

Burden among Caregivers of Mentally- Ill Patients: A Review

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Abstract

The family is the primary unit of which the individual is a member. This being the case everyone in the family plays a major role in the welfare and difficulties of an individual. If a person's performance or social functioning is inadequate or affected, it may lead to greater burden on the family. In such situations, the occurrence of mental illness in the family is perceived as a trauma, which causes family members considerable stress and distress. Despite these tribulations, most families elect to shoulder this burden. The family is an important support system in the care of the mentally ill in the community. The family's responsibility in providing care for people with mental disorders has increased in the past three decades. This has been mainly due to a trend towards community care and the de-institutionalization of psychiatric patients. This review focuses on the different problems faced by the caregivers. Majority of studies found that the caregivers are caught between demands of caring and looking after families. Moreover different groups of caregivers i.e. parents and spouse experience different sets of problems. Mental health professionals need to be aware of and address the stress borne by the family in caring for patients with mental illness as they take care of patient.

Keywords: Caregiving, Mental illness, Family, Burden

Caring for someone with a mental disorder can affect the dynamics of a family. It takes up most of the carers' time and energy. The family's responsibility in providing care for people with mental disorders has increased in the past three decades. This has been mainly due to a trend towards community care and the de-institutionalization of psychiatric patients (Magliano L., McDaid D., Kirkwood S. & Berzins K., 2007). The consequences of care-giving for mentally ill persons have been associated with burden in physical and psychological health (Steele, Nancy, Galynker, 2009, Ogilvie, Morant, & Goodwin, 2005, Jose, 2000, Baronet, 1999).

The concept of burden of care was defined by S.H. Zarit in 1980. Over time interest has increased in the study of burden of care and the development of various scales used in its measure (Novak M. & Guest C., 1989, Chou K.R., Jiann-Chyun L, & Chu H. , 2002). Caregiving burden is usually defined as multidimensional response to the negative appraisal and perceived strain which result from taking care of person suffering from mental illness. It affects the physical, psychological, emotional and functional health of caregivers (Parks & Novielli, 2000, Etters, Goodall & Harrison, 2008).

The aim of this review was to examine the relationship between caregiving, psychological distress, and the factors that contribute to caregivers burden and strain as well as help caregivers successfully manage their role. Carers play a vital role in supporting family members

who are sick, infirm or disabled (Singleton, N., Maung, N. A., Cowie, J., et al., 2002). No doubt that the families of those with mental disorders are affected by the condition of their family members, and research into the impact of care-giving shows caregivers experience many difficulties due to caring for a mentally ill member. Being a carer can raise difficult personal issues about duty, responsibility, adequacy and guilt (Oyebode J.R., 2005).

Up to 90% of people with mental disorders live with relatives who provide them with long-term practical and emotional support (Clausen, JA; Yarrow, MR , 1955, Ivarsson AB, Sidenvall B, Carisson M., 2004). Strong associations have been noted between burden (especially isolation, disappointment and emotional involvement), caregivers' perceived health and sense of coherence (Robinson, 1983).

'Family burden' has been adopted to identify the objective and subjective difficulties experienced by relatives of people with long-term mental disorders (Hoening J. & Hamilton M., 1966). Objective burden relates to the practical problems experienced by relatives such as the disruption of family relationships, constraints in social, leisure and work activities, financial difficulties, and negative impact on their own physical health. Subjective burden describes the psychological reactions which relatives experience, e.g. a feeling of loss, sadness, anxiety and embarrassment in social situations, the stress of coping with disturbing behaviours, and the frustration

caused by changing relationships (Ostman, M. & L. Hansson, 2004). Grief may also be involved. This may be grief for the loss of the person's former personality, achievements and contributions, as well as the loss of family lifestyle (Magliano L., Fiorillo A., De Rosa C., Malangone C. & Maj M., 2005).

Studies on burden in caregiving have been carried out since the 1950s. In one of the earliest studies in this area Yarrow *et al.*, (1955) observed that wives of persons with mental illness reported a high degree of stigma and fear of social discrimination. A restriction in activities due to the patients' presence at home was reported by families (Mandelbrote & Folkard, 1961; Winefield & Harvey, 1994; Rose 1996).

