

Effects of Stress on Caregivers of Chronically ILL Patients

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Abstract

Chronic illnesses like Alzheimer's disease, Parkinson's disease, paralysis and so on can be disabling for a patient. Under these conditions the patient becomes dependent on another person and constantly need help from him/her, even in the activities of daily living. The services provided by this person is called 'caregiving', while the person himself/herself is called the 'caregiver'. Caregivers can be either formal (nurses and trained staffs of hospitals) or informal (family members and friends). In case of informal caregivers, the responsibilities of maintaining a regular family life and career in addition to the duties of caregiving naturally leads to great stress. Dealing with this stress on a regular basis affects both the caregivers' mental as well as physical health, which if not monitored at the right time can become life-threatening. This study can help create an awareness amongst the family members of a primary caregiver as well as medical professionals to keep a check on the health status (both psychological and physical) of the caregiver in order to prevent him/her from becoming a patient himself/herself.

Introduction :

A chronic illness can be referred to as the long-term altered health condition of an individual which cannot be treated by a surgery or by a simple, short-term pharmacotherapy. It may or may not be lifelong or terminal in nature, although it takes away quite a number of years of the patient's life. Chronic illness, in some cases, can be disabling to the individual. Such illnesses include Alzheimer's disease, Parkinson's disease, multiple sclerosis, paralysis and so on.

Individuals suffering from such disabling illnesses cannot often live independently and need constant help and support from another individual in the form of caregiving. Hence, care giving is assisting or helping an individual who is either ill or disabled and cannot perform his/ her daily personal or other non-personal activities on his/her own.

Care giving has been classified into two types: formal and informal. Formal caregivers include trained staffs and nurses of

hospitals, whereas, informal caregivers include spouse, parents, children, brothers, sisters, other relatives or even friends. Informal caregivers are also called family caregivers and provide unpaid services to the disabled patient.

In case of family (or informal) caregivers, the added responsibilities of caregiving, along with the already present pressures of maintaining a family and professional life, are quite likely to produce a lot of stress. This stress in caregivers can be of two types, i.e., primary stress and secondary stress. Primary stress arises from daily personal care services, such as feeding, washing and so on and this results in secondary stress in the form of restricted social life, family conflicts as well as financial hardships and other stress producing consequences. Ultimately, both these primary and secondary stresses are likely to lead to psychological and physiological malfunctioning in caregivers.

Psychological Consequences of Caregiving Stress

Several studies have reported psychological problems like feelings of burden, depression, anxiety, fatigue as well as sleep disturbances among caregivers.

Burden among Caregivers

In a recent study by Sreeja, Gupta, Lal, and Singh (2009), a comparison between caregivers of chronic mental illness (schizophrenia) and chronic physical illness (epilepsy), showed that there was significant level of burden due to caregiving on both the groups. In a study by Elmahdi et al. (2011) on caregivers of patients either suffering from a psychiatric illness or a chronic physical illness, it was reported that level of subjective burden was higher among wives than mothers. Personal tasks like feeding and washing the patient are perceived as more difficult and burdensome than non-personal tasks like doing the groceries (Horowitz, 1985). Given, Stommel, Collins, King, and Given (1990) stated that the more confining the caregiving tasks are, the more they create burden. Race (Horowitz & Reinhard, 1995), perceived social support (Edwards & Scheet, 2002) and depressive symptoms (Caap-Ahlgren & Dehlin, 2002) in caregivers are also important variables for predicting burden in caregivers.

Depression among Caregivers

Higher rates of depressive symptoms are consistently reported in family caregivers of ill patients in comparison to their same age control sample (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch; 1995, Dura, Stukenburg, & Kiecolt-Glaser, 1990; Tennstedt, Cafferata, & Sullivan; 1992). In recent studies, 32% to 50% of caregivers were found to have depressive symptoms of a level suggesting clinical

depression (Burtler, Turner, Kaye, Ruffin, & Downey; 2005, Carter, 2002; Covinsky et al., 2003). Depression is found in caregivers of almost all chronically ill patients. It is found among caregivers of people suffering from HIV/AIDS (Folkman, Chesney, Cooke, Boccellari, & Collette, 1994; Land & Hudson, 2002; LeBlanc, London, & Aneashensel; 1997), Alzheimer's disease (Lawton, Miriam, Mortan, Allen, & Michael, 1991; Semple, 1992) and also of those who are hospitalized for a long time (Rosenthal, 1993). In a study on caregivers of spinal cord injury patients (Weitzenkamp, Gerhart, Charlifue, Whiteneck, & Savic, 1997), it was seen that the spouses reported more symptoms of depression than the patients themselves as well as the non-caregivers. There are a number of factors that lead to the development of depressive symptomatology in family caregivers. Rivera (2009) has given a list of factors which include age, race, sleep disturbances, social support and so on. It was found that younger caregivers have higher depression scores (Given et al., 2004; Kurtz, Kurtz, Given, & Given, 2005; Williams, 2005). In studies related to the gender of the caregivers, it has been found that female caregivers report higher levels of depression as compared to their male counterparts (Cho, Dodd, Lee, Padilla, & Slaughter, 2006; Covinsky et al., 2003; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Thompson et al., 2004). In a study conducted on female caregivers of patients suffering from either a psychiatric illness or a chronic physical illness, it was found that 34% were suffering from major depression (Elmahdi et al., 2011). Studies on race of caregivers have reported that Caucasians have significantly more depressive symptoms than African- Americans and Hispanics (Gallagher-Thompson et al., 2006;

