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Abstract

Aims: To identify what factors are associated with the caregiver burden of spouse caregivers, adult child caregivers and parent caregivers.

Background: Caregivers often feel stressed and perceive caregiving as a burden. The caregiver burden has been little studied from the perspective of the personal relationship between caregiver and care recipient.

Design: Cross-sectional study

Methods: A random sample of 4 000 caregivers in Finland was drawn in 2014 and those who remained either spouse, adult child or parent caregivers at data collection were included in the analysis (n=1 062). Data on the care recipients' characteristics were also collected. Caregivers' perceived burden was measured using the Caregivers of Older People in Europe index. General linear models were used to explain perceived caregiver burden.

Results: Care recipients' low level of cognitive function was associated with greater perceived burden. Higher quality of support was associated with lower perceived burden among female and male spouse caregivers, daughter caregivers and mother caregivers. Low cognitive function explained three to six percent and high quality of support two to five percent of the total variation in the burden explained by the models, which ranged between forty-five and fifty-five percent.

Conclusion: Because cognitive challenges of care recipient are associated with greater perceived burden and high quality of support with lower burden among most of the caregiver groups, high quality tailored nursing interventions will be needed especially for the caregivers of the most frail care recipients.

Key words: adult child caregiver, caregiving, general linear models, nursing, parent caregiver, perceived caregiver burden, spouse caregiver

SUMMARY STATEMENT

Why is this research needed?

- **Informal caregiving is based on an existing relationship and it is usually reciprocal; most often the caregiver is the spouse, adult child or the parent of the care recipient.**
- **There is limited evidence of associations between caregiver – care recipient relationship and caregiver burden.**
- **Better understanding of caregiver burden helps health care providers pay attention to the threat of caregiver burden and support the relatives of their patients.**

What are the key findings?

- **Severe cognitive difficulties of care recipients and the low quality of support (informal and formal) for the caregiver were associated with a higher caregiver burden in all caregiver groups.**
- **Signs of depression was the strongest single factor that explained higher caregiver burden among male spousal caregivers, and perceived poor health among all groups of female caregivers.**
- **The positive value of caregiving was the strongest single factor that explained caregiver burden among the caregiver mothers and female caregiver spouses.**

How should the findings be used to influence policy/practice/research/education?

- **The more challenges (especially cognitive) the care recipients have, the stronger societal support may be needed to avoid caregiver burden.**
- **The findings can be used to conduct tailored interventions for the spouse, the parent and the adult child caregivers.**
- **Future research is needed to understand the dynamics of social relationships and the positive aspects of caregiving as mediators of caregiver burden.**

1. INTRODUCTION

Caregiving for the aged has a substantial impact on Western welfare societies. However, not all care recipients are old. Many caregivers care for an impaired child, and may also need support to cope with the demands of caregiving. Only caregiving deemed demanding is eligible for state support in most countries, and consequently official caregivers often report feeling stressed, which is a well known precursor of psychological (Pinquart & Sörensen, 2003; Smith et al., 2014) and physical disorders (Haley, Roth, Howard, & Safford, 2010; Vitaliano et al., 2002; von Kanel et al., 2008). In contrast, some studies have revealed that caregiving can also have positive impact on a caregiver's life; for example, caregivers live longer than non-caregivers (Brown et al., 2009; Fredman, Cauley, Hochberg, Ensrud, & Doros, 2010; O'Reilly, Connolly, Rosato, & Patterson, 2008; Roth et al., 2013). In the few previous studies highlighting the positive impact of caregiving, the optimal amount of time spent performing caregiving has been reported to be 14 to 19 hours per week (Brown et al., 2009; O'Reilly et al., 2008). Moreover, older female caregivers in particular experienced caregiving as more beneficial than younger caregivers (O'Reilly et al., 2008).

Background

Thus far, caregiving has mostly been investigated from the perspective of specific diagnoses or recipient age. However, the caregiver burden has been little studied from the standpoint of the relationship between caregiver and care recipient. In Finland, two-thirds of caregivers with a caregiver allowance provide care for recipients aged 65 years or older (Sotkanet, 2016), and over half care for their spouse or partner. In contrast, only 14 percent provide parental care (Linnosmaa et al., 2014). For spouse caregivers caregiving is experienced equally as stressful as it is by children who provide care for their parents (Friedemann & Buckwalter, 2014; Kim et al., 2012; Pinquart & Sörensen, 2011). Reed et al.

