Contents lists available at ScienceDirect

Geriatric Nursing

Feature Article

Caregiver distress and associated factors in dementia care in the community setting in China

Jing Wang, PhD [a,b,*], Lily Dongxia Xiao, PhD [b], Xiaomei Li, PhD [a], Anita De Bellis, PhD [b], Shahid Ullah, PhD [b,c]

[a] Faculty of Nursing, Health Science Center, Xi'an Jiaotong University, No. 76 Yanta West Road, Xi'an City, Shaanxi Province 710061, China
[b] School of Nursing and Midwifery, Faculty of Medicine, Nursing and Health Sciences, Flinders University, GPO Box 2100, Adelaide, SA 5001, Australia
[c] Flinders Centre for Epidemiology and Biostatistics, Faculty of Medicine, Nursing and Health Sciences, Flinders University, GPO Box 2100, Adelaide, SA 5001, Australia

ARTICLE INFO

ABSTRACT

The aim of this study was to investigate caregiver distress in reacting to the care recipient's behavioral and psychological symptoms of dementia (BPSD) and factors contributing to caregiver distress in the community setting in China. One hundred and fifty-two family caregivers of people with dementia in community settings were assessed using the Chinese version of the Neuropsychiatric Inventory-Questionnaire and the Social Support Rating Scale. The prevalence of BPSD and caregiver distress in reacting to BPSD was higher in China than those reported in high income countries. The most common individual BPSD were apathy/indifference, depression/dysphoria and night-time behaviors. Delusions, hallucinations and apathy/indifference were rated as the most distressing to caregivers. BPSD contributed most to caregiver distress. The high level of caregiver distress identified in this study suggests that dementia services and caregiver support should be established in the public healthcare system to target the needs of people with dementia and their caregivers.

© 2015 Elsevier Inc. All rights reserved.

Introduction

It is estimated that approximately 35.6 million people were living with dementia worldwide in 2010 and this number will triple by 2050 as the world population ages.[1] Nearly two thirds of the people with dementia live in low and middle income countries (LMICs)[d] and China has the largest population living with dementia.[1,2] Behavioral and psychological symptoms of dementia (BPSD)[e] are very common among people with dementia.[3,4] Caregiver distress associated with care recipient's BPSD has been reported as one of the components of caregiver burden that negatively affects the caregiver's health and quality of life globally.[5] Family caregivers in LMICs experience a higher level of distress due to the lack of resources and support mechanisms in the public health care system to manage and treat BPSD. More researches on caregiver distress in

responding to BPSD and factors associated with caregiver distress in LMICs are needed in order to generate research evidence to inform practice.

BPSD represents a heterogenous range of psychological reactions, psychiatric symptoms and behaviors manifested by people with dementia and the prevalence rate of BPSD in the community setting is up to 88%.[4,6] Causes and triggers of BPSD are complex including biological, psychosocial and caregiver factors. For example, unmet care needs, inadequate interactions between the care recipient and the caregiver and the presence of noisy and unfamiliar environments can contribute to the development of BPSD.[3,7] BPSD are the most treatable aspects of dementia and can be reduced through comprehensive interventions to target contributing factors or triggers.[3,4]

Caregiver distress associated with BPSD differs depending on the caregiver's responses to BPSD and the care recipient's severity of BPSD.[8] It is reported that a low level of severity can contribute to a heavy burden on caregivers if the caregiver is unable to manage the particular type of BPSD.[9,10] The reported prevalence rate of BPSD is largely dependent on the samples and study settings.[3,11] In terms of individual symptoms, the most prevalent BPSD are apathy, depression, and anxiety, whilst the rarest are euphoria, hallucinations and disinhibition.[3,4,11] Delusions, aggression and irritability

Conflict of interest: None.
* Corresponding author. Faculty of Nursing, Health Science Center, Xi'an Jiaotong University, No. 76 Yanta West Road, Xi'an City, Shaanxi Province 710061, China. Tel.: +86 187 8940 0330; fax: +86 29 82657015.
E-mail address: novowj@163.com (J. Wang).
[d] LMICs: low and middle income countries.
[e] BPSD: behavioral and psychological symptoms of dementia.

have been reported as the most burdensome and challenging behaviors for caregivers.[4,10] Information on the prevalence of each individual behavioral symptom and its impact on caregivers are crucial in order to inform the design of tailored management strategies for the wellbeing of the caregivers and people with dementia.[4,10]

Social and cultural factors have a strong influence on caregivers' coping strategies and the use of social support in managing BPSD.[12,13] In China, filial piety places the responsibility of caring for older people on families and consequently government-funded dementia services are undeveloped. In the absence of formal dementia services in the health care system, informal care and support by family members is widely used, and approximately half of the families in urban areas also employ paid caregivers.[14]

