatment. Families or caretakers who were able to act openly, express feelings directly and solve problems effectively had lower levels of depression, less burden and low levels of anxiety whereas the caregivers who do not cope with an exhaustive array of tasks that must be accomplished on a daily basis experience a wide range of physical, psychological, social and financial strains resulting in burden, distress and poor quality of life.

Burden on Caregivers:

A few studies on caregivers’ burden in mental disorders and cancer have been reviewed.

Omne-Ponten, Holmberg, Bergstrom, Sjoden and Burns (1993) measured the psychosocial adjustment among 56 spouses of women operated for breast cancer and concluded that the husbands of the women in the mastectomy group were significantly more depressed after 4 months and reported complaints related to their wives’ disease more often than did those in the breast-conserving surgery group. And when the marital relation was assessed it was more positive in the mastectomy group, a total of 48% of the husbands in the sample expressed some emotional distress during the investigation period, which is similar to levels seen among breast cancer-operated women themselves.
Provencher and Mueser (1997) investigated the relationships of perceived severity and responsibility attribution for positive and negative symptom behaviors to caregiver burden and found that subjective burden was related to both the severity of positive and negative symptom behaviors whereas objective burden was related only to the severity of negative symptom behaviors. Responsibility attribution for negative symptom behaviors was related only to objective burden. Caregivers who perceived patients as being less responsible for their negative symptom behaviors reported higher levels of objective burden. The relationship between responsibility attribution for negative symptom behaviors and objective burden remained significant even after controlling for the severity of negative symptom behaviors. Caregiver’s perception of patient’s responsibility for positive symptom behaviors was not related to objective burden.

Ricard, Bonin and Ezer (1999) described the subjective burden on caregivers of mentally ill patients and indicated that the variables describing the patients’ current state contributed the most to explaining variance in subjective burden. The variables related to psychiatric history and to outpatient treatment also explained a significant proportion of the variance in the burden scores. Ohaeri, Campbell, Ilesanmi, and Omigbodun (1999) assessed the severity of indices of psychosocial and economic burden among relatives of women with breast and cervical cancer and its relationship with patients’ psychosocial distress and found that the financial burden was more problematic than the effect of caring on family routines and these two factors significantly predicted global rating of burden. The severity of patient’s worries and psychopathological symptoms were not significantly correlated with caregiver global rating of burden.

Sisk (2000) investigated whether the perception of burden is related to the health-promoting behaviors of caregivers of the elderly or not and suggested that those perceiving lower subjective burden practice more health-promoting behaviors than those with higher subjective burden scores.

Dore and Romans (2001) determined how the role of caregiver affected them and reported significant difficulties in their relationships with the patient when s/he was unwell, with considerable impact on their own employment, finances, legal matters, co-parenting and other social relationships. Violence was a particular worry
for partner/parent caregivers of both male and female patients when the patient was manic however the caregiver’s own mental health appeared unaffected.

Cameron, Franche, Cheung and Stewart (2002) examined the impact of providing care on lifestyle and emotional well-being in a sample of caregivers to patients with advanced cancer and suggested that caregivers experience increased emotional distress, regardless of the amount of care provided when limited in their ability to participate in valued activities and interests. In addition, caregivers with less than a high school education experience more emotional distress.

Jungbauer, Wittmund, Dietrich and Angermeyer (2003) investigated subjective burden in parents with schizophrenia and suggested that parents of continuously and severely affected patients are overloaded with their long-term caring tasks and also of the opinion that changes in the parent’s burden level was closely interconnected with the illness of the patients. Sales (2003) examined objective and subjective dimensions of family burden and the extent to which illness characteristics and contextual variables have been found to contribute to caregiver stress for different chronic illnesses and suggested several important factors affecting caregiver burden, greater understanding of contextual variables.

Stimmel (2004) pointed out that “bipolar disorder has a clear economic impact on patients with the disorder, their families, caregivers and society as a whole”. Inadequate treatment can affect healthcare costs and add to the burden on the individual and families. Heru and Ryan (2004) investigated thirty-nine caregivers of patients with mood disorders during their relative’s in-patient psychiatric hospitalization and concluded that caregivers of bipolar disorder relatives reported less reward, more subjective burden and worse family functioning than depression caregivers and overall family functioning was unchanged and was in the unhealthy range in all dimensions except for behavior control.

Rossi et al. (2005) described the effect of terminal cancer on the patient’s family, finances and daily life and were of the view that the duration of time the patient was completely dependent strongly determined the effect caregiving had on their regular employment and on the family’s financial situation and further concluded that although families are responsible for a small percentage of the overall costs of patient care, the effect of cancer on savings and daily life can be substantial.
Reinares et al. (2006) indicated that caregivers showed a moderate level of subjective burden. The highest levels of distress were reported regarding the patient’s behavior the most distressing behaviors were hyperactivity, irritability, sadness and withdrawal. Regarding adverse effects on others, caregivers were especially distressed by the way the illness had affected their emotional health and their life in general.

