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Full title

Factors contributing to caregiver burden in dementia in a country without formal caregiver support

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Title

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Abstract

Objectives: To investigate caregiver burden in dementia and explore factors associated with different types of burden in a country without formal caregiver support using a province in China as a case.

Method: Cross-sectional questionnaire survey was used to collect data. One hundred and fifty-two family caregivers of people with dementia in community settings were recruited from 2012-2013 using convenience sampling. Objective burden was measured by caregiving hours and dementia-related financial burden. Subjective burden was measured and analysed using the Caregiver Burden Inventory and the Neuropsychiatric Inventory-Questionnaire. Multivariate regression models were employed to analyse factors associated with each type of subjective burden.

Results: Five types of subjective burden were measured by the Caregiver Burden Inventory namely: physical burden, emotional burden, time-dependence burden, developmental burden, and social burden. Caregiver distress, as a subjective burden was measured by the Neuropsychiatric Inventory-Questionnaire and reported by relating to the severity of care recipients' behavioural and psychological symptoms of dementia. This caregiver cohort showed a high level of physical, time-dependence and developmental burdens, but a low level of emotional and social burdens. Factors

contributing to each type of subjective burden measured by the Caregiver Burden Inventory differed from each other.

Conclusion: The high level of objective burden and subjective burden identified in this study suggests that government-funded formal caregiver support should be established and services should be designed to target different types of burdens and factors contributing to these burdens.

Keywords: dementia; caregiver burden; dementia services; cross-sectional study

Introduction

The increasing prevalence of dementia and its impact on family caregivers is a growing problem worldwide. China has the largest population with dementia, constituting 40% of the dementia population in the Asia-Pacific region and 25% of the people with dementia in the world (Alzheimer's Disease International, 2010). In China, the majority of people with dementia are cared for by family caregivers at home with the cultural emphasis on filial piety. It is estimated that at least 30-35 million people are directly or indirectly affected by dementia in China (Alzheimer's Disease International, 2010; Song & Wang, 2010). With undeveloped dementia services in the Chinese public healthcare system the impact on caregivers is manifested through burden. Studies have identified that caregiver burden has a multidimensional nature influenced by social, political and cultural factors (Brouwer et al., 2004; Verhey, De Vugt, Vernooij-Dassen, Byrne, & Robert, 2007). However, evidence predominantly comes from western countries which have different social, political and cultural contexts to China.

Dementia caregiver burden has been widely studied due to its negative impact on the quality of care for people with dementia and on the quality of life for both care recipients and caregivers. Numerous factors have been identified as associated with caregiver burden, but can be grouped into three categories including the caregiver variables (i.e., gender and age),

care recipient variables (i.e., behavioural problems and duration of dementia), and social context (i.e., social support and finances) (Kim et al., 2009; Verhey et al., 2007). It is strongly suggested that caregiver burden should be classified as objective burden and subjective burden as factors contributing to and the impact of these types of burden on caregiver's health and well-being can differ (Brouwer et al., 2004; Verhey et al., 2007). The more comprehensive the understanding of each type of burden and factors contributing to the burden, the better the establishment of the approaches to relieve caregiver burden can be.

Objective burden refers to the inputs relevant with caregiving activities, including time spent on caregiving, financial problems and practical caregiving tasks. Subjective burden focuses on the self-perceived impact of the objective burden on the person themselves (Chou, Fu, Lin, & Lee, 2011; Montoro-Rodriguez & Gallagher-Thompson, 2009). There are no firm conclusions that caregivers under higher objective burden are necessarily feeling higher subjective burden and any correlations are mediated by formal and informal support for the caregivers (Brouwer et al., 2004; Montoro-Rodriguez & Gallagher-Thompson, 2009).

Numerous studies focus on subjective burden due to its complexity and the significant impacts on the physical and mental health of caregivers. Two studies on caregiver burden in different cultural groups using the Caregiver Burden Inventory have identified five dimensions of subjective burden, namely physical burden, emotional burden, time-dependence burden, developmental burden and social burden (Chou, Lin, & Chu, 2002; Novak & Guest, 1989). This elaboration of subjective burden has enriched understanding of caregiver burden, enabled the comparisons of these types of burden and informed further studies on factors contributing to each type of subjective burden. The Caregiver Burden Inventory was, however, developed by researchers from western countries with established dementia services. The five dimensions of subjective burden identified in western countries may differ in other cultural groups or in countries with undeveloped dementia services

6

considering that caregiver burden is influenced by social and cultural factors (Verhey et al., 2007). Confirming these dimensions of subjective burden by undertaking factor analysis when using the same instrument in different cultural groups is strongly recommended in the literature (Gregorich, 2006; Meredith & Teresi, 2006).

Behavioural and psychological symptoms of dementia (BPSD) have been reported as the leading determinant of caregiver distress, by definition of a subjective burden (Black & Almeida, 2004; Shaji, George, Prince, & Jacob, 2009). Individual differences among caregivers such as education level, knowledge and skills in dementia care play a significant role in reacting to and coping with challenging behaviours (Black & Almeida, 2004). However, challenging behaviours are treatable via effective interventions that target the needs of caregivers and care recipients (Brodaty & Donkin, 2009; Johnson et al., 2013).

