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Feature Article

Exploring the reciprocal relationship between caregiver burden and the functional health of frail older adults in China: A cross-lag analysis

Nan Lu, PhD [a], Jinyu Liu, PhD [b], Vivian W.Q. Lou, PhD [c,*]

[a] Department of Social Work, School of Sociology and Population Studies, Renmin University of China, No.59 Zhongguancun St., Haidian District, Beijing, China
[b] School of Social Work, Columbia University, 1255 Amsterdam Ave., New York, NY 10027, USA
[c] Department of Social Work & Social Administration, Sau Po Centre on Ageing, The University of Hong Kong, Pokfulam Road, Hong Kong

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ABSTRACT

The present study aimed to investigate the reciprocal relationship between caregiver burden and care recipient dependence in activities of daily living (ADLs) from the perspective of frail older adults and their family caregivers in China. Data were derived from a sample of 469 older adult–caregiver dyads that participated in both the 2010 and 2013 waves of the panel study Family Caregivers for the Frail and Very Elderly: Well-Being and Needs in Shanghai. A two-wave cross-lag analysis was used to examine the proposed model. ADL dependence in 2010 was a significant predictor of caregiver burden in 2013. Furthermore, caregiver burden in 2010 was a significant predictor of ADL dependence in 2013. This finding confirms the dyadic model of caregiver burden and care recipient well-being. Implications for interventions and policy to help frail older adults and their family caregivers are discussed.

Introduction

The number of frail older adults worldwide who have limitations in their ability to perform daily activities and who need assistance from others in their daily lives has grown rapidly in the past few decades.[1] Family caregiving is one of the most preferable and important supportive resources for frail older adults across countries and cultures.[2–4] Caregiver burden is one of the key concepts in studies of family caregiving[2,5,6] because it is significantly associated with the caregiver's physical, psychological, and social well-being.[7–10]

Previous studies have largely overlooked the dyadic context of caregiving and care receiving, which has led to an important yet unanswered question: Does caregiver burden affect care recipients' dependence in activities of daily living (ADLs)? Many studies have demonstrated the influence of a care recipient's dependence in ADLs on caregiver burden.[11–13] However, the reverse causal relationship has not been fully examined.

The stress process model (SPM), a widely used conceptual framework in studies of caregiver burden, provides a lens for examining the effects of care recipient ADL dependence on caregiver burden but not vice versa.[14] However, many studies have suggested the importance of caregiver support and involvement in care recipients' recovery and the effectiveness of therapy.[15,16] Furthermore, research has shown that caregiver burden can affect care recipients' welfare, manifesting in symptoms such as risk of being abused by the caregiver, weight loss, hospitalization, and even death.[17–19] In other words, caregiver burden may cause a decline in care recipients' functional health. Consequently, understanding the reciprocal relationship between caregiver burden and care recipient ADL dependence will help health professionals identify whether and how caregiver stress leads to a decline in care recipient health or impedes recovery. Health professionals will also benefit from recognizing the influence of care recipient health deterioration on caregiver burden.

A dyadic model of caregiver burden and care recipient well-being

The purpose of this study was to investigate the reciprocal relationship between caregiver burden and care recipient ADL dependence. We proposed a dyadic model of caregiver burden and care recipient well-being (hereafter, "dyadic model") to demonstrate the reciprocal relationship between caregiver burden and care recipient well-being. The dyadic model included two hypotheses that are discussed in further detail below.

* Corresponding author. Tel.: +852 39174835; fax: +852 28587604.
E-mail address: wlou@hku.hk (V.W.Q. Lou).

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According to the SPM, functional health dependence is an objective primary stressor.[14,20] Objective primary stressors interact with caregivers' subjective appraisals of the difficulties of providing care to their frail family members and can eventually affect their physical and mental well-being.[14,20] Specifically, ADL dependence is an objective primary indicator of caregiving stress.[14] The level of a care recipient's dependence in ADLs indicates the need for personal care. Challenging and long-term caregiving can have a range of negative consequences on caregivers' daily lives, including limited free time, a decline in physical health, role conflicts, emotional distress, and obstacles to personal development.[14,21] Caregivers' appraisals of these difficulties and challenges are also considered part of multidimensional caregiver burden.[6,22–24] Therefore, we hypothesized that care recipient dependence in ADLs would be associated with higher levels of caregiver burden over time (Hypothesis 1).