Goossens, Van Wijingaarden, Knoppert-van Der Klein and Van Achterberg (2008) investigated the consequences caregivers of outpatients with bipolar disorder confronted with, the distress they experience and their coping styles. Caregiver consequences were found to be limited, although approximately 30% reported distress. Male caregivers used a more avoiding coping style and undertook activities to provide diversion. Female caregivers used a less active approach and sought less social support. Distress appears to occur more often in caregivers, who report more consequences, tend to use a more avoiding coping style and have a more passive reaction pattern.

Mitchell, Girgis, Jiwa, Sibbritt and Burridge (2010) outlined a study protocol aimed at developing and evaluating the effectiveness of a general practice-based intervention to better meet the needs of caregivers of patients with advanced cancer and determined whether systematic assessment of caregiver needs supported by caregiver-specific information for general practitioners is effective in alleviating the unmet needs experienced by caregivers caring for patients with advanced cancer.

Jonsson, Skarsater, Wijk and Danielson (2011) elucidated what it means for family members to live with an adult person who has bipolar disorder, with reference to their views concerning the condition of the person affected and the future and showed that family members felt alone with their experiences and struggled to make sense of and to maintain normality as their life was encroached on by the condition. Bearing the burden of responsibility and control made it difficult for family members to focus on their own future. To build hope, they needed opportunities to share their experiences with others increased understanding of the condition and relief from the burden they bore. Panganiban-Corales and Medina (2011) assessed families of children with cancer in terms of family function-dysfunction, family caregiver strain and the adequacy of family resources assessment instrument and concluded that many Filipino families of children with cancer have inadequate resources, especially
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economic and are moderately or severely dysfunctional. Many caregivers are predisposed to caregiver strain or are already experiencing severe strain.

Bevans and Sternberg (2012) of the view that caregivers often experience negative psychological, behavioral, and physiological effects on their daily lives and health and discussed the importance of identifying caregivers at risk of negative health outcomes and intervening to attenuate the stress associated with the caregiving experience. Longacre, Ridge, Burtness, Galloway and Fang (2012) summarized eleven papers regarding the psychological health of caregivers of head and neck cancer patients and found that caregivers experience poorer psychological health including higher levels of anxious symptoms compared to patients and to the general population.

The above studies revealed that caretakers whose loved one is diagnosed with cancer or psychiatric illness had emotional distress in the form of burden like helplessness, depression, anxiety, low performance status, adjustment disorder and maladaptive coping behaviors.

Coping of Caregivers:

Maladaptive coping behaviors include avoidant or negative coping, negative self-coping statements, preoccupation with physical symptoms and catastrophizing. Some of the studies given below describe the coping styles of caregivers and the tendency to seek social support during active caregiving.

Fear of patient cancer recurrence is evident among caregivers and is associated with poorer psychological health outcomes. Nikoletti, Kristjanson, Tataryn, McPhee and Burt (2007) determined the information needs and unmet needs of primary family caregivers of women with breast cancer, their informational coping styles and the relationships among needs, coping styles and caregiver and patient variables in the first three weeks after surgery and concluded that western Australian caregivers have a similar range and priority of needs as those previously reported internationally. Caregivers in the private system where breast centers are not established are at risk for not having their needs met.

Eaton et al. (2011) investigated the coping strategies of families of hospitalized psychiatric patients and identified their positive and negative coping strategies and found that these family members used more emotion-focused coping
strategies than problem-focused coping strategies. The common coping strategies used by family members were communicating with immediate family, acceptance of their situation, passive appraisal, avoidance, and spirituality. The family members also utilized resources and support systems such as their immediate families, mental health care professional and their churches. Renee (2011) examined the relationship between coping styles of family caregivers and the tendency of those caregivers to seek social support during active caregiving and indicated that coping styles of confront coping, problem solving and positive reappraisal were positive and significant predictors of the tendency to seek social support during active caregiving. However, coping styles of distancing, self-control, escape/avoidance and taking responsibility were not significant predictors of seeking social support. Bigatti, Brown, Steiner and Miller (2011) examined the coping strategies of husbands of patients with breast cancer compared with husbands of women without cancer and suggested that coping strategies may be different when dealing with cancer in a wife than at other times and that coping relates to well-being.

Cancer Research Center (2012) investigated the family functioning of cancer patients and the correlativity among family functioning, coping styles of couples and development of disease in cancer patients and reported that significant differences of family functioning found between cancer patients and control. The patients with advanced cancer and their spouses reported more deficits in family functioning and more appliance of negative coping strategies, compared with those cancer had been controlled.