In addition to challenging behaviours, social and cultural factors have a strong influence on caregivers' motivations in their caring role, their coping strategies and the usage of social support and, therefore, have a strong impact on caregiver burden (Chun, Knight, & Youn, 2007; Wu, Low, Xiao, & Brodaty, 2009). Compared with western societies holding individualist values, Chinese culture endorses collectivist values that rate group achievements higher than individual ones. Individuals are encouraged to make sacrifices to satisfy the group objectives (Bodner & Lazar, 2008). The core values of collectivism and filial piety influenced by Confucianism impose the duty of aged care on family members in China. In fact, caring for older people is assigned to family members by law (The 11th Standing Committee of the National People's Congress, 2012). Because countries place importance on family-driven elderly care, government funded dementia care services are undeveloped with informal social support from the immediate and extended family being widely used (Shaji, Smitha, Lal, & Prince, 2003; Xiao et al., 2014).

Although dementia caregiver burden has been widely reported; most of studies are from developed countries and regions with government-funded dementia care services and caregiver support (Kim et al., 2009; Shaji et al., 2003). Dementia caregivers in countries with undeveloped dementia services may experience different types and levels of subjective and objective caregiver burden. There is an increasing demand for dementia services and caregiver support via the public healthcare system in China due to a rapidly ageing population and the decline of available family caregivers (Wang, Xiao, He, & DeBellis, 2013). However, research evidence on caregiver burden and factors associated with the burden is considerably scarce. Conducting an exploratory study to provide a comprehensive understanding of types and levels of dementia caregiver burden and factors contributing to these types of burden is crucial to inform future studies designed to support caregivers and relieve the burden associated with caring for a person with dementia.

This study is part of a larger project that compared caregivers of people with dementia and dementia services between China and Australia for the purpose of building cross-national collaboration to fight dementia, which is reported elsewhere (Wang et al., 2013; Xiao et al., 2014). The aim of this study is to explore the types of subjective burden and factors associated with these burdens in a country without formal caregiver support using a sample of subjects in a province in China as a case study. The specific objectives under the aim of study are to: 1) explore the types of subjective burden; 2) explore factors associated with each type of subjective burden. A cross-sectional questionnaire survey was used to address the aim of the study.

Methods

Participants

Sample size was calculated based on the mean and standard deviation of the CBI score reported in a previous study (Chou et al., 2002). It is assumed that the mean and standard deviation of the CBI score were 48.8 and 19.7 (Chou et al., 2002). A sample size of 149 produces a two-sided 95% confidence interval (CI) with a distance from the mean CBI to the limits between 45.6 and 52.0 that is equal to 3.2 when the estimated standard deviation is 19.7 (Hahn & Meeker, 1991). The Power Analysis & Sample Size Software (PASS) was used to calculate the sample size (Hintze, 2013).

A convenience sample of 152 family caregivers of people with dementia in community settings was recruited from March 2012 to April 2013. Inclusion criteria of the subjects were that they spoke Mandarin and were the primary unpaid caregivers for at least six months, and that there was confirmation of a dementia diagnosis for the care recipients according to the DSM-IV (American Psychiatric Association, 1994).

Recruitment

Ethical approval was granted by the two universities that funded this study. All participants were given a written and verbal description of the study, the benefits, any risk and their role as a participant. Each participant gave informed consent and was also reassured of confidentiality and their anonymity. Participants were recruited via five major tertiary hospitals and 12 community care centres in Hunan Province, China. Medical records of people with dementia were reviewed to confirm a diagnosis of dementia. Face-to-face structured interviews with caregivers were conducted in quiet private rooms according to the administration instructions of the instrument used (Cummings, 1997).

Measures

The instruments used in the study included four sections namely: the demographic information of caregivers and care recipients, Caregiver Burden Inventory, Neuropsychiatric Inventory-Questionnaire and Social Support Rating Scale. Permission to use their instruments was obtained from the authors (Chou et al., 2002; Cummings, 1997; Xiao, 1999). Objective burden was measured by caregiving hours per week and dementia-related financial burden via the demographic information. Dementia-related financial burden was assessed by family income, dementia-related costs and any paid work. Apart from the basic living allowance, if the family income could not afford the dementia-related costs, a financial burden was indicated. The living assistance of care recipients was measured by the demographic information questionnaire under three categories of dependency from independent to totally dependent. Subjective burden was measured and analysed using the CBI and NPI-Q (Figure 1).

Caregiver Burden Inventory (CBI)

This 24-item CBI was developed by Novak & Guest (1989) in Canada and was used to measure self-perceived burden by caregivers. Each item is rated on a 5-point Likert scale ranging from 0 (strongly disagree) to 4 (strongly agree). The higher the score, the higher the level of burden the caregivers perceived. Five dimensions of caregiver burden were identified through factor analysis in the original study namely physical burden, emotional burden, time-dependence burden, developmental burden and social burden (Novak & Guest, 1989). Chou et al (2002) in Taiwan translated the CBI into Chinese and validated the Chinese version of the CBI. The five dimensions of subjective burden were confirmed in the study using factor analysis. The only difference in factor analysis in the two cultural groups was the item described as "I've had problems with my marriage" (Chou et al., 2002). This item was correlated with items under "social burden" in the Western cohort studied by Novak & Guest

10

(1989), but under "emotional burden" in the Chinese cohort studied by Chou et al (2002). Both cohorts were from a country and a region with developed dementia services and caregiver support in the public healthcare system.

This study used the Chinese version provided by Chou et al (2002). A decision was made to undertake an exploratory factor analysis to confirm and compare the dimensions of subjective burden with those reported by Novak & Guest (1989) and Chou et al (2002) because the sample used in this present study had not been exposed to formal dementia care services and caregiver support. The CBI in this study showed acceptable internal consistency reliability (alpha coefficients ranging from 0.65-0.87; Table 3).

