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ORIGINAL RESEARCH

Predictors of caregiver burden in caregivers of individuals with dementia

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Abstract

Aims. This article is a report on a study of the multidimensional predictors of caregiver burden in caregivers of individuals with dementia using nationally representative data.

Background. Caregiver burden affects the health of both caregivers and their care-recipients. Although previous studies identified various predictors of caregiver burden, these predictors have not been confirmed in nationally representative population.

Methods. Data for this secondary analysis was provided by the National Alliance for Caregiving, American Association of Retired Persons. The data were collected through a telephone survey of randomly selected adults in seven states in 2003 (weight adjusted $n = 302$). Descriptive statistics, inter-correlation analysis and a hierarchical multiple regression analysis were performed.

Results/findings. Disease-related factors were the most significant predictors, explaining 16% of caregiver burden; these were followed by caregiver socio-demographical factors and caregiving-related factors ($F = 21{\cdot}28$, $P < 0{\cdot}01$). Significant individual predictors were impairment of activities of daily living or instrumental activities of daily living, the number of hours of caregiving, use of coping strategies, co-residence, spousal status and caregiver gender ($P < 0{\cdot}05$).

Conclusion. Impaired function in care-recipients predicts caregiver burden, and also interacts with demographical- and caregiving-related factors. Thus, it will be beneficial to both care-recipients and caregivers to target nursing interventions and community services to improve the functional abilities of individuals with dementia.

Keywords: caregiver burden, dementia, National Alliance for Caregiving, secondary data analysis

Introduction

Caregiver burden has been defined as a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual. Caregiver burden threatens the physical, psychological, emotional and functional health of caregivers (Zarit *et al.* 1980, Parks & Novielli 2000, Etters *et al.* 2008, Carretero *et al.* 2009). Caregivers frequently suffer from depression, exhibit maladaptive coping strategies and express concern about their poor quality of life (Serrano-Aguilar *et al.* 2006, Papastavrou *et al.* 2007, Molyneux *et al.* 2008). They also report more physical and psychological symptoms, and use more frequent prescription medications and healthcare services than comparable non-caregivers (Brodaty & Green 2002, Schulz & Martire 2004, Serrano-Aguilar *et al.* 2006). Finally, according to Schulz and Beach (1999), primary caregiving role, mediated by caregiver burden, is an independent risk factor for an increasing mortality rate (63%).

In response to these health concerns, researchers and clinicians identified the determinants of caregiver burden. Researchers have found that the degree of burden experienced by caregivers depends on several contextual factors, caregiving-related factors and primary stressors including the socio-demographical status of caregivers and care-recipients, disease progressions suffered by the care-recipient and the perceived stress resulting from caregiving (Gonzalez-Salvador *et al.* 1999, Schulz & Martire 2004, Etters *et al.* 2008, Carretero *et al.* 2009).

Caregivers who are advanced in age (Rinaldi *et al.* 2005, Serrano-Aguilar *et al.* 2006), women (Thommessen *et al.* 2002, Papastavrou *et al.* 2007, Campbell *et al.* 2008) and co-residents experience greater burden than young, male caregivers and those who live apart from the care-recipient (Conde-Sala *et al.* 2010). Although effects of the relationship between the caregiver and the care-recipient on caregiver burden are unclear, several studies have reported that spousal caregivers experience the highest level of burden (Rinaldi *et al.* 2005, Andren & Elmstahl 2008, Conde-Sala *et al.* 2010).

Activities of daily living and instrumental activities of daily living are frequently used as indicators of the functional status of care-recipients, and they independently affect caregiver burden (Rinaldi *et al.* 2005). However, care-recipients' functional decline has been an inconsistent predictor. Some studies suggest that moderate to severe disability affecting basic daily activities in care-recipients is related to high caregiver burden (Rinaldi *et al.* 2005, Molyneux *et al.* 2008, Sussman & Regehr 2009, Conde-Sala *et al.* 2010). However, other studies have found weak or no association between care-recipients' functional decline and caregiver burden (Clyburn *et al.* 2000, Thommessen *et al.* 2002, Campbell *et al.* 2008).

A study that used qualitative methods found that several caregiving-related factors were associated with burden, including the types of tasks that must be performed, level of support and ability to cope with managing the concerns of the care-recipient (Snyder 2000). Vulnerable caregivers without access to supportive resources have been shown to be greater risk for burden than those who can all upon services to support them (Clyburn *et al.* 2000, Sussman & Regehr 2009).

However, the studies have not considered their multidimensional nature of predictors, the ways in which multiple factors in caregiver burden interact with each other. In addition, most studies have had relatively small and homogeneous samples. In the United States, in contrast to Canada and Europe, there has been insufficient research on nationally representative subjects (Clyburn *et al.* 2000, Rinaldi *et al.* 2005, Serrano-Aguilar *et al.* 2006). Thus, there is a need to indentify the major factors contributing to caregiver burden based on large scale data with appropriate methodology to reach conclusions that are valid for a general caregiver population. This study focused on caregivers of individuals with dementia because dementia is a growing public health concern worldwide, and dementia caregivers have been found to be more burdened and more vulnerable to health problems than other caregiver groups (Schulz & Martire 2004, Papastavrou *et al.* 2007, Sussman & Regehr 2009).

