



Association of impairments of older persons with caregiver burden among family caregivers: Findings from rural South India



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ABSTRACT

Aim: In India, owing to cultural norms and a lack of formal long-term care facilities, responsibility for care of the older person falls primarily on the family. Based on the stress process model, we assessed the association of type and number of impairments of older persons (~primary stressors) with caregiver burden among their family caregivers in rural South India.

Methods: All impaired older persons (aged ≥ 60 , with impairment in activities of daily living (ADL) or cognition or vision or hearing) residing in 8 villages in Bangalore district, Karnataka, India, and their primary informal caregivers were interviewed. Caregiver burden was measured using the Zarit Burden Interview (ZBI; higher score indicating greater perceived burden). Linear regression models, adjusting for background characteristics of older persons and caregivers, assessed the association of type of impairment (physical [Yes/No], cognitive [Yes/No], vision [Yes/No] and hearing [Yes/No]) and number (1 or 2 or 3 or 4) of older person impairments with caregiver burden.

Results: A total of 140 caregivers, caring for 149 older persons, were interviewed. The mean (standard deviation) ZBI score was 21.2 (12.9). Of the various older person impairments, ZBI score was associated only with physical impairment ($\beta = 6.6$; 95% CI: 2.1–11.1). Relative to caregivers of older person with one impairment, those caring for an older person with all 4 impairments had significantly higher ZBI score ($\beta = 13.9$; CI: 2.5–25.4).

Conclusion: Caregivers of older persons with multiple impairments, especially physical impairment, are vulnerable.

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1. Introduction

India, home to 104 million individuals aged 60 years and above (hereafter 'older persons'), has the world's second largest population of older persons (Census of India, 2011). Advancing age is a major contributor to the development of physical, cognitive and sensory impairments (Fried & Guralnik, 1997; Havlik, 1986; Kensinger & Corkin, 2009). The presence of such impairments leads to loss of independent living with a need for assistance or care in day-to-day activities (World Health Organisation, 2002). Globally, family members shoulder the responsibility for older persons requiring care, and India is no exception.

The family is the traditional social institution for the care of older persons in India. Cultural and social norms stipulate that family members – particularly children – provide support to older persons, traditionally in the form of co-residence. These norms are reinforced through the relative lack of formal or institutional long-term care facilities (Chandrika, 2014). And, not surprisingly, majority, 70% of older persons in India co-reside with their children (Alam et al., 2012).

Caregiving places a great responsibility on family caregivers; some caregivers may find it to be rewarding while others may be challenged and feel burdened. Caregiver burden, the extent to which caregivers feel that their emotional or physical health, social life and financial status have suffered as a result of caring for their relatives (Zarit, Reever, & Bach-Peterson, 1980), has been shown to directly affect the physical and mental health of caregivers (Malhotra, Malhotra, Østbye, Matchar, & Chan, 2012; Vitaliano,

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Zhang, & Scanlan, 2003). Thus, in a country like India, where older persons with impairments mostly reside at home, with family, it is important to gain an understanding of caregiver burden among family caregivers.

Several factors influence how stressful individual caregivers find their caregiving experience. One commonly used framework or model to understand the interplay of these factors is the stress process model. Pearlin, Mullan, Semple, and Skaff (1990) proposed this model to explain the process whereby caring for a person with dementia affects the well-being of family caregivers. It comprises four domains (1) Background and context of stress – this includes the social and economic characteristics of the caregiver; (2) Stressors – comprising primary stressors, which are directly connected with care provision, such as cognitive status, behavioral problems and extent of dependency of the care recipient, and secondary stressors, which arise from the primary stressors and are more subjective in nature, such as family conflict, self-esteem, mastery (3) Mediators of stress- Coping and social support are the principal mediators which can explain the variability in responses to stressors among the caregivers; and finally (4) Outcomes or manifestations of stress- physical and mental well-being of the caregiver.