The work by Grad and Sainsbury (Grad & Sainsbury, 1963) examined the effects on families of home care as compared with hospitalization of the mentally ill. This research is important because Grad and Sainsbury were the first researchers to conceptualize and measure 'burden' in caregivers of the mentally ill. Severe burden and hardship was reported by a majority of families. This was linked to severity of the patient's symptoms and long duration of illness. Restrictions of social activities and also problems such as social embarrassment, inconvenience due to patient's behaviour were reported by families of schizophrenic patients.

In an extension of this work, Heoning and Hamilton (1966) found that over 40% of the caregivers reported that the patient had some kind of adverse effect on the family. Higher levels of emotional, physical and financial strains were found in the spousal caregiver group than in any of the other kinship groups (Cantor, 1983). Emotional strain was the most pronounced strain for all kinship groups. Hinds (1985) and Oberst *et al.*, (1989) found that the caregiver's physical health was directly related to the patient's health. In a similar study, Noh and Turner (1987) found that subjective burden, rather than objective burden was linked to psychological well being, suggesting that carer's perception of the patient as a burden was an important factor contributing to distress.

The concept of burden as observed by Fadden *et al.*, (1987) is characteristically associated with that of social performance. Poor social performance of one member reciprocally affects the performance of other members of the family, who have to compensate for the deficiencies, thus experiencing burden. Noh and Avison (1988) found that greater burden was reported by wives of the patient, who were older, had children staying at home, who experienced lower levels of mastery and had less social support. The unpredictable nature of the illness, extensive needs of the mentally ill person and inadequate mental illness care infrastructure (lack of information, lack of continuity of care and inadequate resources) were cited as factors contributing to burden in a study by Francell, Cohn and Gray (1988).

The caregivers of psychiatric illness have been found to suffer twice as much as those in general population (Oldridge & Hughes, 1992). The burden is experienced not

only by families who have the patient living with them, but also by families where the patients are living far away. Though the nature of problems is different, need for external support is felt by caregivers (Carpentier, Lesage, Goulet, Lalonde & Renaud, 1992). Lower social class, longer period of illness before hospitalization and male gender are found to be associated with increased burden in the family. Moreover, greater burden and distress was observed in rural areas and in lower income groups when the patient was male (Martyns-Yellowe, 1992).

Spouse reported more burden than any other group (Winefield and Harvey, 1994). Caregivers expressed the need for early treatment, rehabilitation services and counselling support for themselves. Jones, Roth and Jones (1995) found that caregivers reported greater objective than subjective burden. Female caregivers who lived with male patients who were at higher risk for suicide, experienced greater burden. Parents of adult children diagnosed either with schizophrenia or bipolar disorder experienced chronic sorrow (Eakes, 1995). These grief related feelings were most often triggered by the unending caregiving responsibilities. The diagnosis of schizophrenia in a child is experienced as a negative force that interrupts family life. This grief filled experience involves the loss of an imagined, idealized child into a needy stranger (Tuck, *et al*, 1997). Moreover, caregivers have intense anxiety about the future of their relative, lack of knowledge about how to plan, and lack of financial resources were the main obstacles to planning (Hatfield and Lefley, 2000). These findings underline the problems and concerns faced by elderly caregivers in planning for the future of their ill relative. The negative consequences identified most frequently were tense relationships in the household, physical and emotional problems of the primary caregiver, disruption of the lives of other adults in the household and disturbance in the primary caregiver work performance (Provencher,1996).

Women are significantly more likely than men to experience poor mental health (Sveinbjarnardottir and Casterla, 1997). Most carers reported personal and social restrictions, but carers were significantly more likely than non carers to report financial, personal and physical burden (McGilloway, Donnelly & Mays, 1997).

Caregivers suffer ongoing distress (Brown *et al.*, 1998) and the need to live each day as it comes without being able to make long term plans and to rationalize the need to 'look at the world through the others' window', always aware of how the world responds, not only to oneself but also to the person with mental illness (Jeon & Madjar, 1998). Relatives of schizophrenics and major affective disorder were compared with relatives of patients with cancer, infertility and sickle cell diseases. The response patterns of the relatives of the two psychiatric groups were similar with 36% attributing the illness to 'satan' work and 11% to 'witchcraft'. More relatives in the physical illness group attributed the illness to biological cause.