Background

Conceptual framework: stress process model

This study used the conceptual framework of Conde-Sala *et al.* (2010), who integrated the studies of Pearlin *et al.* (1990) and Schulz and Martire (2004) into a stress process model. This conceptual framework categorized predictors of caregiver burden as (i) contextual variables, including caregiving-related factors and socio-demographical factors of both care-recipients and caregivers; (ii) primary stressors, which are related to patient symptoms or disease progression and (iii) secondary stressors, including difficulties in other area resulting from caregiving.

This conceptual framework stresses the multidimensional nature of predictors of caregiver burden, is based on an extensive review of exemplary articles, and integrates both conceptual and empirical aspects. This framework specifically guided selection and categorization of predictors investigated in this study. The conceptual framework was modified in this analysis because of limited availability of data variables. Figure 1 shows the framework used to guide the study, highlighting the areas where attention was focused.

We used the most recent dataset that was available when we conducted the analyses. These data represent a wide range of responders from across the nation, and these data are unique to explain a national perspective on dementia caregiving. Additionally, this result can be a scientific basis to compare to the further data collected (i.e. 2011) to promote health of caregivers.

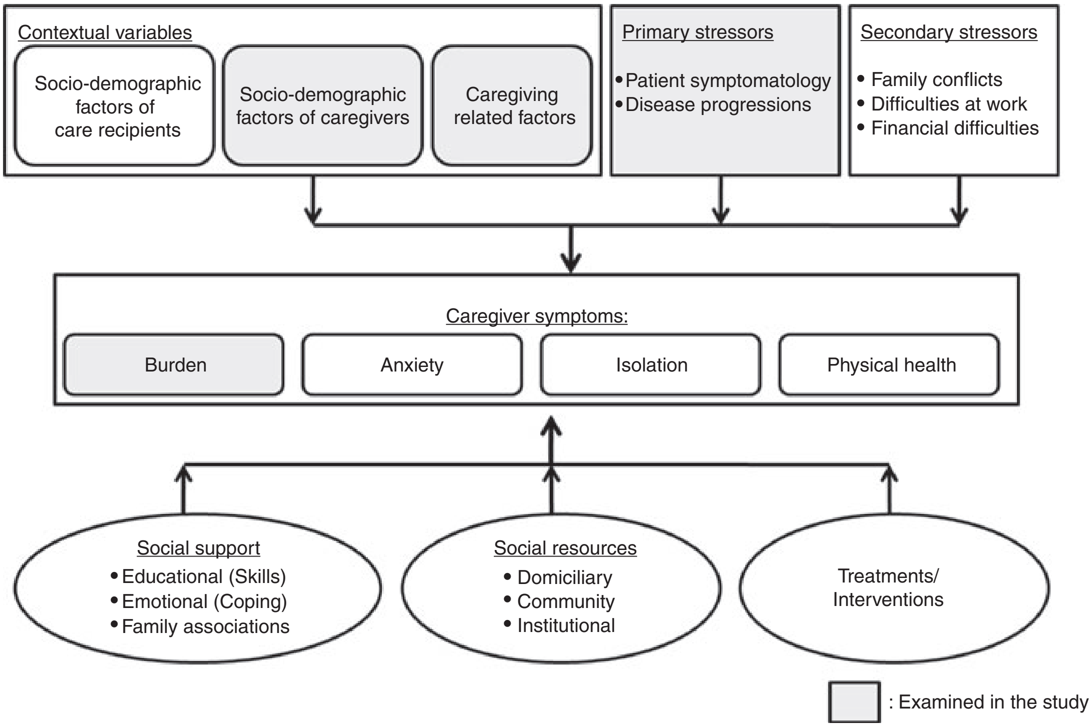

Figure 1 Conceptual framework.

The study

Aims

The aim of the study was to investigate multi-dimensional predictors associated with caregiver burden. Nationwide data were analysed using a hierarchical multiple regression analysis to ascertain the ability of these factors to predict caregiver burden. The following research questions were posed:

- In caregivers of persons with dementia, what are the relationships between caregiver socio-demographical factors (age, gender, relationship and co-residence) and caregiver burden?
- What is the relationship between disease-related factors (functional decline of care-recipients) and caregiver burden?
- What is the predictive value of caregiving-related factors (hours of caregiving, number of helpers and coping strategy) on caregiver burden?

Design

The study was a cross-sectional correlation design with a secondary data analysis.

