
Mental Health and Well-Being of Caregivers: A Review of the Literature

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ABSTRACT

The present piece of work attempts to fill this knowledge gap by capturing different shades of caregiving experiences of family members who were engaged in caregiving for their chronically ill family members or relatives. Maximum studies of caregiving indulge in caregivers of mentally ill. This study intends to apprehend how family caregivers in chronic illness perspective create implication of their caring role in the Indian setup.

Keywords: Mental Health, Well-Being, Caregivers

Caregiving may mean direct care of all types also including work done by paid workers such as nurses, social workers, and counselors. But the focus here is not on professional caregivers, but on family caregivers. Family caregivers are emotionally involved in the process of caregiving, thus although they may undertake caregiving as a responsibility still they may perceive a threat to their physical and psychological being. Thus caregiving being associated with emotional, financial and social turmoil forms a ground for research in itself.

Dr. Bruce Finke states that “Caregiving is a critical issue for the Indian Health System”. In India, caregivers are taken for granted because it is culturally expected that the family will look after the chronically ill patients, regardless of what changes it means. This is widely different from the cultural assumptions made in present literature, where caregivers seem entitled to “having a life” and respected for what they are doing. However, even Indian caregivers find their role difficult and even they perceive stress related to it.

Most literature focuses on caregiving as burden, edifying the negative outcomes. Cox and Monk (1993) informed in their study that 29 percent of caregivers reported that their health had deteriorated as a result of caregiving. According to the study by Juster and Marin (2011), the

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Mental Health and Well-Being of Caregivers: A Review of the Literature

intensity of chronic caregiving is allied to a number of health issues. The caregiving experience places a cumulative toll on the body and psychological strains the caregiving person.

The literature on caregiving fundamentally endorses negative impact of caregiving on the mental health of the caregiver. The study on caregivers of Parkinson's disease by Reilly, Finnan, Allwright, et al (1996) shows that overall, carer spouses have slightly worse social, psychological and physical profiles and increasing care provision is associated with fewer contacts, outings and holidays.

Family caregiving is also associated with increased levels of depression and anxiety as well as higher use of psychoactive medications, poorer self-reported physical health, compromised immune function, and increased mortality (Kiecolt-Glaser & Glaser, 2001; Light & Martin, 1996; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Schulz & Beach, 1999). Sahoo, Brahma and Mohapatra (2010) found in their study that stress burden has been found significantly high in the caregivers of both, patients of mental illness and diabetic patients. But it is higher in case of caregivers of mental illness.

Caregiving not only has an impact on physical illness but also mental illness of individual, although the kind and amount of impact may vary in both. The majority of caregivers experience significant deterioration in their mental health (Barer & Johnson, 1990). The survey by Australian Bureau of Statistics (ABS), 1998 found that approximately 30% of caregivers reported that their well-being had been affected by caregiving, and that they were often worried or depressed. Caregiver burden, depression and life satisfaction have been identified as discrete aspects of caregiver's well-being by O'Rourke & Tuokko (2003). A comprehensive meta-analysis of mental and physical health effects of caregiving by Pinquart & Sorensen (2003) found significantly higher rates of depression and stress in caregivers compared with non-caregivers. Cummins and Hughes (2007) also found in their study that wellbeing decreases linearly as the number of hours spent caring increases and caregivers are more likely to be experiencing chronic pain. They also established that primary caregivers are at considerable risk of high stress, clinical depression, and abnormally low subjective quality of life. Schulz & Sherwood (2008) also established that the detrimental physical effects of caregiving are generally less intensive than the psychological effects.

Caregiving and Physical Health

The caregiving studies reveal that a caregiver's physical health is at loss because of the constant burden that they face. Burton et al. (2003) found evidence of impaired health behaviors, such as neglecting their own health care appointments and eating a poor-quality diet, among caregivers who provide assistance with basic activities of daily living (ADLs) like toileting and eating. A national Survey Study By Evercare (2006) revealed that fifteen percent of the caregivers say their health has gotten a lot worse because of providing care, and four in ten say it has gotten

Mental Health and Well-Being of Caregivers: A Review of the Literature

moderately worse (44%). The remaining 41% say their health is a little worse as a result of their caregiving. The survey also indicated that the most common aspects of their health that have worsened as a result of caregiving are: energy and sleep (87%), stress and/or panic attacks (70%), pain (60%), depression (52%), headaches (41%), and weight gain or loss (38%).

Caregiving as an Obligation

The effect of caregiving is personally felt by the caregivers themselves but still they consider it as a part of their responsibility. Sherrelet.al. (2001) establish that caregiving can be a rewarding and positive experience. Findings of Lopez, et.al. (2005) support satisfaction in caregiving. Robison, Fortinsky, Kleppinger, Shugrue and Porter (2009) found that caregivers rate their health better than non-caregivers and do not report more depressive symptoms or social isolation, although living with the care receiver, inadequate income, and care receivers' unmet need for community-based long-term care services relate to multiple negative outcomes.