(2014) in turn reported conflicting findings among caregivers of patients with Alzheimer's disease and that caregivers of adult children experienced a greater burden than caregivers of a spouse.

In addition to spouse and adult child caregivers, a third major group of caregivers are parents, with 23 percent of Finnish caregivers providing parental care for a child either under or over 18 years old (Linnosmaa et al., 2014). Although the experience of parenting any child can be stressful, parents caring for a disabled child experience a greater level of stress (Hayes & Watson, 2013) or have poorer perceived health than other parents (Brehaut et al., 2011). Moreover, behavioural challenges presented by the care recipient, (Jellett, Wood, Giallo, & Seymour, 2015; Plant & Sanders, 2007) ineffective coping strategies, poor family functioning and poor social support have been associated with the parental caregiver burden in previous studies (Raina et al., 2004).

Previous studies have also shown that there can be gender differences related to perceived caregiver burden. For example, female caregivers have experienced a greater caregiver burden and higher levels of depression than males (Gibbons et al., 2014; Perz, Ussher, Butow, & Wain, 2011; Pinquart & Sörensen, 2006). An increased number of caregiving tasks and assisting the recipient with multiple activities of daily living have been associated with a greater perceived burden (Chan & Chui, 2011; Coleman et al., 2012; Kim, Chang, Rose, & Kim, 2012; Savundranayagam, V., & Kosloski, 2011). Unsurprisingly, female caregivers spend more time on caregiving, help with more tasks, and assist more with personal care than male counterparts (Pinquart & Sörensen, 2006). Although the number of male caregivers has increased in recent years, 70% of all caregivers continue to be women (Linnosmaa, Jokinen, Vilkkö, Noro, & Siljander, 2014).

2. THE STUDY

Aims

The aims of this study were, first, to identify the differences between caregivers who are either the spouse, adult child or parent of the care recipient, and second, to investigate the factors that explain the caregiver burden reported spouse caregivers, adult child caregivers and parent caregivers among females and males, separately.

Design

This study forms part of a large cross-sectional study, the Caregiver Research Project of the Social Insurance Institution of Finland (Tillman, Kallioma-Puha, and Mikkola 2014), which focuses on caregivers who received a caregiver's family allowance in Finland in 2012.

Participants

A random sample of 4 000 caregivers was drawn for the research project from the population of 40 591 caregivers in Finland in 2012. The self-rating questionnaire was mailed on paper in May and June 2014. The response rate was 59.7% (n=2 388). Missing value analysis, adjusted for gender, region and age, showed that responders were slightly more often over 60 years of age than non-responders. Only persons who were still caregivers and who were either spouse caregivers (n=768) or adult child caregivers (n=157) or parent caregivers (n=338) at the time of data collection were included. In addition, data on the care recipients' characteristics were collected. Those with data missing were excluded except the missing data was living area, physical function or cognitive function of care recipient. The total number of caregivers included in the analysis was 1 062. The mean age of the caregivers and care recipients was higher and caregivers were more often spouses in the excluded than included data. However, no other differences were observed between the excluded and included participants.

Ethical considerations

The ethical committee approved this study (1/500/2014).

Data collection

The questionnaire contains items on the caregiver's age, years of education, occupational status (working, nonworking), living area, perceived health, duration of caregiving, hours of caregiving per day, and use of social and health care services. Caregiver burden was measured as the sum score for the seven items of the Negative Impact subscale of the COPE index with a range of values from 7 (minimal burden) to 28 (maximal burden) using questions: 1) Is caregiving too demanding? 2) Does caregiving cause difficulties in your relationships with friends? 3) Does caregiving have a negative effect on your physical health? 4) Does caregiving cause difficulties in your relationship with your family? 5) Does caregiving cause you financial difficulties? 6) Do you feel trapped in your role as a caregiver? 7) Does caregiving have a negative effect on your emotional well-being? (Balducci et al., 2008, McKee et al., 2003). In addition to negative impact, the COPE Index includes the dimensions of Positive Value (indicates satisfaction in caregiving) and Quality of Support. The positive aspect of caregiving was measured as the sum score (range 3-12) of three positive value items: 1) Do you feel you cope well as a caregiver? 2) Do you find caregiving worthwhile? 3) Do you have a good relationship with the person you care for? The different type of social support were measured with the five "quality of support" items (range 5-20): 1) Do you feel that anyone appreciates you as a caregiver? 2) Do you feel well supported by your family? 3) Do you feel well supported by your friends and/or neighbors? 4) Do you feel well supported by health and social services? 5) Overall, do you feel well supported in your role of caregiver? (Juntunen, Nikander, Törmäkangas, Tillman, & Salminen, 2017.) Higher scores in positive value and in quality of support mean better result.