Sample

This study used data from a nationwide telephone survey administrated by the National Alliance for Caregiving, American Association of Retired Persons (NAC/AARP) and published in 2004. Interviews were done with 6,139 US adults aged 18 years or older living in California, Delaware, Illinois, Kansas, Ohio, Virginia and Washington. For sampling, NAC/AARP used a combination of random digit dialling based on surname. The national sample was stratified by geography to produce a set of telephone numbers organized into replicates of 200 numbers each. NAC/AARP randomly selected a respondent from all households (NAC/AARP 2004c). The sample included 1,247 caregivers.

Caregivers were defined as persons who assisted individuals with at least one activity of daily living or instrumental activity of daily living (NAC/AARP 2004c). The question used to identify caregivers was "In the last 12 months, have you or anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you"(NAC/AARP 2004a, p. 1).

Among the 1,247 caregivers in the database, the 274 who took care of an individual with dementia or a dementia-related condition were eligible for this study. In considering the 274 participants, who were selected through a multistage sampling process, the study applied relative weights that were adjusted for generalization and normalization. After applying the weights, a total of 302 participants were used in the analyses.

Data collection

Data were collected using a standardized questionnaire to obtain demographical data on respondents, data on the household and data on both the caregivers and care-recipients. All interviews were conducted via telephone, mostly in the English language. To achieve nationally representative samples of minority groups, NAC/AARP oversampled for Asian and Hispanic groups, lengthened the interview period and provided Spanish language questionnaires for Hispanics. Data were collected from September to December in 2003 (NAC/AARP 2004c).

Ethical considerations

The data use was approved by NAC/AARP, and the data were anonymized and deidentified, with careful protection on confidentiality. Institutional Review Board approval was obtained from the University of Virginia prior to data analysis.

Data analysis

Analysis of variance, inter-correlation analysis and a hierarchical multiple regression analysis were performed. A correlation matrix was constructed among all the variables, based on Pearson's correlation coefficients for significance. The impact of predictors on caregiver burden was tested using hierarchical multiple regression analysis. The caregiver's socio-demographical variables were entered into Block 1, followed by functional decline variables in Block 2 and caregiving-related factors in the final block. Modifiable variables were included in the last block to suggest possible interventions that might help caregivers.

The amount of missing data for all the independent and dependent variables tested was less than 5% to ensure quality of data and generalizability of the research conclusions. All analyses were conducted with population weights sufficient to represent the total population of the United States. The population weight was selected to represent a sex/age/race matrix corresponding to third quarter (October) 2003 US population projection mode based on the 2004 US census (NAC/AARP 2004c).

Prior to the multiple regression analysis, all assumptions were checked including univariate/multivariate normality, linearity, homoscedasticity and diagnostic testing for multicollinearity and independence of errors. After checking univariate normality, the number of hours of caregiving per week was transformed using a log function, and the number of formal/informal helpers and the number of activities of daily living were transformed using a square root function. For multivariate normality, five outliers were dropped based on critical values and degrees of freedom using the Mahalanobis distance function. Data were analyzed using SPSS version 17, and the level of significance was set at 0·05, two-tailed.

Rigour/variables and measurement

Demographical variables

A standard questionnaire was used to collect data on age, gender, race, education, employment, household income, relationship with care-recipients, residential area and caregiving status.

Caregiver burden

Caregiver burden was measured by self-report from caregivers. Three questions assessed physical strain, emotional stress and financial hardship. The measure were on 5-point scale (1 = not at all strain/stressful/hardship; 5 = very much of strain/stressful/hardship). After conducting Pearson's correlation, factor analysis and reliability analysis (Cronbach's alpha = 0·76), we transformed these items into a composite score (caregiver burden) by computing a mean for the three items. The lowest caregiver burden was scored as 1, whereas the highest burden was scored as 5.

Functional status

Functional status of the care-recipients was evaluated by activities of daily living and instrumental activities of daily living (Katz *et al.* 1963, Lawton & Brody 1969). Activities of daily living included transferring, dressing, toileting, bathing, feeding and handling incontinence or diapers, whereas instrumental activities of daily living included managing medications, managing finances, shopping, doing housework, preparing meals, driving or arranging or supervising services from an agency. Higher scores indicated more dependent functional status (NAC/AARP 2004b).

Number of helpers

The number of formal or informal helpers was based upon a composite score of the answers to five questions that asked whether the caregiver had any unpaid aide, hired aide, nurse, housekeeper or other people. A score of zero indicated the absence of assistants, whereas a maximum score was 5, indicating all possible assistants.

Coping strategies

Coping for caregiver stress was a composite score for some ways that caregivers had coped with caregiver stress (talking with or seeking advice from friends or relatives, exercising, talking to a professional or spiritual counsellor, praying, going on the Internet to find information, reading about caregiving in books or other materials and taking any kind of medication) (Cronbach's alpha = 0·64). The possible range of scores was 0–7, with higher scores indicating the use of more coping strategies by caregivers.