Neuropsychiatric Inventory-Questionnaire (NPI-Q)

The NPI-Q was developed to measure severity of BPSD and caregiver distress in relation to BPSD, a type of subjective burden by definition (Cummings, 1997; Kaufer et al., 1998). The NPI-Q included 12 items measuring the severity of BPSD (NPI-S) on a 3-point scale ranging from 1 (Mild) to 3 (Severe), and BPSD related caregiver distress (NPI-D) on a 6-point scale ranging from 0 (Not distressing at all) to 5 (Very severely or extremely distressing). The Cronbach's alpha coefficient of the Chinese version of the NPI-Q was 0.85 and test-retest reliability for NPI-S and NPI-D was 0.86 and 0.48 respectively (Ma, Wang, Cummings, & Yu, 2010).

Social Support Rating Scale (SSRS)

The SSRS was developed and has been widely used among Chinese populations in various settings (Xiao, 1999). This validated 10-item instrument aims at assessing different aspects of social support in the Chinese population with a satisfactory Cronbach's alpha coefficient ranging from 0.83 to 0.90 and test-retest reliability at 0.92. These items were slightly modified in this study to suit the aim of the study with each item rated on a 4-point scale. Four aspects of social support were measured by SSRS including family support, available

social networks, usage of social support and help seeking behaviours. The higher the score indicated the better social support the caregivers had.

Data analysis

All data were double entered into an Excel database on two separate occasions, checked for errors and exported to SPSS software, version 20 for analyses (IBM Corp., Armonk, New York, USA). Descriptive statistics were expressed as means and standard deviations for discrete and continuous measures, whereas percentages were reported for categorical variables. Median and Interquartile ranges (IQR) were also reported for skewed data. A Principal Component Analysis (PCA) with varimax orthogonal rotation was applied to confirm the structures of caregiver burden measured by the CBI in this sample. For the aim of guaranteeing the maximum internal reliability of each dimension of CBI, the Cronbach's alpha coefficient was calculated and a value of coefficients greater than 0.7 was considered being an adequate level of reliability. A p value of less than 0.05 was considered statistically significant. Bivariate analysis was applied to identify variables associated with each type of subjective burden using the Mann-Whitney U test. Multivariate regression models were further employed to identify the net effect of factors associated with each dimension of subjective burden measured by the CBI. Potential factors contributing to subjective burden identified in the bivariate analysis in this study and reported in the literature were entered as independent variables for each dimension of subjective burden measured by CBI in the five separate multivariate regression models.

Results

Socio-demographic information

The majority of caregivers were female (72%), were non-spouse caregivers (64%) and were unemployed (74%). Among the unemployed caregivers 60% were retired and 40% were unemployed specifically because of their caregiving role. The average age of caregivers was

59 years (SD=14 years) ranging from 23 to 93 years. The majority of the participants (77%) lived in the same household with the care recipients and over half (54%) had chronic diseases themselves. The mean duration in a caregiver role was 44 months and caregivers spent an average of 127.6 hours per week on caring activities. Up to 55% of the participants showed a financial burden related to caring for the person with dementia.

The average age of the care recipients with dementia was 79 years (SD=9 years). Over half (59%) were male and the majority (94%) needed total or partial assistance for activities of daily living (ADLs). The mean duration of dementia for the care recipients was 48 months (SD=35 months). The details of the socio-demographic information of the 152 caregivers and the care recipients are outlined in Table 1.

Social support reported by caregivers

The majority of participants reported good support from their immediate family (73%), compared with support from their extended family (43%). The available helpers for caregiving in the family averaged 1.3 persons (SD=1.2 persons). The average number of social networks was 2.7 (SD=1.0) and the average usage of social support in the past was 5.7 usages with a range from 2-12 usages. The majority of the caregivers (88%) showed poor help seeking behaviour (**Table 2**).

Subjective burden measured by CBI and NPI-Q

Prior to conducting a factor analysis, the suitability of the data was examined. The Kaiser-Meyer-Olkin (KMO) measure was 0.83 and the Bartlett's test was significant (X^2=1798, *p* <0.001), which indicated suitability for the factor analysis (Polit, 2010). Five factors were extracted based on examinations of interpretability and a loading value of > 0.40 on each factor (Polit, 2010, p. 348). These five factors were interpreted as physical burden, emotional burden, time-dependence burden, developmental burden and social burden (Table 3).

Caregivers' perceived distress in relation to BPSD was another type of subjective burden. Among the 152 care recipients, 150 (98.7%) experienced at least one individual BPSD. The most common BPSD were apathy/indifference (79.6%), followed by depression/dysphoria (68.4%), sleep and night-time behaviour disorders (59.2%), anxiety (53.9%) and problems with appetite and eating related to BPSD (50.7%). There was a strong positive correlation between the severity of BPSD and caregiver distress (r=0.89, $p<0.01$).

Factors associated with physical burden

Physical burden describes "caregivers' feelings of chronic fatigue and damage to physical health" (Novak & Guest, 1989). Caregivers who were female, unemployed, a spouse or lived in the same household with care recipients reported significantly higher physical burden than their counterparts who were male, employed, a non-spouse or did not live with the care recipients. Caregivers who perceived poor extended family support also experienced a significantly higher physical burden than the caregivers who reported good support from their extended family (Table 4). The overall model using physical burden as the dependent variable was statistically significant and explained 33% of the variance in physical burden (Table 5). Three factors, including caregiver's employment status, duration of dementia and the severity of BPSD of care recipients were found to be significantly associated with physical burden.