It has been evident from the review that the coping styles of confronting coping, problem solving, and positive reappraisal were used by the caretakers and they had a tendency to seek social support during active caregiving. Families bear major responsibility in such care. The burden and coping style is related with gender, age, health status, lack of social support of the caregivers.

Quality of life of Caregivers:

The emotional upheaval and accompanying stress that define grief may lead sometimes to health problems for the caregivers and interfere with their ability to provide care for their loved ones thus affecting their health related as well as other psychological quality of life. The stress of providing care often results in family
caregivers experiencing elevated levels of emotional distress and providing care can interfere with the caregivers' ability to participate in valued activities (e.g. work, recreation, social outings, etc.) disrupting their life style and deteriorating their quality of life.

Chen, Chu and Chen (2004) aimed to examine the correlation between quality of life in cancer patients and that of their spouse caregivers and found that social and functional aspects of patients' quality of life play a significant role in determining the quality of life of their spouse caregivers. Lim and Zebrack (2004) reviewed 19 studies (1987-2004) on quality of life for family caregivers helping those with chronic physical illness and indicated that stress-related variables as possible predictors influencing caregivers' quality of life include patient and caregiver characteristics, stressors, stress appraisal, stress coping methods and social support.

Stanley and Shwetha (2006) determined the extent of change in psychiatric symptomatology in schizophrenic patients attending a community based rehabilitation programme and the family burden and perceived quality of life of their caregivers and indicated significant reduction in patient symptomatology as well as caregiver burden and enhanced quality of life scores of the caregivers.

Northouse et al. (2007) assessed patient's and spouses' quality of life, appraisal of illness, resources, symptoms and risk for distress across three phases of prostate cancer i.e. newly diagnosed, biochemical recurrence and advanced and concluded that the psychosocial experiences of patients and their spouses were similar but differed from dyads in other phases. Dyads in the advanced phase were at highest risk of distress. These patients had the lowest physical quality of life and their spouses had the lowest emotional quality of life of all participants. Dyads in the biochemical recurrence and advanced phases had more negative appraisals of illness and caregiving, greater uncertainty and more hopelessness compared with dyads in the newly diagnosed phase. Spouses in contrast to patients had less confidence in their ability to manage the illness and perceived less support across all phases of illness.

European Oncology Nursing Society (2008) identified and assessed the impact of colorectal cancer patients and their families and concluded that in terms of quality of life, those patients who had a stoma reported lower overall quality of life, lower body image, poorer health related quality of life and poor social activity when
compared with colorectal cancer patients who had no stoma. The stoma patients also had significantly higher depression and anxiety levels and were related to the caregivers’ burden. The caregivers of stoma patients had more depression and anxiety when compared with the caregivers of non-stoma patients.

Talwar and Matheiken (2010) studied the psychosocial and demographic aspects of patients suffering from schizophrenia, the levels of perceived burden of the Malaysian and Indian families caring for a relative with schizophrenia and the determinants that contribute to the caregiver’s perception of burden of care and found that although the Indian caregivers perceived difficulties in several areas such as finance, family relationship, well-being and health, they still perceived burden to be lesser compared to Malaysian counterparts. Andel, Westerhuis, Zijlmans, Fischer and Leijten (2010) investigated health-related quality of life and coping styles of both patients and caregivers and their interaction and indicated that on several specific domains, associations between patient and caregiver health-related quality of life scores within couples were found and caregivers of epilepsy patients have normal health-related quality of life but there are significant associations between patient and caregiver health-related quality of life scores.

Zendjidjian et al. (2012) assessed the quality of life of caregivers of individuals with affective disorders and compared quality of life levels with those observed in caregivers of individuals with schizophrenia and in the general population and showed that caregivers of individuals with affective disorders experienced lower quality of life levels than age-sex-matched controls. Caregivers of individuals with affective disorders reported higher scores than caregivers of individuals with schizophrenia. The quality of life of caregivers of individuals with affective disorders is seriously impaired mainly because of an altered psychological or mental well-being and social life.

Caring for a person with such chronic diseases creates challenges for caregivers. The above mentioned studies give an over view of quality of caregivers that how social and functional aspects of patients’ disease play a significant role in determining and deteriorating the overall quality of life of caregivers.

Even for patients receiving complex, intensive medical care for serious and chronic illness family caregiving is typically at the core of what sustains patients.
Families play an important role in the practical and emotional aspects of patient care and in decision making. At the same time, family members carry significant burdens as a result of their work, like financial costs, emotional burden, mental health risks and physical health risks. Caregiving is a chronic stressor and different coping methods are used to handle such burdens. But in the process of handling the quality of life of caregivers gets affected. A few studies highlight that spouses in contrast to patients, had less confidence in their ability to manage the illness and perceived less support across all phases of illness.