Number of hours spent in caregiving role

The number of hours devoted to caregiving was determined by asking "About how many hours do/did you spend in an average week doing these things?" (NAC/AARP 2004a, p. 12) The exact number of hours per week in caregiving was recorded using caregivers' self-report up to 96 hours per week. Zero indicated less than one hour per week, whereas 97 indicated constant care.

Results

Description of sample

The demographical and clinical profiles of the 302 study participants and their care-recipients are shown in Table 1. The mean age of care-recipients was 70·94 (SD = 19·81) years and 68·1% were female. The average number of activities of daily living in which they required assistance was 1·96 (SD = 2·09) and the mean number of instrumental activities of daily living was 4·33 (SD = 1·90). The mean age of the caregivers was 47·06 (SD = 15·36) years. Over half were female (57%) and primary caregivers (53·4%). Caregivers took care of their parents (46·5%), other relatives (29·0%), friends/non-relatives/neighbours (12·9%), spouses (5·9%) and children (4·7%). Over 75% of the caregivers were Caucasian, followed by African American (12·6%), Hispanic (8·6%) and Asian (2·3%). The residential areas of caregivers were evenly distributed (32·6% urban, 34·9% suburban and 30·1% rural). The majority of the caregivers had a college or higher education (62·7%), held full or part time jobs (59·5%) and had an income of $50,000 or less (49·7%). On average, caregivers reported caregiver burden as 2·41 (SD = 1·12) on a 5-point scale, spent an average of 25·50 (SD = 32·60) hours a week on caregiving and had 1·46 (SD = 1·18) helpers.

Table 1 Demographical description of people with dementia and their caregivers

Variables	(*n* = 302)
Description of the persons with dementia	Mean (SD)
Age (years)	70·94 (19·81)
ADL score needing assistance	1·96 (2·09)
IADL score needing assistance	4·33 (1·90)
Gender	*n* (%)
Female	205 (68·1)
Male	87 (28·9)
Missing	10 (3·0)
Description of the caregivers	Mean (SD)
Age (years), mean (SD)	47·06 (15·36)
Level of caregiver burden, Mean (SD)	2·41 (1·12)
Number of helpers	1·46 (1·18)
Number of hours for caregiving weekly	25·50 (32·60)
Gender	*n* (%)
Female	172 (57·0)
Male	130 (43·0)
Race	
Caucasian	229 (75·8)
African American	38 (12·6)
Hispanic	26 (8·6)
Asian	7 (2·3)
Missing	2 (0·7)
Education	
High school or less	112 (37·1)
Some college or higher	190 (62·9)
Residence area	
Urban	98 (32·5)
Suburban	105 (34·8)
Rural	91 (30·1)
Missing	8 (2·6)
Employment	
Fulltime	157 (52·0)
Part time	22 (7·3)
Unemployed	123 (40·7)
Income	
Less than $30,000	74 (24·5)
$30,000–49,000	76 (25·2)
$50,000–99,000	84 (27·8)
$100,000 or greater	49 (16·2)
Missing	19 (6·3)
Caregiver status	
Primary	161 (53·3)
Secondary	135 (44·7)
Missing	6 (2·0)
Relationship to care-recipient	
Spouse	18 (6·0)
Parents	140 (46·4)
Children	14 (4·6)
Other relative	90 (29·8)
Friend/non-relative/neighbour	39 (12·9)
Missing	1 (0·3)

ADL, activities of daily living; IADL, instrumental activities of daily living.

Table 2 Pearson's correlations for the impact of caregiver demographical, disease- and caregiving-related factors on caregiver burden

	Caregiver burden	1	2	3	4	5	6	7	8	9
1. Caregiver age	0·13*	–								
2. Caregiver gender	0·13*	−0·02	–							
3. Spousal status	0·23**	0·30**	0·01	–						
4. Co-residence	0·34**	0·20**	−0·03	0·42**	–					
5. ADLs	0·27**	0·01	0·02	0·10	0·11*	–				
6. IADLs	0·46**	0·08	0·05	0·20**	0·39**	0·33**	–			
7. Number of helpers	0·03	−0·12*	−0·01	−0·11	−0·12*	0·28**	0·10	–		
8. Coping strategies	0·41**	0·08	0·10	0·06	0·15**	0·24**	0·27**	0·15*	–	
9. Number of hours of caregiving/week	0·50**	0·22**	0·14*	0·31**	0·52**	0·32**	0·50**	−0·05	0·12	–

$^{*}P < 0·05$, $^{**}P < 0·01$.
ADLs, activities of daily living; IADLs, instrumental activities of daily living.