Factors associated with emotional burden

Emotional burden describes "caregivers' negative feelings toward their care receivers" (Novak & Guest, 1989). Spouse caregivers reported a significantly greater emotional burden than their non-spouse counterparts, as did unemployed caregivers. Caregivers who lived with the care recipients suffered a higher emotional burden than those who were not living with their care recipients (Table 4). The multiple regression analysis revealed three significant factors explaining 25% of the total variance in emotional burden (Table 5). Factors associated

14

with emotional burden in this group included the care recipient's age, the severity of the BPSD in care recipients, and the usage of social support reported by caregivers.

Factors associated with time-dependence burden

Time-dependence burden inquires about "the burden due to restrictions on the caregiver's time" (Novak & Guest, 1989). Caregivers, who were female, unemployed, lived with the care recipients in the same household and had a dementia related financial burden suffered significantly higher time-dependence burden compared to those who were male, employed, did not reside with the care recipients and did not have any financial burden. Caregivers with poor family support reported greater time-dependence burden than their counterparts who reported good family support (Table 4). The multiple regression analysis yielded five factors associated with the time-dependence burden significantly (Table 5). These five factors included caregiver's gender, usage of social support reported by caregivers, care recipient's age, duration of dementia, and severity of BPSD, combined explaining 34% of the total variance in time-dependence burden.

Factors associated with developmental burden

Developmental burden investigates "the caregivers' feelings of being 'off-time' in their development with respect to their peers" (Novak & Guest, 1989). Few people have prepared to become caregivers of a person with dementia and they felt continued strain as they could not enjoy their later years as they expected. Caregivers who were unemployed and resided with the care recipients reported higher developmental burden compared to those who were employed and did not live with the care recipients in the same household. Caregivers who had employed a paid caregiver experienced significantly lower developmental burden than those who did not employ a paid caregiver (Table 4). The multiple regression model using the developmental burden as the dependent variable was statistically significant and three factors were identified to be associated with this burden, explaining 21% of the variance in

developmental burden (Table 5). Factors associated with developmental burden included the severity of BPSD among care recipients, the total caring hours per week and the usage of social support.

Factors associated with social burden

Social burden describes "caregivers' feelings of role conflict" (Novak & Guest, 1989). A caregiver may have to limit the energy that they invest in relationships or in their jobs because of the caregiving role. Caregivers who lived with care recipients in the same household had a greater social burden score than those who did not reside with the person with dementia (Table 4). The overall model using social burden as the dependent variable was statistically significant, explaining 11% of the variance in social burden (Table 5). Three variables, including care recipient's age, co-residing with care recipients and dementia related financial burden were identified to be associated with social burden in this sample.

Factors associated with caregiver distress in relation to BPSD

Two variables showed a significant impact on caregiver distress measured by the NPI-D. Female caregivers reported higher BPSD related distress than their male counterparts, as did caregivers who had a financial burden related to the caring role (Table 4).

Discussion

The present study not only confirmed the multiple dimensions of subjective burden reported in previous studies, but also explored factors contributing to each dimension of subjective burden using a sample from a province in China with undeveloped dementia services (Figure 1). This type of study is timely given the fact that the majority of people with dementia live in developing countries with undeveloped dementia services and establishing dementia services and caregiver support should be grounded on research evidence that takes considerations of social and cultural factors in the country. This study investigated two types

of caregiver burden, objective burden and subjective burden with a priority on the latter due to its complexity in measurement and its impact on caregivers' health and well-being.

This study revealed three main findings about subjective burdens for these Chinese caregivers. First, six dimensions of subjective burden were investigated. Among the six dimensions, five dimensions were measured using CBI namely physical burden, emotional burden, time-dependence burden, developmental burden and social burden. Caregiver distress in relation to BPSD was measured as another type of subjective burden. Second, the level of physical and time-dependence burdens was much higher than emotional or social burden and these findings refuted findings from similar studies from western countries (Alzheimer's Association, 2013; Alzheimer's Disease International, 2009). The lack of formal caregiver support may have contributed to this situation as discussed further below. Third, five BPSD namely apathy/indifference, depression/dsyphoria, sleep and night-time behavioural disorders, anxiety, and problems with appetite and eating related to BPSD were identified as very common and contributed to BPSD related caregiver distress (Figure 1).

This study supports previous studies reporting BPSD as a major factor contributing to caregiver burden as evidenced by the significant correlation between the severity of BPSD and five of the six dimensions of subjective burden namely physical, emotional, time-dependence and developmental burdens, as well as caregiver distress (Brodaty & Donkin, 2009; Huang, Lee, Liao, Wang, & Lai, 2012; Shaji et al., 2009). The prevalence of BPSD in this group was 98.7%, which is much higher than the estimated rates of BPSD of around 61% to 88% in developed countries (Brodaty, Draper, & Low, 2003; Lyketsos et al., 2002). The lack of government-funded formal dementia services to manage BPSD may, therefore, contribute to the higher BPSD prevalence. The analysis revealed that caregivers with a financial burden experienced a significantly higher distress in relation to BPSD, which was consistent with prior studies stating that financial burden was a concern for caregivers and

prevented caregivers from seeking help for BPSD (Alzheimer's Association, 2010; Wang et al., 2013).