**Burden, Coping and QOL:**

Rammohan, Rao and Subbakrishna (2002) examined burden and coping in parents and spouses of persons with schizophrenia and indicated that spouses reported greater emotional burden. Parents used more of denial as coping strategy while spouses used more of negative distraction strategies.

Pearce, Singer and Prigerson (2006) investigated the association between religious coping, mental health and the caring experience among caregivers of terminally ill cancer patients and found that more use of positive religious coping strategies was associated with less burden and in contrast more use of negative religious coping strategies was related to more burden, poorer quality of life and less satisfaction.

van der Voort, Goossens and van der Bijl (2007) aimed to highlight the factors which influence experienced burden, coping and needs for support of caregivers for patients with bipolar disorder and found that subjective burden is extremely influenced by illness beliefs. High burden is associated more with severity of symptoms (than diagnosis), difficulties in the relationship with patient, lack of support and stigma. Coping is influenced by appraisal and burden. Different phases in the process of caregiving require different coping mechanisms. Caregivers of patients with bipolar disorder experience high burden and try to cope in different ways.

Grandon, Jenaro and Lemos (2008) explored family burden in relation to relatives’ coping strategies and social networks as well as in relation to the patients’ severity of positive and negative symptoms and showed low levels of burden with the exception of moderate levels on general concerns for the ill relative.
Ganguly, Chadda and Singh (2009) assessed the qualitative dimension of care giving and burden coping strategy and intervention were designed thereafter to help improve quality of coping strategy and reduce the burden of the care givers and it was evident from the study that the sessions had positive impact for coping behavior and increased confidence.

Hassan, Mohamed, Elnaser and Sayed (2011) explored burden and coping strategies in caregivers of schizophrenic patients and identified the relationship between burden and coping strategies among them. The results revealed that level of burden reported by caregivers of schizophrenic patients was high. The most coping strategies used by caregivers of schizophrenic patients were self controlling, positive reappraisal and escape-avoidance. Burden was negatively and insignificantly correlated with confront coping, distancing, seeking social support and positive reappraisal coping strategies. However, it was positively and insignificantly correlated with self controlling, accepting responsibility, escape-avoidance and planful problem solving. Morgan, Small, Donovan, Overcash and McMillan (2011) examined effects of financial concerns and pain on cancer patients’ and their partners’ quality of life. The partner relationship and the partners’ coping style were explored for mediating the couples’ outcomes and found that the partners’ relationship lessened pain’s negative effect. Financial concerns were a significant issue for both dyad members, but the quality of life of the relationship was not compromised.

Khanjari, Oskouie and Langius-Eklof (2012) studied the quality of life, well-being, sense of coherence, spirituality, and religious coping in family caregivers of patients with breast cancer at the time of diagnosis and concluded that despite improved quality of life in the sample from diagnosis to six months, family caregivers struggle to cope with the situation.

**Gender differences:**

The role of a family caregiver is traditionally viewed as the responsibility of women and multiple socio-cultural factors provide the moral basis for caregiving i.e. socially demanded by wives and also daughters as a filial obligation and not as a matter of personal choice (Rudd, Vinay and Preston, 1999).

Caregiving may be influenced by gender and by the expected caregiver roles within a family unit. Caregiving is physically and emotionally demanding and gender
differences in caregivers’ physical and psychological health have been reported and documented.

Lutzky and Knight (1994) explained the gender differences in caregiver distress and the results supported the importance of seeking explanations for observed gender differences. Matthews (2003) found female caregivers to be high on cancer-related anxiety, future diagnostic tests.

Carter, Mikan and Simpson (2007) studied the gender differences in quality of life of caregivers of patients with advanced cancer and reported that male and female caregivers respond differently to the stressors of caregiving thus reported different levels of sleep, depression and QOL. Dyer (2008) found significant gender differences with female caregivers engaging in more coping efforts and reporting more negative affect than male caregivers.

Papastavrou, Tsangari, Kalokerinou, Papacostas and Sourtzi (2009) found that female caregivers higher levels of burden and using more social support and denial as coping style as compared to male caregivers.

Kohler, Perner, Anders, Brahler, Papsdorf and Gotze (2012) investigated the family caregivers of cancer patients on account of HRQOL and burden and found that female and older caregivers reported a stronger home care burden than male and younger caregivers.

However, there is a very little work which documented no sex difference between the caregivers. Sreeja, Gupta, Lal and Singh (2009) found no significant difference in total burden between male and female caregivers.

The above findings from the review afford a comprehensive understanding of the caregiving situation and its outcomes. Keeping in view the background and the above literature now the problem, objectives and hypotheses for the present investigation will be formulated.