Williams, 2005). In a study on cancer caregivers by Carter (2002), the family caregivers showed depression and chronic sleep loss. The family caregivers have reported that the chronic sleep loss made them feel irritable towards the patients. This irritability in turn led to anger with the patients' increasing care demands, which further resulted in feelings of guilt. This guiltiness later made the caregivers feel depressed. Depression has been reported to be the cause of coronary heart disease and mortality in both the genders of caregivers (Ferketich, Schwartzbaum, Frid, & Moeschberger, 2000; Ford et al., 1998; Kouzis, Eaton, & Leaf, 1995).

Anxiety among Caregivers

Anxiety is also found to occur significantly in caregivers of chronically ill patients. Deshmukh, Patwardhan, Bakshi, Paranis, and Kelkar (2011) reported significant levels of anxiety in caregivers of cancer patients. In a study by Grov, Dahl, Moum, and Fossa (2005), the anxiety level in caregivers of both genders was found to be significantly higher than age and gender adjusted controls. Similar results were also found in caregivers of dementia patients (Cooper, Balamurali, & Livingstone, 2007). Elmahdi et al. (2011) reported a 22.3% prevalence of generalized anxiety disorder in female caregivers of patients suffering from either a psychiatric illness or a chronic physical illness. Like depression even anxiety in caregivers depends on several factors. Higher anxiety scores have been reported by female caregivers (Gaston-Johansson, Lachica, Fall-Dickson, and Kennedy, 2004; Iconomou, Viha, Kalofonos, and Kardamakis, 2001; Langer, Abrams, and Syrjala, 2003; Matthews, 2003). Singlehood, lower income, higher levels of sleep disturbances,

increased fatigue and caregiver strain are other factors related to higher anxiety in caregivers (Flaskerud, Carter & Lee, 2000; Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004; Iconomou, Viha, Kalofonos, & Kardamakis, 2001; Rossi Ferrario, Zotti, Massara, & Nuvolone, 2003). Younger caregivers are reported to be more anxious than their older counterparts (Deshmukh et al., 2011).

Fatigue among Caregivers

Fatigue is yet another outcome of caregiving. Studies showed higher fatigue scores in the family caregivers of patients with cancer, dementia and Parkinson's disease (Sato, Kanda, Anan, & Watanuki, 2002; Teel & Press, 1999). In family caregivers, fatigue has been found to be physically induced by the constant demands of caregiving and psychologically induced by concerns regarding the diagnosis, treatment and prognosis of the patient (Jensen & Given, 1993). Female gender (Cho, Dodd, Lee, Padilla, & Slaughter, 2006), lower income levels (Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004), number of hours of daily care (Jensen & Given, 1993) and levels of caregiver strain (Passik & Kirsh, 2005) are some factors related to higher fatigue in caregivers.

Sleep Disturbances among Caregivers

Sleep disturbance is yet another outcome of caregiver stress. In a study on caregivers of Parkinson's disease patients it was reported that spouses involved in daily caregiving had a seven-fold increased risk of sleeping badly compared to partners not involved in caregiving (Happe & Berger, 2002). In a study on caregivers of Parkinson's disease patients it was reported that 48% female, in contrast to only 27% male, caregiver spouses suffered from sleep disturbances (Smith,

Ellgring, & Oertel, 1997). Caregivers of adults with dementia also reported more sleep complaints than healthy controls of similar age (Wilcox & King, 1999). In studies on caregivers of cancer patients it was reported that more than 95% of the caregivers were experiencing moderate to severe overall sleep problems (Carter, 2002; Carter & Chang, 2000). Teel and Press (1999) reported higher levels of sleep disturbances in caregivers of cancer, dementia and Parkinson's disease patients than non-caregivers. In other studies on caregivers of dementia patients, family caregivers showed higher sleep problems than non-family caregivers (Sato, Kanda, Anan, & Watanuki, 2002; Smith et al., 1997; Wilson, 1989). It may be added here that both anxiety and depression are predictors of sleep disturbances (Quan et al., 2005; Spira et al., 2005). Female gender (Smith et al., 1997), lower levels of education, psychological distress, care recipient disruptions (Wilcox & King, 1999), lack of social support, fatigue and other familial issues (Aslan, Sanisoglu, Akyol, & Yetkin, 2009) lead to sleep disturbances. Caregivers' sleep disturbances are associated with higher levels of fatigue, anxiety, depression, lowered immune function, elevated stress hormones, increased risk for cardiovascular diseases and premature mortality (Martire & Hall, 2002; von Kanel et al., 2006).