Caregiver depression was elicited using two dichotomous questions: “During the past month, have you often been bothered by feeling down, depressed or hopeless?” and “During the past month, have you often been bothered by feeling little interest or pleasure in doing things?”

The personal characteristics of the care recipients included age and the main reason for receiving care (“physical weakness” i.e. frailty of old age, “dementia” such as Alzheimer disease, “dementia, and other disability” meaning combination of dementia and other illness, “developmental or psychiatric disability”, “physical impairment or illness” such as cerebral palsy or stroke). In addition, information on the physical mobility (physical ability to move) of the care recipient was collected using a five-step ordinal scale; 1=is able to move without difficulties inside, outside and on stairs; 2= is able to move independently inside or with assistive devices; 3=has much difficulty moving and needs assistance, e.g. to transfer from one place to another or using stairs; 4=is able to move only with assistance (even inside); 5=is completely immobile or bedridden. Cognitive functioning was as well measured on a five-step ordinal scale; 1=thinking is logical and memory good; 2=small difficulties in logical thinking and memory; 3= moderate difficulties in logical thinking and memory; 4=many difficulties in logical thinking and memory; 5= incapable of logical thinking or orientation.

Statistical analysis

The descriptive data are shown as means and standard deviations for continuous variables and as frequencies and percentages for categorical variables. Group differences were tested using the t-test for continuous variables, Mann-Whitney test for ordinal variables and χ^2 -test for categorical variables. Physical mobility and cognitive functioning of the care recipients were imputed with mode using information on the disability of the care recipient. The best factors of the

caregiver burden were assessed in general linear models; here, we report the unstandardized regression coefficients, their standard errors, p-values, model R-squared, adj. R-squared, and variable-specific partial eta-squared estimates. Variables for analyses were selected based on a significant correlation with the negative impact score (Supplement Tables S1, S2, S3 and S4 in Appendix). Due to the high correlation between the variables of the caregiver's age and care recipient's age as well as care recipient's diagnosis and cognitive functioning, we included only one of each pair in the model (care recipient's age and cognitive functioning). All variables were inserted into the general linear model in the same time; the continuous variables (positive value, quality of support, services not used but perceived necessary, services used and more needed, age of care recipient) were inserted as covariates and the ordinal and categorical variables were inserted as fixed factors. The groups of father and adult son caregivers were excluded from the analysis owing to their small number in the study. Models were constructed using IBM SPSS for Windows (Version 22).

Validity and reliability

The COPE Index -questionnaire has previously demonstrated international (Balducci et al., 2008) and national validity and satisfactory to good reliability using a varied range of ages of care recipients (Juntunen et al., 2017). The questions indicating depressive symptoms have a sensitivity of 96%-97% and a specificity of 57%-67% for depression (Arroll, Khin, & Kerse, 2003; Whooley, Avins, Miranda, & Browner, 1997). The whole questionnaire was pre-tested with a sample of caregivers.

3. RESULTS

The caregivers' age ranged between 20 and 92 years, and 72% of them were females. Table 1 presents the personal characteristics of the female and male

caregivers who were spouses, adult children or parents in their relationship to the care recipient.

Female and Male Spouse Caregivers

Occupational status, living area, perceived health, use of social and health care services and quality of support due to caregiving did not differ between the female and male spouse caregivers. However, the female spouse caregivers were three years younger and they had 0.9 more years of education than the males ($p < 0.01$). Furthermore, the female spouse caregivers had been a caregiver for 0.9 years longer ($p < 0.05$), and 8.3 percentage points more of them spent 13 to 24 hours per day providing care than their male counterparts. Half of the female spouse caregivers reported that they had felt down (50%) and/or had little interest in doing things during the previous month (48%), whereas among male spouse caregivers the corresponding figures were 33% and 33%. The female spouse caregivers scored 8% higher on the perceived negative impact of caregiving ($p < 0.01$) and 6% lower on the positive value of caregiving than the male spouse caregivers ($p < 0.01$).

Adult Child Female and Male Caregivers

No significant differences were observed between daughter and son caregivers.