A body of evidence demonstrates that BPSD are manageable through effective caregiver interventions delivered by the multidisciplinary team (Brodaty & Donkin, 2009; Johnson et al., 2013). Given the prospect of rapid growth in the dementia population and the high prevalence of BPSD of concern in China, it is crucial to develop simple, culturally acceptable and government-funded BPSD management programs for healthcare staff and caregivers. Including dementia in the list of government-funded chronic disease management through policy intervention could be considered by public health authorities.

In this study, the number of hours devoted to caregiving contributed the most to developmental burden, which refuted the findings from developed countries that objective burden was less important in predicting subjective burden (Brouwer et al., 2004; Montoro-Rodriguez & Gallagher-Thompson, 2009). This was also intensified by the significant positive association between the financial and social burdens. On average, caregivers in this group spent 127.6 hours per week on caregiving, which is much more intensive than the 25.5 hours per week reported by their counterparts in developed countries (Alzheimer's Association, 2013; Alzheimer's Disease International, 2009). In China, the overwhelming objective burden may be influenced by the filial piety and Confucianism, whereby caring for older family members is viewed as the family's responsibility and is regulated by law (Alzheimer's Disease International, 2013). The formal dementia caregiver supports, as part of social welfare in developed countries, has not been developed in China to date.

This study identified three further important findings. First, unemployed caregivers experienced higher physical burden than their employed counterparts. Second, the more usage of social supports was associated with a higher level of emotional burden. Third, the number of helpers in the family or paid caregivers had no significant effect on any types of

subjective burden. To understand these findings, the reasons for unemployment and the social support used by caregivers were examined. In this sample, the majority of caregivers sacrificed their employment for the carer role.

Reflecting Chinese cultural norms, caregivers had more tolerance of subjective burden and sought social support in a crisis (Chan, 2010). This is similar to the findings from previous studies that identify a positive association between stress levels and efforts to relieve stress (Kim, Chang, Rose, & Kim, 2012; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). However, due to the limitation of a cross-sectional design, the temporal relationship between emotional burden and the usage of social support was unable to be established at a significant level.

In this study physical assistance such as increasing helpers in the family or the provision of direct physical resources by hiring paid carers outside of the family did not show any impact on the participants' subjective burden. This finding confirmed previous studies that subjective burden was influenced by the caregivers' appraisal of their ability to master caregiving skills and their satisfaction with their role as a carer of a person with dementia (del-Pino-Casado, Frias-Osuna, & Palomino-Moral, 2011; Montoro-Rodriguez & Gallagher-Thompson, 2009).

The study yielded different findings from prior studies in developed countries (Alzheimer's Disease International, 2009; Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch, & Lopez-Pousa, 2010; Kim et al., 2012; Xiao et al., 2014). First, the majority of caregivers were not spouses of care recipients and the spousal relationship showed no significant impact on caregiver burden. This finding may be explained as being influenced by filial piety that imposes the duty of elderly care on the children. The family members take the responsibility of caregiving tasks as part of their familial duties and older Chinese normally would like to live together with their adult children in the same household. Second,

cohabiting with the care recipients only showed positive correlation with social burden. This may be due to the widely used shared caregiving among family members in China (Xiao et al., 2014).

A similar structure of subjective burden measured by the CBI was identified from participants in this study. There were two additional items stating "I don't do as good a job at work as I used to" and "I don't have a minute's break from my caregiving chores" that were correlated with physical burden. This result reflected the increased physical burden identified from other similar studies (Wang et al., 2013; Xiao et al., 2014). These two items were correlated with social and time-dependence burdens respectively from previous studies (Chou et al., 2002; Novak & Guest, 1989). The salient finding from the analysis in this study was that all the items under "social burden" were about family issues. One possible explanation may be that the family was the main source for caregivers to seek support due to undeveloped formal social supports in dementia care and the compromises made with other family members to keep this source of support (Shaji et al., 2003; Wang et al., 2013).

There are a number of limitations in the study. First, the use of face-to-face structured interviews may have generated interview bias. Caregivers in this study may have felt reluctant to share their feelings about emotional and social burdens with the researcher and may have tended to give the researcher socially acceptable answers (Polit, Beck, & Owen, 2007; Ross & Mirowsky, 1984). Second, the nature of cross-sectional design prevents the inference of causal relationships. Third, this study focused on a community sample from one province in China and may not have reflected the situation of other family caregivers in other provinces in China. Fourth, the analysis was unable to test all of the potential factors such as the duration of caregiving, type of dementia and stage of dementia that may have contributed to caregiver burden. This was due to an inability to gain information in these areas and it is suggested incorporating these factors into future studies. In addition, the overall multiple

20

regression models explained only up to 34% of the variance in the different types of subjective burden, which were relatively lower. This may be due to the nature of this exploratory study that tried to include potential independent variables in the models. Future studies need to improve the models to better explain the changes in each type of subjective burden.

This study reveals the comprehensive structure of caregiver burden and advances knowledge on the associated factors contributing to the different types of caregiver burden in countries without formal dementia caregiver support such as China. The high level of objective and subjective burdens identified in this study suggests it is imperative to establish government-funded formal caregiver support considering the rapid growth of people with dementia and the decrease of available family caregivers in China. Moreover, caregiver support services and interventions designed to relieve caregiver burden should be targeted or based on research evidence describing the types of burdens and factors associated with each type of the burden. Further studies, especially longitudinal studies are needed to identify further factors contributing to caregiver burden in China, which will also provide important evidence for dementia care service development in other countries with a similar cultural and social context.