Anger and stigma to a larger extent were reported by relatives in the psychiatric illness group (Ohaeri and Fido (2001).

Based on Spaniol and Jungs' stress and coping framework (1993), Wong (2000) examined the difficulties and stresses experienced by carers with relatives suffering from schizophrenia in Hong Kong. Caregivers with a stronger sense of mastery have better mental health. Cultural issues such as family shame and face saving, family obligations and reciprocal expectations, external orientation to personal control and the 'Confucian work ethics' were put forward as an explanations for these findings. This study suggests that there is need for culturally sensitive practices. Subjective burden was negatively correlated with the age of the patient, while objective burden was positively correlated with the duration of illness. (Hasui *et al.*, 2002).

The majority of patients with mental illness have a lifelong disability that creates stress in families that care for them. Studies have reported financial hardships, disruption in family relationships, psychological distress and curtailment of family social activities (Gibbons *et al.*, 1984; Anderson, Hogarty & Reiss, 1980; Hatfield & Lefley, 1987; Birchwood & Smith, 1987) in families caring for a mentally ill relative. Emotional disorders, somatic symptoms, and impairment of social role performance occur commonly in relatives of patients especially among primary caregivers (Birchwood, Hallett, & Preston, 1989; Gibbon *et al.*, 1984). Platt, Weyman, Families of mentally ill relatives have reported psychiatric distress, depression (mediated by stigma and patient's suicidality), anxiety and psychotic symptoms as a result of care-giving responsibilities (Chessick *et al.*, 2007, Perlick, *et al.*, 2005).

For families who are already confronted with a range of day-to-day problems that affect all aspects of their lives, a member with a severe mental illness may have a significant impact on the entire family system (Saunders, 2003). Studies agreed with the consideration that, especially in mental illness, caregiver burden is first of all linked with personality and mood of the caregiver himself (da Silva, *et al.*, 2013; Hou, Ke, Su, & Huang, 2008) The stress of dealing with a family member suffering from a mental illness is inversely proportional to a healthy personality and a great resilience (Lautenschlager, Kurz, Loi, Cramer, 2013).

Physical and Emotional Burden

Most of the research on the impact of caregiving focuses on 'caregiver burden' a multidimensional construct which includes the physical, emotional, social, and financial cost to the caregiver and most research does conclude that caregiving is associated with significant subjective burden (George & Gwyther, 1986; Snyder & Keefe, 1985). The impact on physical health is somewhat mixed. Both objective and subjective burdens are higher for female than for male caregivers (Chang & White-Means, 1991;

Miller & Montgomery, 1990; Mui, 1995a). The degree of burden can be predicted by the level of assistance required, the amount of dependency, the extent of individual responsibility for the dependent person and the availability of help from others (Jutras & Veilleux, 1991). Mackinlay, Crawford, and Tennstedt (1995) using seven year longitudinal data showed that 61% of caregivers rated their caregiving responsibilities to be the most disruptive aspect of their lives and this was particularly likely if they lived with the person cared for.

Ostacher *et al* (20082) underscores the important impact of bipolar depression on those most closely involved with those whom it affects. Results showed that episodes of patient depression, but not mood elevation, were associated with greater objective and subjective caregiver burden. Burden was associated with fewer patient days well over the previous year.

Davenport (2008) reported that objective burden was significantly associated with fewer days well, depression symptom score, patient's socio-economic status, and whether the patient and caregiver lived together, while subjective burden was significantly associated with fewer days well and whether the patient and caregiver lived together.

Recognized negative effects of caregiving include physical and emotional strain (White-Means, 1993), increased psychiatric illness, physical symptoms (Schulz, Visintainer & Williamson, 1990), depression (Mc Naughton, Patterson, Smith & Grant, 1995), back pain, headache and emotional exhaustion, (Snyder & Keefe 1985), increased use of medication, physical exhaustion and subjective overload (Schofield *et al.*, 1997), adverse affect on the immune system and resulting increase in viral illness (Glaser & Kiecolt-Glaser, 1997) and reduced leisure time (Miller & Montgomery, 1990).