Mother and Father Caregivers

The caregiver mothers were six years younger ($p < 0.05$) and had been providing 4.6 years longer ($p < 0.05$) than the caregiver fathers. Over half of the caregiver mothers (55%) and 27 % of the caregiver fathers worked ($p < 0.01$).

Insert Table 1 about here

Comparison between female spouse, adult child and parent caregivers

The female spouse caregivers scored 7% higher on the negative impact of caregiving than the female adult child caregivers ($p<0.05$) and 9% greater than the caregiver mothers ($p<0.01$). Nearly half of female spouse caregivers reported indicator of depression when under 40% of daughters ($p<0.05$) and third of mothers ($p<0.01$) reported so. Nearly half of female spouse caregivers were being bothered by having little interest or pleasure in doing things, and third of daughter caregivers ($p<0.01$) and 28% of mother caregivers ($p<0.01$) were being bothered by it. The caregiver mothers scored 6% higher than daughters ($p<0.01$) and 7% higher than spouses ($p<0.01$) on the positive value of caregiving, and 6% lower on the quality of support than the female spouse caregivers ($p<0.01$). The female spouse caregivers had the lowest perceived health when 17% of them reported that their health is very good or good, while over half of the caregiver mothers and 45% of the caregiver daughters reported so ($p<0.01$).

Care Recipients

The care recipients of the female spouse caregivers were two years older than the care recipients of the male spouse caregivers ($p<0.01$, Table 2). The care recipients of the adult caregiver daughters were three years older than the care recipients of the adult son caregivers ($p<0.05$).

Insert Table 2 about here

Factors associated with perceived caregiver burden

A general linear model to explain caregiver burden (experienced negative impact of caregiving) were based on 13 factors: the caregiver's positive value score (i.e. self-reported positive meaning of caregiving to the caregiver), perceived health (better health vs. poor health), indicators of depression (bothered vs. not bothered by depressive symptoms, lack of interest (bothered vs. not

bothered), years of education, hours spent caregiving (13 to 24 h/day vs. less), quality of support, number of services not used but considered necessary, number of services used but considered insufficient, and the care recipient's age, cognitive functioning (difficulties in thinking vs. incapable of logical thinking) and physical mobility (some level of mobility difficulties vs. completely immobile); see Tables 3 and 4.

Insert Table 3 and 4 about here

In the model explaining the burden of *female caregivers caring for their spouse/partner* (Table 3), the strongest factor was poor perceived health, which explained 5% of total variation in the perceived burden (partial eta-squared, $\eta_p^2 = 5\%$, $p < 0.001$). Other significant factors were lack of interest ($\eta_p^2 = 4\%$, $p < 0.001$), care recipient's low level of cognitive function ($\eta_p^2 = 3\%$, $p = 0.011$), caregiver's high education ($\eta_p^2 = 3\%$, $p < 0.001$), greater number of services not used but considered necessary ($\eta_p^2 = 2\%$, $p = 0.006$) and more time spent providing care (13-24 h/day vs. 0-4 h/day; $\eta_p^2 = 1\%$, $p = 0.045$). The significant factors explaining lower caregiver burden were a high score on the positive value (i.e. high self-reported positive affect) of caregiving ($\eta_p^2 = 5\%$, $p < 0.001$) and high quality of support ($\eta_p^2 = 2\%$, $p = 0.003$). The multiple regression model explained 47% of the total variation in the perceived burden of caregiving ($F(22, 399) = 16.269$; $p < 0.001$; adj. $R^2 = 0.444$).

In the model explaining the burden of *male spouse caregivers caring for their spouse/partner* (Table 3), the strongest factor was being bothered by depressive symptoms ($\eta_p^2 = 8\%$, $p < 0.001$). Other significant factors were care recipient's low level of cognitive function ($\eta_p^2 = 5\%$, $p = 0.021$), more time spent providing care (13-24 h/day vs. 5-6 h/day; $\eta_p^2 = 3\%$, $p = 0.015$) and more services used but considered insufficient ($\eta_p^2 = 2\%$, $p = 0.030$). Significant factors of lower

caregiver burden were high quality of support ($\eta_p^2=2\%$, $p=0.035$) and high the positive value score ($\eta_p^2=2\%$, $p=0.030$). The multiple regression model explained 45% of the total variation in perceived burden ($F(22,215)=7.938$; $p<0.001$; $\text{adj. } R^2=0.392$).

