ABSTRACT

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, Galyner, 2009, Ogilive, 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. We reviewed that 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 & Montogmery, 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 tangibly
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, & Kosier, 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
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
Organisation, 2001b). Studies confirm the process of stigma by
association in family members (Leffley, 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; Leffley, 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
causes and consequences of mental illness and would be more
responsive to treatment.

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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