One major limitation of the SPM is that it tends to linearize the process of caregiver stress. The dyadic model, in contrast, suggests that long-term caregiver burden can eventually affect the amount and quality of care provided to frail older adults.[2,22] A reduced amount of care or poor-quality care could accelerate older adults' physical decline and lead to higher levels of dependence in ADLs, which in turn could lead to higher levels of caregiver burden at a later time point. This creates a vicious cycle driven by care recipients' ADL dependence that has negative effects on the well-being of both caregivers and care recipients. Therefore, another hypothesis of the dyadic model was that caregiver burden would be associated with higher levels of care recipient dependence in ADLs over time (Hypothesis 2). The complete hypothesized model is presented in Fig. 1.

Family caregiving in China

China is an ideal place to study family caregiving and its consequences for both frail older adults and their caregivers. An estimated 40 million frail older adults ages 60 and older lived in China in 2015.[25] The proportion of the Chinese population older than 65 has grown steadily in the past few decades and is expected to reach 20% in 2040 and 31% in 2050.[26] Moreover, the average family size in China decreased from 4.41 in 1982 to 2.98 in 2013.[27]

On the one hand, family is considered the main source of support for frail older adults in China. Families' obligations to care for their frail older members are reinforced and promoted by both cultural values and the law.[13,28,29] On the other hand, given the increasing life expectancy of the Chinese population as well as decreasing family sizes,[27] Chinese family caregivers are likely to experience higher levels of stress and burden and less support from other family members in the next few decades. Simultaneously, Chinese frail older adults and their family members are likely to have limited access to formal support from local governments, health care services, and communities because of the shortage of health professionals, lack of social policy, and scarcity of supportive programs.[30] This might result in the provision of poorer quality care to frail older adults.[17–19]

Therefore, it is particularly important to understand the reciprocal relationship between frail older adults' ADL dependence and caregiver burden in the Chinese social and cultural context. Findings will provide insight into the development of associated programs and services to support caregivers of frail older adults in China. In the present study, we tested the dyadic model using survey data collected from both caregivers and care recipients in Shanghai, China.

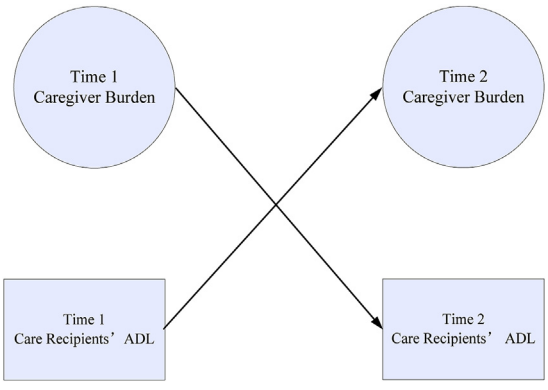

Fig. 1. A dyadic model of caregiver burden and care recipients' well-being.

Methods

Design

This study used a two-wave longitudinal design to evaluate caregiver burden and care recipient ADL dependence over time. Ethics approval was obtained from the ethics committee of the University of Hong Kong. Consent forms were obtained from each respondent before data collection.

Sample

This study was an original study using data from the 2010 and 2013 waves of the panel study Family Caregivers for the Frail and Very Elderly: Well-Being and Needs in Shanghai, which was jointly conducted by the University of Hong Kong and East China Normal University. The target population was frail older adult–caregiver dyads. To be selected for the panel study, care recipients had to 1) have Shanghai *Hukou* (household registration status); 2) live in one of six districts of urban Shanghai during the time of survey; 3) be 75 years old or older; 4) score 90 or less on an ADL scale, meaning that they had at least two limitations in ADLs or the equivalent; and 5) have at least one primary caregiver 18 years old or older.

Data collection

A quota sampling method was used to select a sample from local communities. In the first stage, six districts were randomly selected from the urban Shanghai region. In the second stage, one street office was randomly selected from each of the six urban districts selected. In the third stage, 120 older adult–caregiver dyads were identified and screened from each street office.

All interviewers received a 6-h standardized training before conducting face-to-face interviews. The first 3-h training session covered the following topics: study rationale, the design of the questionnaire, screening procedures, obtaining consent, interview strategies, and quality assurance. The second 3-h session covered the questionnaire section by section, including the purpose of each session, answering patterns and potential difficulties in each question. In both training sessions, the research team, and in particular the principal investigator, answered questions raised by the interviewers. The coding of items was described and explained so as to ensure inter-rater reliability.

To optimize quality assurance, the survey process included three layers of monitoring. First, each neighborhood was assigned a supervisor, who was responsible for checking screening results and recording missing data or errors on questionnaires. All supervisors received the same training as the interviewers. Second, six postgraduate students and/or lecturers in the field of population studies