



ORIGINAL RESEARCH PAPER

Psychology

'FAMILY BURDEN' - THE ROLE OF FAMILIES AS CARERS

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Dr. Meeta Malhotra

PhD psychology, Associate Prof. Amity Institute of Behavioural and Allied Sciences
Amity University Haryana India

ABSTRACT

Family care is an emerging area of research. The purpose of the current review was to present insights in how caregiving is experienced by family members, the prevalence of psychological stress and burden experienced by the family caregivers of the mentally ill. Caregivers experience various problems, associated with their caregiving role. As such it becomes imperative to identify the areas of burden and provide necessary support. From the review it is apparent that the patient's illness is constructed as a burden in terms of finance, time and special effort required for the treatment, physical and emotional burden, family relations and occupation. The need is to formulate interventions keeping into considerations the various areas of burden as reported by caregivers. The present paper which focus on family care is significant not only because of the contemporary relevance of family caregivers, but also because it focuses on mental illness, which is a little understood condition because of its stigmatizing and long drawn nature.

Introduction

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 four 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). 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. Caregiving burden is 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 is to examine the relationship between caregiving, psychological distress, and the factors that contribute to caregivers' burden and strain. 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).

'Family burden' has been adopted to identify the objective and subjective difficulties experienced by relatives of people with long-term mental disorder (Hoenig 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 et al., 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.

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). 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). 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).

Many caregivers have some assistance from a family member or friend (e.g. Penrod, Kane, Kane & Finch, 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, male 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).

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. 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; Lauber, Eichenberger, Luginbühl, Keller, & Rössler, 2003).

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). 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, 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 overwhelming. 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.

Stigma and Burden

The negative impact of the stigma of mental illness unfortunately extends beyond individuals with a diagnosis to their family members and close friends. 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 (World Health Organization, 2001b). Studies confirm the process of stigma by association in family members (Lefley, 1989; Phelan et al, 1998; Byrne, 2001).

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).

Summary and General Evaluation

The findings reviewed indicate that chronic mental illness has

significant consequences for families and society at large. 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. Caregivers experience problems in dealing with illness as well as feelings of grief, loss and guilt compounded by the stigma attached to the illness.

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.

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. 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 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. 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.

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.

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