The support for health promoting and preventive behaviour is mixed. Burton, Newsom, Schulz, Hirsch and German (1997) found that the extent of the demands of caregiving affected caregiver's capacity to care for their own health. High demand caring was associated with significant increase in the probability of inadequate exercise, inadequate rest, inability to take time to visit the family doctor or to rest and recuperate from illness.

Emotional burden has been more clearly established as a consequence of caregiving. Jutras and Lavoie (1995) found that there was no difference in the physical health of caregivers and that of controls but caregivers psychological health was significantly poorer. Mui (1995b) concluded that the level of emotional strain, rather than physical symptoms or financial burden was the best predictor of poor perceived health and well-beings. Existence of social support network and the occupancy of other fulfilling roles (Moen, *et al.*, 1995), also improved well-being and satisfaction level of caregivers as did provision of community and institutionalized professional support (Bass-Noelker & Rechlin, 1996).

While most caregivers are married women (Schofield *et al.*, 1997) the impact of family and of other roles is not

always positive. Married women cope better with caregiving (Brody, Litwin, Hoffman & Kleban, 1992), but a high proportion of family caregivers are simultaneously dealing with major conflict with at least one other member of their family, frequently over issues related to caregiving and the provision of support (Strawbridge & Wallhagen, 1991).

Many caregivers have some assistance from a family member or friend (e.g. Penrod, Kane, Kane & Finch, 1995), or make use of professional services (Snyder & Keefe, 1985), the size of the support network does not seem to affect the work load of the primary caregiver (Penrod *et al.*, 1995). Stress is negatively associated with informal support for both parents and positively associated with increased caregiving requirements for mothers (Beckman, 1991). However, when the children take care of their parents, studies show that males tend to become caregivers only in the absence of females. Generally, males children are more likely to rely on the support of their own spouses; they provide less overall assistance and tend to have less stressful caregiving experiences, independent of their involvement (Horowitz, 1985).

Chun Chieh Fan & Ying-Yeh Chen (2009) in a study in caregivers in China found that burden scores were significantly correlated with the number of care hours the caregivers spent daily with the patient, irrespective of their age, gender, kinship and educational level. Caregivers of patients with different psychiatric illnesses had similar levels of burden. Higher burden scores were correlated with a lower quality of life. Constant caregiving also impact the interpersonal relationships in the family. The outcome was that physical and emotional problem of the patient place caregivers in a new and confusing matrix of relationship with their loved ones. This has also been reported in some of the studies as Provencher (1996), identified the most negative consequence of caregiving was tense relationship in the household. Family life and children were the most affected. Providing care led to a disruption in family life and often led to behavioural and emotional problems in children. As a means of coping, children detached themselves and at times acted as if they did not care about the parent. (Woolis, 1992).

When the patient is actually ill and acts in a bizarre, unusual or socially unacceptable manner children are frightened and embarrassed as Sargent (1985) said that having a parent who is mentally ill can be experienced as loss for children. Children sense that they have a parent "who is there (physically), but not these (emotionally), and at times children feel abandoned and alienated from the family. Schmitt (1986) reported that few families properly harass their overburdened family member and they do not know how to express their own needs appropriately for the caregiver time and attention. Stigmatized caregivers had poorer self care than effective caregivers (Perlick, 2008). Zergaw *et al.* (2008) bipolar patients' family caregivers were found to be more

burdened, for about 8-10 months of the year of the study, than family caregivers of other groups. Family members are less satisfied with their overall quality of life and are significantly distressed as a result of having a family member with a mental disorder (Foldemo, Gullberg, Ek, & Bogren, 2005; Martens, & Addington, 2001). Greater burden and lower quality of life were predicted by three fundamental parameters: duration and severity of illness, decreased tangible social support with restriction of caregiver social life and negative feelings of caregiver such as shame, embarrassment, guilt and self-blame (Dyck, Short, & Vitaliano, 1999; Grover, & Dutt, 2011; Lauber, Eichenberger, Luginbühl, Keller, & Rössler, 2003). From the studies reviewed it is clear that many factors have been associated with caregiver stress, and these may include behavioural disturbances shown by the dependent person (Levin, Sinclair & Gurbach, 1989), gender of the caregiver (Morris, Woods, & Davies & Morris, 1991) and the quality of interpersonal relationship (Gihooly, 1986). In addition, factors that may affect the caring role are the psychiatric status of the patient, the degree of social support received by the family and quality of mental health services and their utilization by the family.