Arbitrators of Caregiving

The personal characteristics and nature of caregiver also plays a role in determining the impact caregiving has on the caregiver. Wright, et.al. (1993) found that caregiver's sex, ethnicity, education level, self-related health and relationship to the care receiver have been associated with the psychological well-being of the caregivers. Grotberg (2004) examined the needs of fathers as caregivers, the stress of caregiving, and adolescents with special needs. He concluded that the role of resilience is a critical element of managing the problems inbuilt in having a family member with special needs. Older caregivers, people of low socioeconomic status, and those with limited support networks report poorer psychological and physical health than caregivers who are younger and have more economic and interpersonal resources (Pinquart, 2001; Schulz et al., 1995; Vitaliano et al., 2003). Clark (2002) has provided strong data on the effects of individual and family hardiness on caregiver depression and fatigue. In her study, she found that the more hardy the caregiver the less depression and fatigue marked in them.

The Role of Psychological Resources

Direct effects of social and psychological resources on caregiver's experiences were found to be fewer to none in the study of Nijboer (2000). In his study, it was also found that caregivers with a low level of daily emotional support, with a low score on mastery, and with negative perception of caregiving could be identified to develop more depression over time. A study by Glaser et.al. (1991) revealed that caregivers experienced significantly more prolonged illness from infectious disease, primarily upper respiratory tract infections, and they visited physicians often. The data on social support indicated that caregivers had fewer people in their networks as well as less frequent contacts with network members. Also the study revealed that caregivers showed higher levels of depressive symptoms. Cohen and colleagues (2002) present in their study that positive feelings about caregiving were associated with lower depression symptom

Mental Health and Well-Being of Caregivers: A Review of the Literature

scores, lower perceived burden of being a caregiver, and better self-assessed health. Few studies present that the psychological resources, such as resilience, hardiness, optimism, hope and self-efficacy, mediate the resulting effect of caregiving on the caregiver.

Being a Resilient Caregiver

Resilience has been found as predictor of mental health in caregivers in the study of Clark and Hartman (1996). Findings of study of Fraser & Pakenham (2009) suggest that some resilience factors have a differential impact on adjustment and caregiving, and support the focus of interventions on modifying resilience factors. Though studies also suggest that psychological resilience constructs don't contribute to the prediction of life satisfaction (Kupferschmidt, 2009). Scott (2010) established in his study that as resilience increased, caregiver burden decreased. Cassidy, Giles & McLaughlin (2013) identified resilience and benefit finding as accounting for significant amounts of variance in positive health and mediating the impact of caregiving in young caregivers, where benefit finding seems to be related to social recognition of the caregiving role and to family support.

Hope in Caregiving

Hope is also found to be a component of caregiving by Boland and Sims (1996). In their study, the caregivers described home as being healing and a source of hope where the patients could improve, if not physical, at least mentally. Hope for family caregivers of chronically ill population emerged as four interconnecting themes: engaging, strengthening, and maintaining connections; easing of self; finding meaning in the situation; and acceptance (Revier, Meiers & Herth, 2012). Hope is an important determinant of caregiver burden; findings of study by Utne, Miaskowski, Paul & Rustoen (2013) suggests that family caregivers with lower levels of hope represent a high-risk group for higher levels of caregiver burden. The study by Duggleby, Williams, et.al. (2014) formulated that participants with higher hope scores had higher mental health scores, lower perceptions of loss and grief scores, and higher scores in their confidence in their ability to deal with difficult situations (self-efficacy).

Role of Optimism in Caregiving

Optimism is also found to arbitrate the effect of caregiving on caregivers. Shifren & Hooker (1995) studied the stability of optimism in caregivers and concluded that the caregivers showed variability in optimism over time, and their state optimism could be differentiated from their affect. Fotiadou, Barlow, Powell & Langton (2007) established in their study that parents of children with cancer had higher levels of anxiety and depression, together with greater levels of optimism, satisfaction with life and subjective health perception. Also, optimism was significantly correlated with satisfaction with life, subjective health perception, anxiety and depression. Optimism was found to be related to better mental and

Mental Health and Well-Being of Caregivers: A Review of the Literature

physical health, also dispositional optimism played a significant role as a psychological resource in the study conducted by Greenberg, Seltzer, Krauss, Chou & Hong (2010).