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22

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Table 1 Socio-demographic characteristics of family caregivers and care recipients (n=152)

Characteristics	Summary statistics
Caregivers	
Gender, n (%)	
Male	43(28.3)
Female	109(71.7)
Age (years), Mean (SD)	58.8(14.1)
Employment, n (%)	
Employed	39(25.7)
Unemployed	113(74.3)
Chronic disease, n (%)	
0	70(46.1)
1	48(31.6)
2	25(16.4)
>=3	9(5.9)
Paid carer, n (%)	
No	103(67.8)
Yes	49(32.2)
Relationship to care recipient, n (%)	
Spouse	55(36.2)
Non-spouse[§]	97(63.8)
Co-residence, n (%)	
No	35(23.0)
Yes	117(77.0)
Financial burden, n (%)	
No	68(44.7)
Yes	84(55.3)
Hours/week, Mean (SD)	127.6(62.7)
Caring duration [month] , Mean (SD)	44.0(39.3)
Care recipients	
Gender, n (%)	
Male	90(59.2)
Female	62(40.8)
Age (years), Mean (SD)	78.9(8.7)
Duration of dementia [month], Mean (SD)	48.2(34.8)
Living assistance, n (%)	
Independent	9(5.9)
Partly dependent	76(50.0)
Totally dependent	67(44.1)

Note: SD=Standard Deviation; **[§] for example, son, daughter, siblings, etc.**

Table 2 Social support of family caregivers and NPI-S scores of care recipients (n=152)

Characteristics	Summary statistics
Caregivers	
Family support-immediate, n (%)	
Poor	41(27.0)
Good	111(73.0)
Family support-extended, n (%)	
Poor	86(56.6)
Good	66(43.4)
Available helper in family, Mean (SD)	1.3(1.2)
Social network, Mean (SD)	2.7(1.0)
Usage of social support,	5.7(1.8)

Mean (SD)

Helpseeking behavior, n (%)	
Poor	133(87.5)
Good	19(12.5)

Care recipients

NPI-S score [n=150], Mean (SD)	11.4(4.9)

30

Note: SD=Standard Deviation

Table 3 Subjective burden structures (n=152)

Factors and Items	Median (IQR)	Factor loading	Alpha
Factor 1 Physical burden	14(9-18)	-	0.87
1. I'm not getting enough sleep.	3(1-4)	0.73	-
2. I'm physically tired.	3(2-4)	0.81	-
3. Caregiving has made me physically sick.	1(1-3)	0.80	-
4. My health has suffered.	3(1-3)	0.85	-
5. I don't do as good a job at work as I used to.	2(1-3)	0.59	-
6. I don't have a minute's break from my caregiving chores.	3(1-3)	0.67	-
Factor 2 Emotional burden	1(0-4)	-	0.81
1. I feel ashamed of my care-receiver.	0(0-0)	0.85	-
2. I feel embarrassed over my care-receiver's behaviour.	0(0-0)	0.81	-
3. I feel angry about my interactions with my care-receiver.	1(0-3)	0.52	-
4. I feel uncomfortable when I have friends over.	0(0-1)	0.80	-
5. I resent my care-receiver.	0(0-1)	0.66	-
Factor 3 Time-dependence burden	15(12-16)	-	0.78
1. My care-receiver needs my help to perform many daily tasks.	4(3-4)	0.88	-
2. My care-receiver is dependent on me.	4(3-4)	0.50	-
3. I have to watch my care-receiver constantly.	4(3-4)	0.62	-
4. I have to help my care-receiver with many basic functions.	4(3-4)	0.88	-
Factor 4 Developmental burden	7(5-9)	-	0.76
1. I feel that I am missing out on life.	2(1-3)	0.60	-
2. I wish I could escape from this situation.	1(1-3)	0.75	-
3. My social life has suffered.	1(1-3)	0.55	-
4. I expected that things would be different at this point in my life.	2(1-3)	0.78	-
Factor 5 Social burden	1(0-2)	-	0.65
1. I don't get along with other family members as well as I used to.	0(0-1)	0.74	-
2. I've had problems with my marriage.	0(0-0)	0.41	-
3. My caregiving efforts aren't appreciated by others in my family.	0(0-0)	0.77	-
4. I feel resentful of other relatives who could but do not help.	0(0-1)	0.62	-

Note: IQR=Interquartile range; Alpha=Cronbach's alpha coefficient

Table 4 Bivariate analysis of subjective burden (n=152)