Correlations predictors and caregiver burden

Results from the correlation analyses are shown in Table 2. There were small to moderate positive relationships between caregiver socio-demographical factors, disease-related factors, caregiving-related factors and caregiver burden. Caregivers who were older ($r = 0·13$, $P < 0·05$), female ($r = 0·13$, $P < 0·05$), a spouse ($r = 0·23$, $P < 0·01$) or lived in the same household with care-recipients ($r = 0·34$, $P < 0·01$) experienced significantly higher caregiver burden than caregivers who were younger, male, a non-spouse or did not live in the same household. The more impairments of activities of daily living ($r = 0·27$, $P < 0·01$) and instrumental activities of daily living ($r = 0·46$, $P < 0·01$) care-recipients suffered from, the greater the burden caregivers experienced. Caregivers who provided longer hours of caregiving reported higher level of burden ($r = 0·50$, $P < 0·01$). Unexpectedly, caregivers who used more coping strategies had higher levels of burden ($r = 0·41$, $P < 0·01$). The number of helpers was not related to the caregiver burden in the study patients ($P = 0·29$).

Table 3 Results of hierarchical multiple regression analysis

	R^2 Change	F ratio for R^2 change	B	SE	β
Caregiver age	0·15	12·06**	0·01	0·00	0·06
Caregiver gender			0·28*	0·13	0·12
Spousal status			0·69*	0·33	0·13
Co-residence			0·73**	0·16	0·28
ADLs	0·16	31·46**	0·21**	0·06	0·18
IADLs			0·21**	0·03	0·34
Number of helpers	0·11	16·25**	0·05	0·09	−0·03
Coping strategies			0·17**	0·03	0·27
Number of hours of caregiving/week			0·63**	0·13	0·32
R^2			0·419**		

$^{*}P < 0·05$, $^{**}P < 0·01$.
ADLs = activities of daily living; IADLs = instrumental activities of daily living.

Overall model: hierarchical multiple regression

The results of the hierarchical multiple regression using caregiver burden as the dependent variable and nine predictors in three blocks are shown in Table 3. The overall model with all nine predictors was statistically significant and explained 41·9% of the variance in caregiver burden with $F(9, 266) = 21·28$, $P < 0·01$. In Block 1, caregiver age, gender, spousal status and co-residence explained 15·1% of the variance in caregiver burden, which was statistically significant, with $F(4, 270) = 12·06$, $P < 0·01$. In Block 2, the number of impaired activities of daily living and instrumental activities of daily living uniquely explained a statistically significant amount, 16·1%, of the variance of caregiver burden, after controlling for socio-demographical factors in Block 1, with $F(2, 268) = 31·46$, $P < 0·01$. In Block 3, after controlling for all the other predictors, the number of helpers, coping strategies and the number of hours of caregiving uniquely explained 10·7% of variance of caregiver burden, statistically significant with $F(3, 265) = 16·25$, $P < 0·01$. Therefore, all three blocks of variables significantly contributed to the prediction of caregiver burden.

When individual predictors using standardized beta scores were examined, impairments in the instrumental activities of daily living ($B = 0·21$, $P < 0·01$, $\beta = 0·34$) explained the most variance in caregiver burden, followed by the number of hours of caregiving ($B = 0·63$, $P < 0·01$, $\beta = 0·32$), co-residence ($B = 0·73$, $P < 0·01$ $\beta = 0·28$), coping strategies

($B = 0{\cdot}17$, $P < 0{\cdot}01$, $\beta = 0{\cdot}27$), impairment in activities of daily living ($B = 0{\cdot}21$, $P < 0{\cdot}01$, $\beta = 0{\cdot}18$), spousal status ($B = 0{\cdot}69$, $P < 0{\cdot}05$, $\beta = 0{\cdot}13$) and caregiver gender ($B = 0{\cdot}28$, $P < 0{\cdot}05$, $\beta = 0{\cdot}12$). Controlling for all the other predictors, when the number of instrumental activities of daily living that the care-recipients impaired increased by 1 point, the caregiver burden increased by 0·21 points. If the care-recipient was impaired in one more activity of daily living than the average level (1·96), caregiver burden increased from 0·30 to 0·36 points on the 5-point scale. The number of hours of caregiving doubled, and caregiver burden increased by 0·19 points. When caregivers used one more strategy for relieving stress, they tended to have 0·17 points more in caregiver burden. Caregivers who were female, a spouse or lived with their care-recipients had burdens of 0·28, 0·69 and 0·73 points higher, respectively, than male, non-spouse and their non-co residential counterparts.

Discussion

Study limitations and future directions

Two measurement limitations were identified in the study as a nature of the use of a secondary data source. The psychometric properties of caregiver burden were not clearly defined in the primary data. In addition, there was inevitably some responder bias due to self-report data. In particular, caregivers tend to overestimate or fail to report patient functional impairments and caregivers' own problems (Loewenstein *et al.* 2001). In an attempt to address these issues, strict statistical controls and analyses were used in this study, such as data transformation and checking and adjustment of errors to draw accurate conclusions. In future studies, other more complex disease- or caregiving-related factors should be included as predictors, such as caregiver overload, caregiver role captivity, caregiver level of confidence, caregiver current relationship quality with a patient and the caregiver's experience of adverse life events (Campbell *et al.* 2008). Finally, because a cross-sectional design makes it impossible to infer causal effects, a longitudinal design is recommended to assess the true predictive value of the factors we investigated.