The 'Dharma' of Indian Caregivers

Mostly excerpts of caregiving literature is drawn from western literature. Among Asians and Asian Indians in the United States, caregiving is a product of cultural expectations, duty, love, and a positive attitude towards aging in general (Bhagat & Unisa, 2006; Gupta, 2000). Banerjee and Dixit (2012) maintain that the family caregivers in India accept their role as caregivers and consider their work as part of their lives or 'dharma' (the social responsibilities towards others, which are mandatory). Research on Indian caregivers is diminutive and even those that exist talk of caregivers of mentally ill and do not focus on the reciprocity aspect that exists in Indian caregiving. Reciprocity is described as giving back to parents or other family members during one's lifetime. It is viewed as an obligation to provide for those who provided for you. Reciprocity is taught to children both implicitly and explicitly. "Being there" and "unconditional regard" were two concepts also related to reciprocity (Clark & Huttlinger, 1998). Lack of reciprocity in caring may lead to the gradual detachment in relationship between patients and their caregivers (Banerjee & Dixit, 2012). Thus, together with reciprocity, the relationship quality also plays a major role in deciding the outcome of caregiving (Gupta, 2009). Gupta, Pillai & Levy (2012) also found that role overload and role conflict influence caregiver burden indirectly, where role conflict is associated with lower quality of relationship between a caregiver and the elderly care recipient. Also, religious beliefs and practices and positive appraisal of the caregiver role in terms of "value" emerged as the most frequently cited intrapersonal sources of strengths in caregivers of cancer (Mehrotra & Sukumar, 2007). The participants also described several interpersonal sources of strengths, e.g., family, medical fraternity, and care recipients themselves. Indian caregivers of patients with schizophrenia enjoy positive aspects of caregiving while taking care of their ill relatives. In these caregivers, the positive aspects of caregiving were associated with better quality of life (Kate, Grover, Kulhara & Nehra, 2013). Although certain positive outcomes stick to caregiving in India, still evidences talk of some sort of existing burden. In a study by Shaji, Smitha, Lal & Prince (2002) on dementia' caregivers, the majority of caregivers experienced significant deterioration in their mental health and one caregiver unfortunately committed suicide after the death of her husband. Nevertheless, studies also show that coping strategies of denial and problem solving, strength of religious belief and perceived burden were significant predictors of wellbeing of caregivers (Rammohan, Rao & Subbakrishna, 2008). Also, evidences show that caregivers learn to adjust to the behaviour patterns and changes in the patients over the years, perhaps becoming more resilient individuals as a result of habituation (Jain and Singh, 2014).

CONCLUSION

Caregiving not only has an impact on physical illness but also mental illness of individual, although the kind and amount of impact may vary in both. The majority of caregivers experience

Mental Health and Well-Being of Caregivers: A Review of the Literature

significant deterioration in their mental health (Barer & Johnson, 1990). The survey by Australian Bureau of Statistics (ABS), 1998 found that approximately 30% of caregivers reported that their well-being had been affected by caregiving, and that they were often worried or depressed. Caregiver burden, depression and life satisfaction have been identified as discrete aspects of caregiver's well-being by O'Rourke & Tuokko (2003). A comprehensive meta-analysis of mental and physical health effects of caregiving by Pinguart & Sorensen (2003) found significantly higher rates of depression and stress in caregivers compared with non-caregivers. Cummins and Hughes (2007) also found in their study that wellbeing decreases linearly as the number of hours spent caring increases and caregivers are more likely to be experiencing chronic pain. They also established that primary caregivers are at considerable risk of high stress, clinical depression, and abnormally low subjective quality of life. Schulz & Sherwood (2008) also established that the detrimental physical effects of caregiving are generally less intensive than the psychological effects.

Most of the literature views caregiving as a burden, focusing more on its negative aspects. We know more about the emotional distress and behavioral disruption in caregivers than we know how to avoid such distress and disruption. By gaining knowledge about the positive aspects of caregiving, we could try to design effective programs, services, and interventions to enhance family member functioning and long-term adjustment.

Not only fewer evidences exist on positive outcomes of caregiving, but also only scarce amount of literature is available related to caregivers of chronically ill patients, most of the studies focus on people who care for the mentally ill. Family caregivers of cancer patients communicated unmet needs for social, volunteer, and professional support as their own physical and emotional health suffered (Weitzner, Haley & Chen, 2000). Molloy, Johnston, et.al. (2010) in their study on informal caregivers of heart failure patients also found that the demand-control model of job strain predicts caregiver burden and caregiver satisfaction in the informal caregivers of heart failure patients.

Most caregiver research focuses on how to avoid negative outcomes (physical and psychological), not on how to create positive experiences (Coons, 2012). Also, Indian view of caregiving as sum of 'Dharma' (responsibility), values and reciprocity is missing in literature. The present piece of work attempts to fill this knowledge gap by capturing different shades of caregiving experiences of family members who were engaged in caregiving for their chronically ill family members or relatives. Maximum studies of caregiving indulge in caregivers of mentally ill. This study intends to apprehend how family caregivers in chronic illness perspective create implication of their caring role in the Indian setup.

Mental Health and Well-Being of Caregivers: A Review of the Literature

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Conflict of Interests

The author declared no conflict of interests.

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Mental Health and Well-Being of Caregivers: A Review of the Literature

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