Restriction of Choice and Alternatives

Caregiving covers a wide range of responsibilities and commitments and involves a considerable degree of variability in commitment and responsibility.

Time spent on family caregiving obviously cannot be devoted to other pursuits. Caregivers not only have reduced leisure time, but they also reported that caregiving interferes with job (Abel, 1991). Stone, Cafferata & Sangl (1987) found that 10% of caregivers had left a paid job specifically to care for a family member, while 20% of employed caregivers had to reduce their working hours and 29% had rearranged their working schedule in other ways to meet the demands of the caring role. Schofield *et al.*, (1997) found that 17% of unemployed caregivers had given up a job, while 58% of those in paid jobs found this to provide some relief from the stresses of caregiving. Caregivers who managed to combine caregiving with full time employment generally believed that caregiving has interfered with productivity and led to reduced career opportunities, stress, loss of income and negative effect on their family and social lives (Wagner & Neal, 1999). Caregivers are likely to face restriction in their social activities (Waters & Northover, 1965) and have a reduced social network of their own (Anderson, Reiss & Hogarty, 1986). They may be lonely in their own home with few other social contacts (MacCarthy, 1988). The stigma of mental illness in the family is still wide spread and may contribute to social isolation (Kuipers, 1993).

Schene *et al.*, (1998) demonstrated the expected correlation between current level of symptoms and the burden of caregiving. Caregivers of individuals who fell ill

suddenly, with major medical illness, or got better suddenly, Nieboer *et al.* (1998) hypothesized that activity restrictions of the caregivers is the mediator for burden in caregiving. A significant correlation between depressive symptoms in the caregivers and activity restrictions was demonstrated.

Kumar and Mohanty (2007) investigated the effects of socio-demographic variables on spousal burden of schizophrenic patients. Female spouses experienced greater burden. They feel more anxious, tired, frustrated, isolated and greater work loaded. Besides full domestic responsibilities, the illness in husband places extra financial, caring, treatment and social responsibilities on female spouses which add to the burden.

Economic and Social Burden

An analysis of caregiving burden (Pohl *et al.*, 1994; Orbell, 1996) concluded that giving up work in order to care led to social isolation and thus to a range of other negative consequence. Conversely, combining family caregiving with paid employment increased the burden of caregiving, with King, Oka and Young (1994) showing that middle aged women who combined the roles of family caregiver and paid worker tended to feel most negatively about their caregiving and to demonstrate excess cardiovascular reactivity, an indication of chronic stress. Financial and employment difficulties are emphasized in large number of studies (Hoening & Hamilton, 1966; Stevens, 1972). Because schizophrenia usually occurs in early adulthood and is likely to affect long-term caring and employment capacity, greater impact is felt where the patient had formerly been working.

With the onset of an illness, the family's social life contracts and becomes mostly family centered. Within the restricted existence, the patients often become the focus of the family with other family members forced into the background (Chowane & Binik, 1982). Furthermore, most agree that the more severe and long lasting the illness or impairment, the greater the potential for family disruption. The effect on the caregivers' social life can be devastating. Relatives may feel unable to invite people at home because they feel they might be shocked or embarrassed by the patient's behaviour. Also, the caregivers may avoid going out, as the patient cannot be left alone for long.

Cook and Pickett (1988) found that parents of patients who were older and female experienced greater burden. The continuing financial dependency of the patient and worry about his/her future were the two main sources of concern. Caregivers reported financial burden and impact of the illness on their own mental health as the main source of burden in a study carried out by McCarthy *et al.*, (1989). Managing medications or talking to doctors and nurses on someone's behalf; Help to bathe or dress someone who is frail or disabled; (Grunfeld, *et al.*, 2004) Take care of household chores, meals, or bills for someone who cannot do these things alone (Levine, & Barry, 2003). are sources of burden.