Discussion of results

This study examined the predictive ability of multidimensional factors to assess burden in caregivers of individuals with dementia, using nationally representative data based on stress process model. The analysis revealed that the three categories of predictors (caregiver socio-demographical factors, disease-related factors and caregiving-related factors) uniquely explained caregiver burden. Disease-related factors, reflecting functional decline in care-recipients, were the most significant predictors in the study, explaining approximately 16% of caregiver burden, followed by caregiver socio-demographical factors and caregiving-related factors, each of which accounted for 15% and 11% of caregiver burden. These results are consistent with the findings of Conde-Sala *et al.* (2010) who reported that care-recipient factors were more significant predictors of caregiver burden than caregiver- or caregiving-related factors.

One of the salient findings of the study is that the more impaired the care-recipients were in terms of either activities of daily living or instrumental activities of daily living, the greater the burden reported by caregivers. Some authors had argued that activities of daily living and instrumental activities of daily living are significant predictors of caregiver burden (Rinaldi *et al.* 2005, Molyneux *et al.* 2008, Sussman & Regehr 2009, Conde-Sala *et al.* 2010), but others disagreed (Clyburn *et al.* 2000, Thommessen *et al.* 2002, Campbell *et al.* 2008). Our data indicate that any decline in basic activities of daily living and instrumental activities of daily living requires a higher level of caregiver engagement and devotion to managing daily life because of increasing dependence of care-recipients, and results in lowering health-related quality of life (Serrano-Aguilar *et al.* 2006). In addition, this study found that caregiver burden was more strongly associated with deteriorating instrumental activities of daily living compared with activities of daily living. However, there is very limited literature on instrumental activities of daily living because most hours of caregiving are expended in helping activities of daily living or because the decline in activities of daily living is disease-relevant, whereas decline in instrumental activities of daily living is assumed to be due to the unavoidable ageing process (Rinaldi *et al.* 2005, Sussman & Regehr 2009).

In this analysis, the number of hours devoted to caregiving was a significant predictor of caregiver burden. On average, caregivers in our sample provided 25·50 hours of caregiving per week. Doubling these hours (from 25·50 to 51 hours) increased their burden by about 0·19 points on the 5-point scale. This is consistent with findings of Serrano-Aguilar *et al.* (2006) that lower levels of caregiver wellbeing on both physical and psychological measures were associated with a greater number of hours spent providing caregiving. This result also seems reasonable when viewed in conjunction with functional decline: when care-recipients had more impairments activities of daily living or instrumental activities of daily living, caregivers would be expected to devote more time and higher intense caregiving to meet their needs (Conde-Sala *et al.* 2010). In addition, 25·50 hours a week is

What is already known about this topic

- Caregivers of individuals with dementia suffer from caregiver burden more frequently than other caregiver groups and are more vulnerable for various health problems.
- Caregiver burden is a critical indicator of the negative impact of caregiving on physical, psychological and emotional health.
- Factors associated with caregiver burden include the socio-demographical status of the caregiver and care-recipient, the nature of the disease of the care-recipient and the perceived stress resulting from caregiving.

What this paper adds

- Caregivers in this study suffered from a moderate level of caregiver burden, and they spent more time on caregiving than previous study findings.
- Factors associated with functional decline were the most significant predictors of burden followed by caregiver socio-demographical factors and caregiving-related factors.
- Specific predictors included care-recipients' impairment of activities of daily living or instrumental activities of daily living, the number of hours of caregiving, use of coping strategies, co-resident status, spousal status and caregiver gender.

Implications for practice and/or policy

- The study provides basic information on the appropriate priority and modifiability of each factor to create more effective interventions for clinicians and clients.
- The findings suggest that clinicians comprehensively assess health problems of a caregiver, use an interdisciplinary approach and reduce unnecessary patient and staff burdens.
- This study can assist researchers to identify prediction of caregiver burden based on nationwide data, and this enhances generalizability of the findings.

a large amount of work time for caregivers and can cause burnout. In the review, Etters *et al.* (2008) concluded that when caregivers spent more than 16 hours a week in direct caregiving, the rate at which care-recipients were placed into nursing homes increased.

Our study had two intriguing findings. First, the more coping strategies caregivers used to relieve their stress, the greater burdens caregivers reported. Second, the number of helpers did not have a significant effect on decreasing caregiver burden. To understand the findings, we first examined the coping strategies used by caregivers in the survey; we found that most caregivers used mainly emotion-focused strategies, such as seeking advice from friends or relatives or praying. This is similar to the findings of Papastavrou *et al.* (2007), in which highly burdened caregivers tended to resort to emotion-focused coping strategies. This result also supports Lazarus and Folkman's (1984) that there is a positive relationship between recognized stress level and efforts to alleviate stress. Subjective caregiver burden did not seem to be affected by physical assistance such as provision of direct physical resource or increasing number of helpers in home as appeared in our study.

