



Caregiver Burden Among Caregivers of Individuals With Severe Mental Illness: Testing the Moderation and Mediation Models of Resilience



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A B S T R A C T

The association between the socio-demographic characteristics of caregivers, such as gender and caregiver burden, is well documented; however, the process underlying this relationship is poorly understood. Based on the stress process model, we designed a cross-sectional study to examine the mediating and moderating effect of resilience on the relationship between gender and caregiver burden. Caregivers of individuals with severe mental illness ($n = 201$) were recruited in two psychiatric outpatient clinics in Malaysia. The relationship between the gender of the caregiver and caregiver burden was mediated by resilience, thus supporting the stress process model. The findings from the present research contribute to the growing evidence of the interaction between socio-demographic variables of caregivers and resilience, and caregiver burden.

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A report by the World Health Organization reveals that approximately 151 million people suffer from depression and 26 million from schizophrenia (World Health Organization, 2010). Data from the Asian region shows that a steady increase of mental illness cases is reported each year. For example, the findings from the Malaysian National Health Morbidity Survey (NHMS) demonstrate that the prevalence of morbidity related to mental illness increased from 10.6% in 1996 to 11.2% in 2006. In addition, recent studies conducted by the NHMS in 2011 reported that the occurrence of depression and suicidal ideation among adults aged 16 and above was 1.8% and 1.7%, respectively (Ministry of Health, 2014).

In many cases, individuals with severe mental illness require long term care; thus, the responsibility for patient management has been placed on informal caregivers or family members. Unfortunately, the resources and support available in the community in Malaysia are inadequate to fulfill caregivers' needs, and, as a result, they report a lack of training and preparation to care for their relatives with mental illness (Chong, Mohamad, & Er, 2013). Past studies have found that caregivers play an imperative role in influencing patients' prognosis as well as reducing the rates of hospital admission, relapse and episodes of self-harm (Haddad, Brain, & Scott, 2014). However, caring for mentally ill family members also affects the caregivers' physical and mental health. Parents who are caring for children with severe mental illness have hyperactive cortisol profiles, which indicates a chronic stress level compared to parents of individuals without a severe mental illness (Barker, Greenberg, Seltzer, & Almeida, 2012). In addition, the

caregivers of patients with mental illness also appear more prone to depression as a consequence of their experiences. Previous qualitative research findings have also shown that tiredness, sadness, constant stress, uncertainty and frustration are the common feelings of burden expressed by caregivers (Johansson, Anderzen-Carlsson, Ahlin, & Andershed, 2010). Unlike other chronic illnesses, the stigma embedded with perceptions of mental illness is another predisposing factor associated with caregiver burden.

FACTORS ASSOCIATED WITH CAREGIVER BURDEN

The definition of caregiver burden as an outcome measure refers to the extent to which caregivers recognize their emotional, physical and social life, as well as the distress caused by the financial status due to their caregiving activities (Zarit, Todd, & Zarit, 1986). In relation to socio-demographic and caregiving-related factors associated with caregiver burden, it is widely accepted that these factors are complex and multidimensional, affecting people differently throughout the disease process. Previous studies suggested that, older and female caregivers, caregivers with depressive symptoms and caregivers with a higher self-perceived stigma are more likely to experience a higher level of caregiver burden (Hassan-Ohayon, Levy, Kravetz, Vollanski-Narkis, & Roe, 2011; Jones, Hadjistavropoulos, Janzen, & Hadjistavropoulos, 2011; Magana, Garcia, Hernandez, & Cortez, 2007). Furthermore, other factors that have been associated with caregiver burden are the availability of social support, spending more time with patients, patients' behavioral disturbances and duration of caregiving (Rodrigo, Fernando, Rajapakse, De Silva, & Hanwella, 2013; Zauszniewski, Bekhet, & Suresky, 2008). However, some of these factors are not definitive in predicting caregiver burden as some inconsistencies exist. For example, a study among Malaysian caregivers of patients with dementia found that the

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external support received by caregivers was associated with caregiver burden (Nurfatihah, Rahmah, & Rosnah, 2013); however, in Italian caregivers of patients with the same illness, these variables were not significantly associated (Zucchella, Bartolo, Pasotti, Chiapella, & Sinforiani, 2012). The cultural differences in caregiving and coping style may also reflect differences in the way that caregiving affects caregivers from different ethnic groups and cultural backgrounds. Thus, the involvement of caregivers in caregiving activities may be examined from a cultural perspective.

Many studies have agreed that female caregivers are more involved in the caregiving activities of family members with mental illness compared to male caregivers (Magana et al., 2007; Zucchella et al., 2012). According to the role theory (Biddle, 1986), an individual's social behavior largely depends on society's expectations of the role that the person is assuming. Role overload or role conflict occurs either as a result of limited resources for carrying out caregiving activities, or if the caregiver does not agree with the role expectations. Based on historical assumptions, most societies expect women to be involved in the caregiving of their children and their parents, as well as any sick members of the family, and expectations concerning the women's role as a caregiver are still relevant in today's world. In fact, numerous studies suggest that women are also the main caregivers when caring for individuals with mental illness (Hastrup, Berg, & Gyrd-Hansen, 2011; Tan et al., 2012), dementia (Papastavrou, Charalambous, Tsangari, & Karayiannis, 2012), and older adults with chronic illness (Gräßel & Adabbo, 2011). Previous studies have reported that women experience a higher level of burden compared to male caregivers (Chou, Fu, Lin, & Lee, 2011; Hsiao, 2010). In addition, female caregivers are more often subjected to stigma, guilt, caregiver strain and client dependency than their male counterparts (Fujino & Okamura, 2009; Hassan-Ohayon et al., 2011; Hsiao, 2010), which might explain why female caregivers have reported a higher level of burden.