Categories	Physical burden		Emotional burden		Time-dependence burden		Developmental burden		Social burden		NPI-D [n=150]	
	Median (IQR)	p-value	Median (IQR)	p-value	Median (IQR)	p-value	Median (IQR)	p-value	Median (IQR)	p-value	Median (IQR)	p-value
Gender												
Male	12(6-15)	<0.01	1(0-3)	0.27	13(10-16)	<0.01	6(4-9)	0.25	1(0-2)	0.39	11(7-15)	0.03*
Female	15(12-19)		1(0-4)		15(13-16)		8(5-9)		1(0-3)		13(9-17)	
Employment												
Unemployed	15(12-19)	<0.001	2(0-4)	<0.01	15(13-16)	<0.01	8(5-10)	0.04*	1(0-2)	0.27	12(8-17)	0.59
Employed	9(6-13)		0(0-3)		13(11-15)		6(3-9)		0(0-3)		12(10-16)	
Paid caregiver												
No	13(11-18)	0.34	1(0-4)	0.27	15(12-16)	0.33	8(6-10)	<0.01	1(0-3)	0.09	12(8-16)	0.09
Yes	15(7-18)		1(0-3.5)		14(12-15)		5(3-8)		0(0-2)		14(10-18)	
Relationship												
Non-spouse	13(8-16)	<0.01	1(0-3)	<0.001	15(12-16)	0.91	7(4-9)	0.31	1(0-2)	0.36	12(9-16)	0.40
Spouse	17(12-19)		3(1-7)		15(12-16)		7(5-10)		1(0-3)		13(9-18)	
Co-residence												
No	9(6-14)	<0.001	0(0-1)	<0.001	12(10-14)	<0.001	5(3-8)	<0.01	0(0-1)	0.02*	14(11-16)	0.16
Yes	15(12-19)		2(0-5)		15(13-16)		8(6-10)		1(0-3)		12(7-17)	
Financial burden												
No	13(12-16)	0.29	1(0-3)	0.13	15(13-16)	<0.01	8(5-9)	0.94	1(0-2)	0.20	11(7-16)	<0.01
Yes	15(8-19)		2(0-5)		14(11-16)		7(4-10)		1(0-3)		14(10-18)	
Family support-immediate												
Poor	13(12-14)	0.18	1(1-3)	0.91	15(14-16)	<0.01	8(6-9)	0.73	1(0-2)	0.92	11(9-15)	0.15
Good	15(8-19)		1(0-5)		14(12-16)		7(4-10)		1(0-3)		13(9-18)	
Family support-extended												
Poor	15(12-19)	0.02*	2(0-4)	0.19	15(14-16)	<0.001	8(5-10)	0.14	1(0-2)	0.78	12(9-17)	0.67
Good	13(7-16)		1(0-4)		13(11-15)		7(4-9)		1(0-3)		13(9-17)	
Help seeking behaviour												
Poor	13(8-18)	0.34	1(0-3)	0.09	15(12-16)	0.58	7(5-10)	0.83	1(0-2)	0.16	13(9-17)	0.36
Good	15(12-17)		3(0-7)		13(12-16)		7(6-9)		3(0-4)		11(9-15)	

Note: IQR=Interquartile range. The *p*-value is based on Mann-Whitney U test. P values of less than 0.05 were considered statistically significant. * *p*<0.05

33

Table 5 Factors associated with each dimension of subjective burden identified in five multiple regression models

Variables	Physical burden		Emotional burden		Time-dependence burden		Developmental burden		Social burden	
	B	95% CI	B	95% CI	B	95% CI	B	95% CI	B	95% CI
Gender (female=1)	1.78	-0.127–3.691	0.50	-0.785–1.792	1.27 *	0.294–2.249	0.27	-0.969–1.499	-0.14	-1.098–0.826
Caregiver's age	0.01	-0.118–0.147	-0.02	-0.108–0.071	0.03	-0.034–0.102	-0.05	-0.134–0.038	-0.02	-0.085–0.049
Care recipient's age	0.06	-0.074–0.185	-0.10*	-0.185–-0.010	0.08*	0.011–0.144	-0.08	-0.162–0.005	-0.07*	-0.138–-0.008
Employment (employed=1)	-3.13*	-5.748–-0.516	0.01	-1.757–1.775	0.43	-0.910–1.768	-1.03	-2.717–0.665	0.51	-0.806–1.830
Paid caregiver (yes=1)	-1.12	-3.250–1.006	0.08	-1.355–1.518	0.33	-0.762–1.417	-1.26	-2.632–0.119	-0.17	-1.239–0.906
Relationship (spouse=1)	0.92	-2.646–4.483	2.18	-0.228–4.585	-1.00	-2.827–0.823	0.63	-1.672–2.937	-0.23	-2.026–1.566
Co-residence (yes=1)	0.76	-4.078–5.596	-1.04	-4.305–2.226	0.80	-1.677–3.276	-1.91	-5.035–1.219	2.55*	0.114–4.989
Financial burden (yes=1)	0.94	-0.907–2.794	0.33	-0.919–1.580	-0.76	-1.711–0.183	-0.24	-1.435–0.957	1.02*	0.087–1.952
Duration of dementia [months]	0.03*	0.002–0.058	-0.01	-0.024–0.014	0.02*	0.004–0.032	0.02	-0.001–0.035	0.01	-0.004–0.024
NPI-S score	0.44***	0.271–0.615	0.20**	0.083–0.315	0.09*	0.002–0.178	0.15**	0.040–0.262	0.07	-0.020–0.153
Helpers in family	-0.28	-1.063–0.499	-0.47	-0.998–0.056	-0.10	-0.502–0.298	-0.27	-0.772–0.237	0.02	-0.374–0.413
Caring hours/week	0.00	-0.030–0.285	0.02	-0.005–0.036	0.01	-0.005–0.026	0.02*	0.001–0.041	0.00	-0.019–0.011
Help seeking behaviour	1.42	-1.099–3.943	1.56	-0.146–3.258	-0.79	-2.079–0.502	0.19	-1.443–1.817	0.90	-0.372–2.169
Usage of social support	-0.27	-0.782–0.246	0.40*	0.053–0.747	-0.29*	-0.554–-0.028	-0.46**	-0.788–-0.124	-0.09	-0.344–0.174
Adjusted R^2, p value	0.325, p <0.001		0.250, p <0.001		0.342, p <0.001		0.211, p <0.001		0.106, p <0.01	