This study confirmed three major findings of previous studies: (i) caregivers of individuals with dementia experience moderate or severe levels of burden (Papastavrou *et al.* 2007, Sussman & Regehr 2009), (ii) female caregivers experience a greater caregiver burden than male caregivers (Rinaldi *et al.* 2005, Serrano-Aguilar *et al.* 2006) and (iii) caregivers who live with their care-recipients or who are spouses having a higher burden (Rinaldi *et al.* 2005, Andren & Elmstahl 2008, Conde-Sala *et al.* 2010). This was not unexpected, as those who live with a care-recipient tend to be a spouse or a family member, provide more hours of caregiving, feel more responsible for caregiving tasks as part of their familial duties and experience the greater physical and emotional closeness of the care-recipients (Carretero *et al.* 2009). In addition, the findings indicate that our society still imposes the caring role on women in terms of a family responsibility (Papastavrou *et al.* 2007).

This study arrived at two different findings from previous studies. First, caregivers' age was not a predictor of caregiver burden, which is inconsistent with several previous studies (Rinaldi *et al.* 2005, Serrano-Aguilar *et al.* 2006). However, the effect of caregiver's age on caregiver burden should be explored further, as there may be aspects of this issue that did not come to light in the survey. For example, caregiver's age may be an indirect predictor of burden as older adult caregivers experience physical vulnerability caused by ageing, such as increasing health problems. Second, unlike a prior study in which found that the majority of caregivers were spouses (Schulz & Martire 2004, Serrano-Aguilar *et al.* 2006, Campbell *et al.* 2008), we identified only 5·9% of patients as spousal caregivers. However, we found that their spousal relationship affected caregiver burden in spite of the small number in the sample.

Our findings contribute to the evidence on the health issues of caregivers. Previous studies did not consider the relative weight of each risk factor and failed to categorize or prioritize predictors when designing interventions or setting up outcome measures (Belle *et al.* 2006). This study provides data that help to address limitations. First, our study emphasized the multi-component aspects of caregiver burden, including both primary stressors from patient morbidity and contextual variables. When designing screening tools or interventions, these variables should be included to help clinicians perform a comprehensive assessment of the health problems of caregivers. Second, our results provide information on modifiability and significance of each factor. If certain domains of predictors of caregiver burden can be identified as having higher priority and modifiability, targeting those factors may lead to the creation of more effective interventions for clinicians and clients.

Conclusion

This research adds knowledge on the associations between multidimensional predictors and caregiver burden in caregivers of individuals with dementia, using nationally representative US data. Care-recipients' functional decline was the most important predictors on caregiver burden. In addition, socio-demographical factors and caregiving-related factors aggravated burden. The findings point to the importance of examining multifactual components of burden and taking comprehensive approach to help caregivers cope with providing care to a person with dementia.

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Conflict of interest

No conflict of interest has been declared by the authors.

Author contributions

HK, MC and KR were responsible for the study conception and design. HK performed the data collection. HK, MC and SK performed the data analysis. HK, MC and KR were responsible for the drafting of the manuscript. HK, MC and KR made critical revisions to the paper for important intellectual content. MC and SK provided statistical expertise. MC and KR supervised the study.

References

Andren S. & Elmstahl S. (2008) The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *Journal of Clinical Nursing* **17**(6), 790–799.

Belle S.H., Burgio L., Burns R., Coon D., Czaja S.J., Gallagher-Thompson D., Gitlin L.N., Klinger J., Koepke K.M., Lee C.C., Martindale-Adams J., Nichols L., Schulz R., Stahl S., Stevens A., Winter L. & Zhang S. & Resources for Enhancing Alzheimer's Caregiver Health (REACH) II Invetigators (2006) Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized, controlled trial. *Annals of Internal Medicine* **145**(10), 727–738.

Brodaty H. & Green A. (2002) Defining the role of the caregiver in Alzheimer's disease treatment. *Drugs and Aging* **19**(12), 891–898.

Campbell P., Wright J., Oyebode J., Job D., Crome P., Bentham P., Jones L. & Lendon C. (2008) Determinants of burden in those who care for someone with dementia. *International Journal of Geriatric Psychiatry* **23**(10), 1078–1085.

Carretero S., Garces J., Rodenas F. & Sanjose V. (2009) The informal caregiver's burden of dependent people: theory and empirical review. *Archives of Gerontology and Geriatrics* **49**(1), 74–79.

Clyburn L.D., Stones M.J., Hadjistavropoulos T. & Tuokko H. (2000) Predicting caregiver burden and depression in Alzheimer's disease. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences* **55**(1), S2–S13.