In the model (Table 4) explaining the burden of *adult daughter caregivers caring for their parents*, significant factors were being bothered by depressive symptoms ($\eta_p^2=5\%$, $p=0.044$), poor perceived health ($\eta_p^2=11\%$, $p=0.013$), care recipient's low level of cognitive function ($\eta_p^2=5\%$, $p=0.039$) and care recipient's physical immobility ($\eta_p^2=5\%$, $p=0.044$). High quality of support ($\eta_p^2=5\%$, $p=0.044$) was associated with lower caregiver burden. The multiple regression model explained 51% of the total variation in perceived burden ($F(22, 86) = 4.062$, $p<0.001$, $\text{adj.}R^2 = 0.384$).

In the model explaining the burden of *caregiver mothers caring their child*, significant factors were poor perceived health ($\eta_p^2=7\%$, $p=0.001$), care recipient's low level of cognitive function ($\eta_p^2=6\%$, $p=0.012$), care recipient's physical immobility ($\eta_p^2=4\%$, $p=0.004$), a greater number of services used but also more needed ($\eta_p^2=4\%$, $p=0.003$) and a greater number of services not used but considered necessary ($\eta_p^2=2\%$, $p=0.027$). High positive value (i.e. high self-reported positive affect of caregiving: $\eta_p^2=11\%$, $p<0.001$) and high quality of support ($\eta_p^2=5\%$, $p=0.002$) were significant factors to explain lower perceived burden. The multiple regression model explained 55% of the total variation in perceived burden ($F(22,206) = 11.654$, $p<0.001$, $\text{adj.}R^2 =0.507$).

4. DISCUSSION

In this study, we observed two significant variables associated with perceived caregiver burden that were common to all four caregiver subgroups; first, high quality of support was associated with lower caregiver burden, and second, severe cognitive challenges of the care recipient was associated with higher caregiver burden.

High social support has previously been shown to be a significant mediator of caregiver burden in previous studies (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Rodakowski, Skidmore, Rogers, & Schulz, 2012; van der Lee, Bakker, Duivenvoorden, & Dröes, 2014). In this study, the quality of support was assessed with five questions inquiring i) how much perceived support the caregiver received from family members, and ii) from friends or neighbors; iii) the caregiver's perception of the level of health and social services; iv) how the caregiver felt about the caregiver role, and v) how appreciated the caregiver felt as a caregiver. Thus, we believe that the information collected in this way covered the main types of social support, such as perceived support from both family and society. We also observed that the number of services used did not correlate significantly with the negative impact of caregiving. However, unmet need for services was a significant factor of the caregiver burden in the spouse-caregivers' and caregiver mothers' models. Previous studies have revealed that perceived support is a stronger predictor of the caregiver burden than received support (Chiou, Chang, Chen, & Wang, 2009). Therefore, it cannot be overstated how important is for the caregiver to feel that, if needed, help can be obtained from family and neighbors, and that constructive and respectful collaboration with social and health care professionals is available.

In this study the cognitive status of the care recipients were measured by fairly simple five step scale to make sure that a caregiver could assess her/his care recipient's status regardless of recipient's age or reason for care. Severe cognitive

challenges of the care recipient was the other factor, besides quality of support that was consistently associated with a higher perceived caregiver burden in all the caregiver groups. Physical dysfunction of the care recipient was also significantly associated with caregiver burden among the caregiver mothers and weakly associated with the burden among the caregiver daughters. This finding is also consistent with previous studies: caregiver burden has been influenced by the cognitive status of recipient with dementia (Kamiya, Sakurai, Ogama, Maki, & Toba, 2014; Sansoni, Anderson, Varona, & Varela, 2013) and children with neurodevelopmental disorders (Craig et al., 2016). Savundranayagam et al. (2005) found that the care recipient's cognitive and functional status indirectly predicted his or her problem behavior via challenges in communication. Our questionnaire did not include problem behavior of the care recipient, although this has been strongly associated with caregiver burden in previous studies (del-Pino-Casado, Millán-Cobo, Palomino-Moral, & Frías-Osuna, 2014; Savundranayagam et al., 2011; van der Lee et al., 2014).