While several studies assessing the extent or correlates of family caregiver burden in India have been conducted, they have their limitations. Many of them are specific to family caregivers of those with neurological or psychiatric diseases, (Das et al., 2010; Jagannathan, Thirthalli, Hamza, Nagendra, & Gangadhar, 2014; Jathanna, KS, & Bhandary, 2011) thus are not directly generalizable to caregivers of older persons with physical, cognitive and sensory impairments. Or, they derive their samples from hospital-registries, (Jagannathan et al., 2014; Jathanna et al., 2011) thus likely comprise caregivers looking after sicker individuals. Or, they are restricted to family caregivers residing in urban areas (Das et al., 2010; Gupta, Rowe, & Pillai, 2009). It is important to focus on family caregivers of older persons residing in rural areas in India as nearly three-fourth (73%) of older persons in India live in rural areas, (Census of India, 2011) and the proportion of older persons who require assistance in activities of daily living (ADLs) is reported to be higher in rural (7.9%) than in urban (6.9%) India (Alam et al., 2012). Only few studies (Brinda, Rajkumar, Enemark, Attermann, & Jacob, 2014; Prasad & Rani, 2007) are rural-based, however they either have a small sample size (Brinda et al., 2014) or are restricted to caregivers of older persons with physical impairment (Brinda et al., 2014) or do not evaluate sensory impairments, in the form of visual and hearing impairment, as potential correlates of caregiver burden (Brinda et al., 2014; Prasad & Rani, 2007). We address the limitations of previous studies of family caregiver burden in India by focusing on a community-based sample of family caregivers of older persons, with physical, cognitive and sensory impairments, residing in a rural area of India.

Further, we concentrate on assessing the association of specific impairments of the older person with family caregiver burden. Most previous studies on correlates of caregiver burden consider only impairments in physical function (measured as an ADL limitation score, or number of ADL limitations, or limitation in a particular ADL item, or extent of ADL limitation) (Awad, El Gammal, Fahmy, & Imam, 2010; Faison, Faria, & Frank, 1999; Garcés, Carretero, Ródenas, & Sanjosé, 2009; Lee, Yoon, & Kropf, 2007; Salama & El-Soud, 2012) and/or cognition (measured as a score) (Awad et al., 2010; Lee et al., 2007) of the older person, neglecting sensory impairments such as in vision and hearing. Considering the stress process model (Pearlin et al., 1990), detailed above, which portrays impairments of the older person as 'primary stressors', as the theoretical basis for our analysis, we test the following hypotheses: (1) Presence of each type of impairment (in physical function, cognition, near vision and hearing) of older

persons is independently associated with family caregiver burden, and (2) Increase in the number of impairments of older persons is associated with an increase in family caregiver burden.

2. Methods

2.1. Study setting and participants

This cross-sectional study was conducted in August 2012 in the eight villages in an administrative unit (Mutthanallur Sub-centre, Anekal taluk, Bangalore district) in the state of Karnataka situated in the southwestern region of India. The villages, with a total population of 7500, were selected for two reasons. First, the study team's institution (St John's Medical College, Bangalore) runs a monthly geriatric clinic in these villages, thus had an established rapport with the community. Second, in 2010–11, to inform the planning of geriatric care services in the villages by the study team's institution, all households in all the 8 villages were visited (i.e. a door to door survey) to identify older persons i.e. those aged 60 years and above in the household. And, through this process door survey, a total of 726 older persons (9.7% of the total population) were identified. All the 726 older persons identified in the door to door survey were subjected to a brief questionnaire and physical examination. In the process, 216 of them were found to have impairment in physical function (i.e. in activity of daily living) or near vision or hearing or cognition (criteria listed under Section 2.2 – 'Measures'). By the time of initiation of this study, in 2012, of the 216 older persons with one or more impairments in 2010–11, 33 had passed away, 17 had migrated and 17 could not be contacted. Thus, the remaining 149 elderly with one or more impairments formed the sample for this study.

These 149 older persons were contacted and their ADL status, near vision, hearing and cognition was reassessed to confirm and document their current impairment status. They and/or their family were also asked to identify their primary informal caregiver (family member who cared for the older person for the maximum duration in the last year). Of the 149 older persons, 18 shared the same caregiver; thus the final sample comprised 149 older persons with one or more impairments and 140 primary informal caregivers. After obtaining written informed consent, the study participants were interviewed, using an interviewer-administered questionnaire in the local (Kannada) language and examined at their residence. The interview and examination for the impairments of older person were conducted by the first author (SA). The study was approved by the St John's Institution ethical review board.

2.2. Measures

2.2.1. Impairments of the older person

Impairment in physical function was defined as reported dependence in one or more ADL items, assessed through the Barthel Index of ADLs (Collin, Wade, Davies, & Horne, 1988). The index asks about ten ADLs: bathing, grooming, dressing, eating, transferring from bed to chair and back, voluntary control of bladder, voluntary control of bowel, using the toilet, walking and use of stairs.

Impairment in cognition was defined as a score of 20 or less on the Kannada language version of the Hindi Mental Status Examination (HMSE) (Chandra, Sharma, Gilby, & Panda, 1995). The HMSE is an Indian version of Mini-Mental State Examination, a widely used, validated screening tool for cognitive impairment.

Impairment in near vision was defined as a score of N10 or less (i.e., N10 or N12 or N18 or N36) on the Roman test type near vision chart (Khurana, 2008). The chart was held at a distance of 14 inches from the eye and the older person was asked to read the words as

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