Conde-Sala J.L., Garre-Olmo J., Turro-Garriga O., Vilalta-Franch J. & Lopez-Pousa S. (2010). Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: an exploratory comparative design. *International Journal of Nursing Studies* **47**(10), 1262–1273.

Etters L., Goodall D. & Harrison B.E. (2008) Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of the American Academy of Nurse Practitioners* **20**(8), 423–428.

Gonzalez-Salvador M.T., Arango C., Lyketsos C.G. & Barba A.C. (1999) The stress and psychological morbidity of the Alzheimer patient caregiver. *International Journal of Geriatric Psychiatry* **14**(9), 701–710.

Katz S., Ford A.B., Moskowitz R.W., Jackson B.A. & Jaffe M.W. (1963) Studies of illness in the aged. The index of ADL: a standardized measure of biological and psychosocial function. *JAMA: The Journal of the American Medical Association* **185**, 914–919.

Lawton M.P. & Brody E.M. (1969) Assessment of older people: self-maintaining and instrumental activities of daily living. *The Gerontologist* **9**(3), 179–186.

Lazarus R.S. & Folkman S. (1984) *Stress, Appraisal, and Coping*. Springer, New York.

Loewenstein D.A., Arguelles S., Bravo M., Freeman R.Q., Arguelles T., Acevedo A.& Eisdorfer C. (2001) Caregivers' judgments of the functional abilities of the Alzheimer's disease patient: a comparison of proxy reports and objective measures. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences* **56**(2), P78–P84.

Molyneux G.J., McCarthy G.M., McEniff S., Cryan M. & Conroy R.M. (2008) Prevalence and predictors of carer burden and depression in carers of patients referred to an old age psychiatric service. *International Psychogeriatrics* **20**(6), 1193–1202.

National Alliance for Caregiving, American Association of Retired Persons (NAC/AARP) (2004a) *Caregiving in the U.S. Appendix C: CATI Questionnaire*. Retrieved from http://www.caregiving.org/data/04questionnaire.pdf on 1 June 2010.

National Alliance for Caregiving, American Association of Retired Persons (NAC/AARP) (2004b) *Families Care: Alzheimer's Caregiving in the United States 2004*. Retrieved from http://www.caregiving.org/data/alzcaregivers04.pdf on 1 June 2010.

National Alliance for Caregiving, American Association of Retired Persons (NAC/AARP) (2004c) *Caregiving in the U.S. Appendix A: Detailed Methodology* Retrieved from http://www.caregiving.org/data/04methodology.pdf on 13 May 2010.

Papastavrou E., Kalokerinou A., Papacostas S.S., Tsangari H. & Sourtzi P. (2007) Caring for a relative with dementia: family caregiver burden. *Journal of Advanced Nursing* **58**(5), 446–457.

Parks S.M. & Novielli K.D. (2000) A practical guide to caring for caregivers. *American Family Physician* **62**(12), 2613–2622.

Pearlin L.I., Mullan J.T., Semple S.J. & Skaff M.M. (1990) Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist* **30**(5), 583–594.

Rinaldi P., Spazzafumo L., Mastriforti R., Mattioli P., Marvardi M., Polidori M.C., Cherubini A., Abate G., Bartorelli L., Bonaiuto S., Capurso A., Cucinotta D., Gallucci M., Giordano M., Martorelli M., Masaraki G., Nieddu A., Pettenati C., Putzu P., Tammaro V.A., Tomassini P.F., Vergani C., Senin U. & Mecocci P. & Study Group on Brain Aging of the Italian Society of Gerontology and Geriatrics (2005) Predictors of high level of burden and distress in caregivers of demented patients: results of an Italian multicenter study. *International Journal of Geriatric Psychiatry* **20**(2), 168–174.

Schulz R. & Beach S.R. (1999) Caregiving as a risk factor for mortality: the caregiver health effects study. *JAMA: The Journal of the American Medical Association* **282**(23), 2215–2219.

Schulz R. & Martire L.M. (2004) Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry* **12**(3), 240–249.

Serrano-Aguilar P.G., Lopez-Bastida J. & Yanes-Lopez V. (2006) Impact on health-related quality of life and perceived burden of informal caregivers of individuals with Alzheimer's disease. *Neuroepidemiology* **27**(3), 136–142.

Snyder J.R. (2000). Impact of caregiver-receiver relationship quality on burden and satisfaction. *Journal of Women & Aging* **12**(1–2), 147–167.

Sussman T. & Regehr C. (2009) The influence of community-based services on the burden of spouses caring for their partners with dementia. *Health & Social Work* **34**(1), 29–39.

Thommessen B., Aarsland D., Braekhus A., Oksengaard A.R., Engedal K. & Laake K. (2002) The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease. *International Journal of Geriatric Psychiatry* **17**(1), 78–84.

Zarit S.H., Reever K.E. & Bach-Peterson J. (1980) Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist* **20**(6), 649–655.