Physiological Consequences of Caregiving Stress

Apart from psychological problems, caregiving stress also leads to physiological malfunctioning.

Hypertension and Heart Disease among Caregivers

Eventhough caregiving stress has been reported to cause somatic complaints like heart

palpitations, headaches and digestive problems (Grasel, 2002, Kreutzer et al., 2009; Thompson et al., 2004), studies also indicate that it can lead to hypertension and coronary heart disease (Aronson, 1988). Moritz, Kasl, and Ostfeld (1992) reported that systolic blood pressure was higher among men whose wives were more cognitively impaired. Shaw et al. (1999) reported that caregivers experienced 67% increase in the risk for borderline hypertension compared with controls and this difference remained statistically significant after controlling for age, gender, education, socioeconomic status, body mass index and use of anti-hypertensive medications. Lee, Colditz, Berkman, and Kawachi (2003) reported that there is almost two-fold increased risk of coronary heart disease in family caregivers of ill spouses when compared with non-caregivers. In another study it was found that male caregivers had greater chances of coronary heart disease than non-caregivers (Vitaliano et al., 2002).

Altered Insulin Level among Caregivers

Insulin levels are also influenced by caregiving. Vitaliano, Scanlan, Krenz, Schwatz, and Marcovina (1996) observed significantly elevated insulin levels in non-diabetic spousal caregivers of dementia patients as compared with gender-matched spouses of non-demented older adults. Higher rates of diabetes is also reported in informal caregivers (Haley, Levin, Brown, Berry, & Hughes, 1987; Pruchno & Potashnik, 1989).

Disturbed Metabolic Functioning among Caregivers

With respect to metabolic functioning, significant differences between caregivers and non-caregivers were revealed. Older male caregivers had a significantly higher body mass

index and were more obese than controls and female caregivers showed a greater increase in weight than controls over a fifteen to eighteen months period of time (Vitaliano, Russo, Scanlan, & Greeno, 1996). These metabolic changes put caregivers at risk for adverse health outcomes including elevated lipid levels, high blood pressure, cardiovascular diseases and arthritis in weight bearing joints (hips and knees).

Immune System Deterioration among Caregivers

Chronic stress related to caregiving also results in deterioration of the immune system. In a study conducted by Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, and Sheridan (1996) on spousal caregivers of dementia patients, it was indicated that chronic elevations in stress can lead to impairments in immunity and in turn may result in increased vulnerability to infectious diseases. The study also reported that response to vaccination against influenza virus was compromised in caregivers as compared to same aged non-caregivers. Caregivers of relatives with Alzheimer's disease have shown increased wound healing time as compared to age matched control (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995).

Other Physiological Disturbances among Caregivers

Informal caregivers are reported to have higher rates of arthritis, ulcers and anaemia than non-caregivers (Haley, Levine, Brown, Berry, & Hughes, 1987; Pruchno & Potashnik, 1989). Health issues like back problems and peptic ulcers have been associated with demands of providing full time care to a spouse (Cohen, 1982; Snyder & Keefe, 1985). In a descriptive report on caregivers of

Parkinson's disease patients, it was stated that caregivers had higher rates of medical conditions including arthritis, asthma, diabetes, cardiac problems and also hypertension (Guinta, Parrish, & Adams, 2002). Caregiving stress is also reported to result in faster aging and mortality. In a study conducted by Epel et al. (2004), on mothers of chronically ill children, it was found that chronic stress accelerates the effects of aging by actually shortening cell life which in turn leads to weakened muscles, skin wrinkles and even organ failure. Caregivers of Alzheimer's patients experiencing emotional or physical strain were found to have 63% greater mortality than caregivers without strain or non-caregivers (Schulz & Beach, 1999).

Conclusion

The ill effects of caregiving stress has gradually come to the forefront. It is observed that the caregiver's stress leads to feelings of burden, which in turn leads to depression, anxiety, sleep disturbances and fatigue, and ultimately affects the physical well-being of the caregiver to the extent that if neglected it can also claim the caregiver's life. It is therefore very essential for the family and friends of a primary caregiver to be vigilant towards the caregiver's mental and physical health. Any slight change should not be ignored and reported to the physician as early as possible. Medical and psychiatric professionals should also be aware of the ill consequences of caregiving stress and identify those caregivers who are "at a risk" of developing psychological and physical health problems and hence provide early and proper interventions to minimize the risk of any long lasting damage. The significance of the problem needs to be realized firstly, in context to the reducing sizes of families which makes the

availability of caregivers, especially the informal caregivers, less feasible. Secondly, and more importantly it needs to be remembered that informal caregivers provide an all important quotient of love, affection and emotional care which is paramount for the patient's physical and psychological well-being.

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