Caregiver distress in responding to the care recipient's BPSD and factors contributing to this distress are largely unknown in the community setting in China and other LMICs due to lack of research in the area. This study was part of a larger collaborative project in dementia care between a Chinese university and an Australian university, which has been reported elsewhere.[5,15,16] The aim of the study reported in this article was to explore the level of caregiver distress in relation to BPSD and factors contributing to caregiver distress in the community setting in a Chinese social-cultural context. It was hypothesized that: (1) the level of caregiver distress in China would be high when compared to reports from research in high income countries and; (2) BPSD would be a major predictor of caregiver distress among other variables associated with caregiver distress.

Methods

As part of a cross-sectional survey, this descriptive study was approved by the ethics committees of the two universities, one in China and the other in Australia. Three instruments were used to collect the data from the Chinese participants.

Participants

A convenience sample of 152 family caregivers of people with dementia was recruited between March 2012 and April 2013 in a capital city of a province in China. Inclusion criteria for participants were: (1) the primary family caregiver had been in the role for at least six months; (2) the caregiver was able to read and speak Mandarin; and (3) the care recipient lived at home and had a diagnosis of dementia according to the DSM-IV.[17]

Sample size was calculated based on the relationship between severity of BPSD (NPI–S score) and caregiver distress (NPI-D score) using Pearson correlation. The correlation between NPI-S and NPI-D scores is expected to be high and is assumed to be a strong correlation of 0.92 between the scores based on previous studies.[9,15] The Power Analysis & Sample Size Software (PASS) was used to calculate the sample size.[18] A sample size of 152 participants produces a two-sided 95% confidence interval with a width equal to 0.05 when the estimate of Pearson's product–moment correlation between NPI-S and NPI-D scores is 0.92.

Recruitment

The family caregivers were recruited from outpatient clinics of five major tertiary hospitals and 12 community care centers in Hunan Province, China. Only caregivers were investigated and information about care recipients was collected through interviews with caregivers using the instruments detailed below. Nurses working in the geriatric clinics of the tertiary hospitals or the community care centers helped to distribute letters of recruitment to potential participants, explaining the aims of the study, the inclusion criteria and the voluntary participation in the study. Caregivers who met the inclusion criteria and were willing to participate in the study were asked to provide their contact information on the "participant response slip" and return it to the nurses. The first author then contacted the caregiver and made an appointment for the interview. Prior to interview, participants were given a written and verbal explanation about the study, the benefits and any risks. Following this participants provided written consent. Confidentiality and anonymity were assured. Of the 168 caregivers who responded, 152 (91%) consented to participate and completed the survey.

Data collection

Data were collected by face-to-face interviews using structured questionnaires. The medical record and diagnosis certificate of dementia for the care recipients were reviewed before the interview. Interviews were conducted in private rooms at the participants' respective homes or the community care centers. Every participant was interviewed personally with no other people present in the room to avoid any inconvenience and to assure confidentiality.

Measurements

Three instruments were applied with the permission from the authors. Demographic information of the caregivers and care recipients was collected via demographic information questionnaire. The Chinese version of the Neuropsychiatric Inventory-Questionnaire was used to measure BPSD and caregiver distress related to BPSD. Social Support Rating Scale provided additional data for analyzing the factors contributing to caregiver distress.

Chinese version of Neuropsychiatric Inventory-Questionnaire (NPI-Q)

The NPI-Q was developed to assess the neuropsychiatric symptoms associated with dementia and the impact of BPSD on caregiver distress.[19,20] It evaluated twelve common BPSD and caregiver distress related to each BPSD domain. NPI-Q included two sections named as NPI-S and NPI-D, respectively. The severity of BPSD was measured by NPI-S on a 3-point scale and the caregiver distress was rated by NPI-D on a 6-point scale. The higher the score indicated the more severe the BPSD and the higher level of caregiver distress.[21] In this study, the internal consistency reliability (Cronbach's alpha) of NPI-D scores and NPI-S scores were 0.87 and 0.89 respectively.

Social Support Rating Scale (SSRS)

The SSRS was developed to assess different aspects of social support in a Chinese population and has been widely used in various settings.[22,23] The SSRS included ten items and these items were slightly modified based on the aim of the study. Each item was rated from 1 to 4, with higher scores indicating better social support. The internal consistency reliability (Cronbach's alpha) of this scale in this study was 0.82. Four aspects of social support for the Chinese context were measured in this study including family support, help seeking behavior, available social networks and usage of social supports.

Demographics and related variables

Socio-demographic characteristics of the caregivers were collected on gender (0 = male, 1 = female), age (in years),