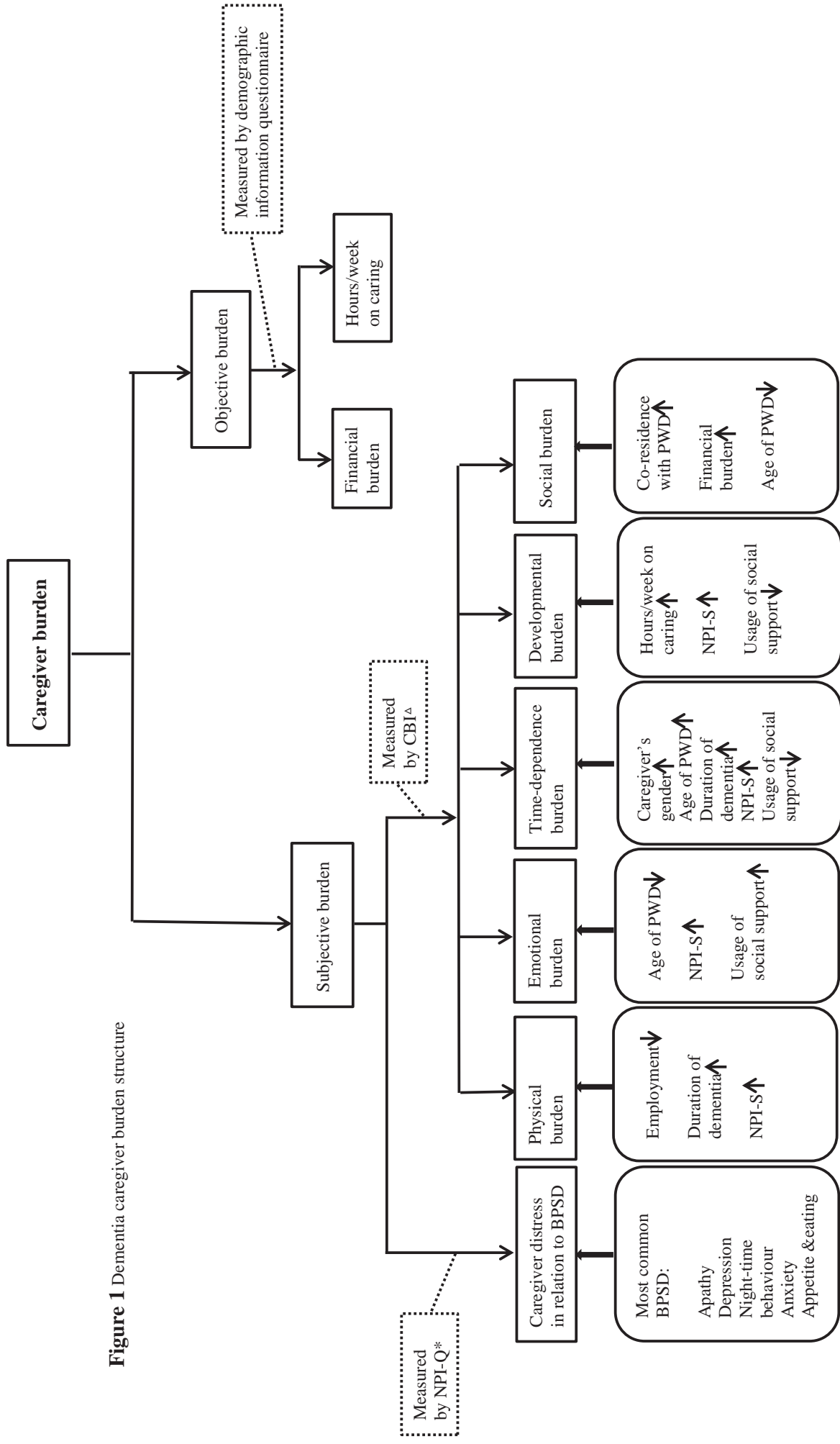Note: B=unstandardized coefficients; CI=Confidence Interval for B; * $p<0.05$, ** $p<0.01$, *** $p<0.001$

34

Figure 1 Dementia caregiver burden structure

Caregiver burden

Objective burden
- Financial burden
- Hours/week on caring

Measured by demographic information questionnaire

Subjective burden

Measured by CBI^A

Measured by NPI-Q*

Caregiver distress in relation to BPSD
- Most common BPSD:
  Apathy
  Depression
  Night-time behaviour
  Anxiety
  Appetite &eating

Physical burden
- Employment↓
- Duration of dementia↑
- NPI-S↑

Emotional burden
- Age of PWD↓
- NPI-S↑
- Usage of social support↑

Time-dependence burden
- Caregiver's gender↑
- Age of PWD↑
- Duration of dementia↑
- NPI-S↑
- Usage of social support↓

Developmental burden
- Hours/week on caring↑
- NPI-S↑
- Usage of social support↓

Social burden
- Co-residence with PWD↑
- Financial burden↑
- Age of PWD↓

Note:
^ACBI: Caregiver Burden Inventory
*NPI-Q: Neuropsychiatric Inventory-Questionnaire
PWD: People with Dementia
NPI-S: Severity of BPSD measured by NPI-Q
↓Factors associated negatively with caregiver burden
↑Factors associated positively with caregiver burden

35