Stigma and Burden

Stigma affects not only people with mental illnesses, but their families as well. The stigmatization of mental illness is currently considered to be one of the most important issues facing the mental health field (Crisp, 2000). Although individuals with mental illness suffer from a wide range of negative effects and impairments related to the disorder itself, these outcomes are exacerbated by societal stigmatization of their illness. In fact, harsh stigmatization of mental illness occurs across nations and cultures around the world, creating significant barriers to personal development and receipt of treatment (Tsang, Tam, Chan, & Cheung, 2003; World Health Organization, 2001b). Stigma by association has received comparatively little attention from empirical researchers. According to Mehta & Farina (1988), being a close relative of a person with severe mental illness creates 'a particularly difficult and delicate position if they cannot remove themselves, for they are both marker and marked'. Other studies confirm the process of stigma by association in family members (Lefley, 1989; Phelan *et al.*, 1998; Byrne, 2001).

Stigma leads to poorer individual and family functioning: High percentages of individuals with mental disorders avoid seeking treatment, even though public awareness of problems related to mental illness has increased (Jorm, Christensen, & Griffiths, 2006). Individuals are frequently deterred by the potential stigmatization associated with a diagnosis, and suffer lack of access to responsive care even when treatment is sought because of the limited funding for treatment that is a direct result of mental illness stigma (Kessler *et al.*, 1996; Regier *et al.*, 1993). Negative effects of stigmatization are evident even when pre-existing symptomatology or functioning is controlled, meaning that stigma's effects add to those emanating from mental illness itself.

The negative impact of the stigma of mental illness unfortunately extends beyond individuals with a diagnosis to their family members and close friends. Families perceive stigma as a major issue, not only for their mentally ill family member but for themselves as well (Wahl, 1999; Wahl & Harman, 1989). Family members feel shame, self-blame, and mistrust; they must often cope with the objective burdens related to caregiving and the subjective burdens related to societal rejection and embarrassment over the relative's behavior patterns, with a resultant negative impact on their own mental and physical well-being (Corrigan & Miller, 2004; Lefley, 1989; Martens & Addington, 2001). Such attitudes are not surprising, given that the predominant professional orientation for much of the 20th century was to blame nearly all forms of mental illness on faulty parenting or caregiving (Hinshaw, 2005). Stigma thus prevents many individuals from ever seeking treatment because they and their families are ashamed of the existence of mental illness and concerned that they may face significant discrimination and prejudice from neighbors, friends, and

even mental health providers if their diagnosis is known (Wahl, 1999).

Need for Interventions for Caregivers

The burden of care can be managed not only through the care of the patient, but also by caring for the caregivers. The literature provides substantial evidence that caregivers are hidden patients in need of protection from physical and emotional harm. Interventions should be directed toward caregivers and need to support the caregiver as client, directly reducing caregiver distress and the overall impact on their wellbeing and health. Moreover, interventions can be aimed to help make the caregiver become more competent and confident, providing effective care to the patient, which can reduce caregiver distress by reducing their load or increasing their sense of certainty and control. Despite the importance of information and support to help family caregivers, studies on interventions to increase support for family caregivers have lagged far behind those provided for patients. The need is to focus on the family as a part of the patient's therapeutic plan of care. Few randomized clinical trials of educational interventions directed toward family caregivers have been conducted or published, and there is limited research to inform us about skills training for caregivers to prevent back injuries, infection, and other potential risks inherent in the caregiver situation.

There are a number of approaches to consider in providing optimal support to caregivers. Counselling, education and support programs provide the core of these interventions. The focus on the individual which is apparent in research on caregiver burden is also apparent in intervention programs. These interventions are at the individual level (Gallagher-Thompson & Steffen, 1994) and include support groups (Peak, Toseland & Banks, 1995), attempts to improve performance and coping skills of the caregiver together with regular day care (Feinberg & Kelly, 1995) and occasional respite care (Orbell, 1996). Direct clinical interventions like counselling/therapy should be designed for caregivers of mentally ill. Such interventions, give caregivers a chance to express their problems and negative affect and gave them an opportunity to share their caregiving experience, reducing their burden as a lot of studies done in west have found that the strongest effect of clinical intervention was found upon objective stressors (Croake & Kelly 1985; Faloon *et al.*, 1983). This information would help others, particularly family members in understanding mental illness, and mentally ill person, Information about mental illness in general and particularly about the patient would help them in dealing with the patient in a more confident manner.