Many families in Malaysia consist of the 'sandwich generation', in which women hold greater responsibilities than before (Norzareen & Nobaya, 2010). They are expected to care for the older generation or their parents, and, at the same time, care for their own children. In relation to caring for individuals with mental illness, females are generally the primary caregiver and compared to their male counterparts, female caregivers have commonly reported higher levels of caregiver burden. However, the process underlying this relationship is poorly understood. Some authors suggest that female caregivers are more affected because they are less resilient than male caregivers (Cassidy, Giles, & McLaughlin, 2013; Scott, 2013; Zauszniewski et al., 2008). Furthermore, female caregivers may express and handle their burden differently than male caregivers, adapting an 'emotion-focused' rather than 'problem-focused' coping style in caregiving (Cherry et al., 2013). Emotion-focused coping style refers to strategies aimed at reducing psychological distress by avoiding the stressors without trying to adjust the situation (Lazarus & Folkman, 1984). Seoud and Ducharme (2015) suggested that, resilience was associated with problem-focused coping strategies and emotion-focused coping strategies in female caregivers. However, no study has investigated the mediating and moderating effect of resilience on the relationship between the gender of the caregiver and caregiver burden.

Resilience and Caregiver Burden

Resilience might be a key variable in explaining how male caregivers are able to 'bounce back' and deal with the challenges in caring for individuals with severe mental illness. In the context of nursing practice, resilience can be defined as a psychological phenomenon referring to effective coping and adaptation when dealing with loss, hardship, or adversity (Wilks & Croom, 2008). Most authors agree that two core characteristics must exist in resilience – adversity and positive adaptation (Fletcher & Sarkar, 2013; Gillespie, Chaboyer, & Wallis, 2007). Thus, in caring for individuals with mental illness, caregiver burden can be

considered as an adversity, and caregivers who exhibit resilience are commonly the ones who survive and adapt well to adversity.

In the published analyses of this concept, similar attributes of resilience are identified; namely, rebounding, positive outcomes, personal mastery and presence of support (Earvolino-Ramirez, 2007; Garcia-Dia, DiNapoli, Garcia-Ona, Jakubowski, & O'Flaherty, 2013; Gillespie et al., 2007). Studies have reported that individuals who are more resilient demonstrate a better mental state and physical health, perceive sufficient support from either family or friends, and cope well with adversity (Jonker & Greeff, 2009; O'Rourke et al., 2010). Resilience has also been found to predict lower levels of caregiver burden (Cassidy et al., 2013; Scott, 2013). Thus, in this study, we hypothesize that resilience explains why the relationship between the gender of caregivers and caregiver burden exists, and, also, the fact that resilience reduces the strength of this relationship.

Theoretical Framework

The stress process model (Pearlin, Menaghan, Morton, & Mullan, 1981) explains why caregiving is stressful, and provides a useful framework to guide the research presented in this paper. Five domains contribute to caregiver burden: demographic/context of caregiving, primary stressors, secondary stressors, appraisal and mediators/moderator (coping and resources). The primary stressors are described as the patient's condition or impairment and the associated factors, including the severity of the illness and aspects of caregiving activities, such as time spent on caring tasks. In this model, the primary stressor contributes to the development of secondary stressors, such as family conflict, financial problems, and interruption of leisure activities. Further, in this model appraisal refers to the caregiver's subjective assessment of their role (Sörensen, Duberstein, Gill, & Pinquart, 2006). The level of burden experienced by the caregivers differs based on their assessment and the resources available to them. Subsequently, primary stressors, secondary stressors and appraisal influence the outcome of the stress process, such as distress, depression or caregiver burden. The interaction between stressors and outcomes is mediated by coping strategies and social resources.

In this model, mediators (often an attribute or an intrinsic characteristic of an individual) explain why a relationship exists among the socio-demographic factors, primary stressors and the outcome variable of caregiver burden. A moderator variable may reduce or enhance the direction of the relationship between a predictor variable and a dependent variable, or it may even change the direction of the relationship between the two variables from positive to negative or vice versa. Thus, moderating factors, such as knowledge or social, economic, and intrapersonal resources; for example, caregivers' levels of resilience, are factors that influence which primary stressors lead to secondary stressors and the outcomes of the burden.

In the conceptual framework of this study, three factors that contribute to the outcome of caregiver burden; namely, the socio-demographic characteristics of the caregiver, primary stressors or caregiving-related stressors and resilience as the mediating/moderating variable, were included. The factors associated with each domain are based on previous work by other researchers (Chiou, Chang, Chen, & Wang, 2009; Hsiao, 2010; Onishi et al., 2005; Pattanayak, Jena, Tripathi, & Khandelwal, 2010; Razali, Ahmad, Rahman, Midin, & Sidi, 2011; Rodrigo et al., 2013; Tan et al., 2012; Zauszniewski et al., 2008). In the context of this study, we hypothesize that caregiver burden is the outcome associated with the socio-demographic characteristics of caregivers and caregiving-related stressors (primary stressors). Reports from previous studies show that the gender of caregivers has been consistently reported as a significant predictor of caregiver burden (Chou et al., 2011; Hsiao, 2010; Zauszniewski et al., 2008); however, this does not tell us very much about the process that underlies the relationship between these variables. Thus, in this present study, we aim to examine the

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