In addition to direct interventions, there is also a need to work with the family. Some kind of family psychotherapy, where all family members discuss their problems together, would help in reducing some of the

problems that result from lack of communication. One of the major problems identified was lack of communication among family members which adds to the stress of the caregiver. Moreover, family members would also come to know about the causes and consequences of mental illness and would be more supportive of caregivers, thus promoting cohesion in the family.

Summary and General Evaluation

The findings reviewed indicate that chronic mental illness has significant consequences for families and society at large. It is clear that severe mental illness has a devastating impact on the family as well as on family members. Families are burdened considerably by their largely unsupported roles as caregivers for their mentally ill relatives. Mental health professionals focus on the index patient and the relatives' needs and concerns are often ignored. Patients often become dependent on their families and require continued assistance to maintain themselves in community. Mental illness interferes with one's ability to form and maintain interpersonal relationships, care for oneself, complete one's education and maintain employment. The capacity for social relationship is often reduced and these individuals become dependent on their family and in particular on caregivers. Caregivers experience problems in dealing with illness as well as feelings of grief, loss and guilt compounded by the stigma attached to the illness.

Studies have documented that family members suffer tremendous burden and stresses in the care of individuals with mental illness (e.g. Noh & Turner, 1987). Many studies have documented both the physical and mental health consequences of the caregiving role. For example several investigators suggest that the physical health of the caregiver is poorer than the non-caregiver (Fuller-Jonap & Haley, 1991, Prunchno & Potashnik, 1989). It has also been reported that caregivers exhibit greater psychological distress and in particular elevated levels of depression (Dura Stukenberg & Kiecolt-Glaser, 1991; Gallanher, Rose, Riveria, Lovett & Thompson, 1989; Russo, Vitalino & Brewer, Katon & Becker, 1995; Schulz, O'Brien, Bookwala, & Fleissner, 1995). Because of negative health effects increasing attention is being given to the stress experienced by these caregivers. Having a family member with mental illness is found to be very disruptive of the family life and may lead to reorganized task and role assumed by family members. The stress of chronic illness on families can lead to family conflicts and can affect the health of individual family members (Bruhn, 1977; Leventhal *et al.*, 1985). Although it is now well established that caregiving is a prolific source of persistent stress (Pearlin *et al.*, 1990), formal resources for caregiving are inadequate and there remains no common model to assess the needs of the caregivers (Turner & Street, 1999).

The degree of burden experienced is influenced by patient and caregiver related demographic factors and

also illness characteristics. Among patient variables, age and gender of the patient have been studied. Greater burden is associated with older patients, but the findings on gender are equivocal. Some researchers have reported greater burden in families with male patients, while other studies have found the reverse to be true. The gender of the caregiver is also a factor related to burden, with female caregivers reporting greater distress and burden. The economic status of caregivers also has a significant impact on perceived burden. The impact is in terms of accessibility to resources. From a life cycle perspective, the relationship of burden to the process of aging is an important issue. When spouses themselves are aging, their deteriorating health can add to existing physical strain.

The families of caregivers have specific needs and effective family interventions should include family support, advocacy groups, family consultation, family education, family psycho-education and psycho-therapy (Marsh *et al.*, 1997). It is important to address the needs of different caregivers- spouse, parents, siblings or children. Parent caregivers have intense anxiety about the future of their relative, lack of knowledge about how to plan, and lack of financial resources were the main obstacles to planning (Hatfield and Lefley, 2000). These findings underline the problems and concerns faced by elderly caregivers in planning for the future of their ill relative. These are some of the major psychosocial problems faced by the caregivers. The patient's illness is constructed as a burden in terms of finance, time and special effort required for the treatment.

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