Disturbed behavior has also been associated with challenges in the relationship between caregiver and care recipient (Caqueo-Urizar, Urzúa, Jamett, & Irarrazaval, 2016). In the present study, the quality of the relationship was included in the positive value continuum. A high score on the positive value of caregiving was associated with lower negative impact among the spouse caregivers, and it was the strongest single factor among the caregiver mothers. The female spouse caregivers experienced caregiving as giving positive value to their life less often than the male or mother caregivers but as often as the caregiver daughters. Ekwall and Hallberg (2007) found that male caregivers were more satisfied than female caregivers. Balanced reciprocity, reported to be higher in male caregivers, in the caregiver-recipient relationship was also found to have a protective effect on the caregiver burden (del-Pino-Casado, Frías-Osuna, & Palomino-Moral, 2011). It is, therefore, important that healthcare providers pay

attention to resources that can maintain or further enhance a good relationship between caregiver and care recipient, especially in where the care recipient shows disturbed behavior.

To highlight differences between female and male caregivers, female spouse caregivers differed from the other groups in two ways: first, they experienced caregiving as a greater burden than any other caregiver group, and second, they were more often bothered by depressive symptoms. This is consistent with previous findings that female spouse caregivers experience caregiving as a greater burden than male caregivers (Chan & Chui, 2011; del-Pino-Casado, Frías-Osuna, Palomino-Moral, & Ramón Martínez-Riera, 2012; Gibbons et al., 2014), and adult child caregivers as a lower burden than spouse caregivers (Friedemann & Buckwalter, 2014; Kim et al., 2012; Pinquart & Sörensen, 2011). In contrast, Chappell and colleagues (2015) found that daughters experienced a higher burden than female spouse caregivers. In the present study, caregiver mothers gave a slightly less stressful rating of caregiver burden and reported signs of depression less often than females in the other caregiver groups. However, raising a child with a disability has been shown to be more stressful than raising a child without a disability (Yamaoka et al., 2016). Differences of perceived burden between female and male caregivers have been explained by a gendered approach to self-appraisal and coping (Friedemann & Buckwalter, 2014, Hong & Coogle, 2016). Moreover women may believe that caregiving is their duty regardless their perceived insufficient capabilities in caregiving (Friedemann & Buckwalter, 2014). However this does not explain the differences of burden between female spouse, daughter and mother caregivers.

Signs of depression (such as often feeling down, depressed, or hopeless, or feeling little interested or pleasure in doing things) explained caregiver burden both among the caregiver daughters and the spouse caregivers. This association, again, was consistent with earlier findings (Jones, Whitford, & Bond, 2015;

Perlick et al., 2016; Springate & Tremont, 2013). In this study, signs of depression was the strongest single factor of caregiver burden among the male caregivers of a spouse. Mother caregivers were the only group in which signs of depression were not a significant factor in perceived burden. Poor health of the caregiver explained caregiver burden among all the female caregivers, and was the strongest single factor among the caregiver daughters. No differences between female and male caregivers in perceived health, however, was observed. This is also consistent with previous findings that have indicated an association between caregiver burden and caregiver health (Chan & Chui, 2011; Rodakowski et al., 2012).

Limitations

Strengths of the study were the inclusion of standardized instruments and pre-testing of the questionnaire items. The internal consistency of the positive value of caregiving scale has been found satisfactory (Juntunen et al 2017). However, it may not be robust enough to identify different levels of positive meaningfulness experienced by caregivers, and thus meaningfulness in caregiving may be an even stronger mediator of caregiver burden than our results indicate. The present data were obtained from a random sample (4 000) of Finnish registered caregivers, accounting for about 10 % of registered caregivers and approximately 1 % of all Finnish caregivers. However, this study is only representative of caregivers who provide intensive care. Moreover, spouses and older caregivers did not respond to our questionnaire as often as the other caregiver groups and younger caregivers. Accordingly, our sample may be biased when compared to the original random sample, and thus comparing our results with caregivers in general must be done with caution.

Our study has further limitations. We sought to identify factors that explain the negative impact of caregiving for the caregiver. More specifically, our goal was to detect the factors that are associated with caregiver burden among

spouse caregivers, adult child caregivers and parent caregivers. These caregiver categories were chosen because they cover three major groups of caregivers based on the relationship between caregiver and care recipient. However, only caregiver daughters, representing the adult child category, and caregiver mothers, representing the parent category were used in the models, as the number of son and father caregivers was statistically too small. These male caregiver groups merit separate study. Nevertheless, our analyses were not focused on specific diagnoses or age groups of care recipients, as in most previous caregiver-studies, but instead caregivers were classified according to the relationship between caregiver and care recipient.

5. CONCLUSION

To conclude, low level of cognitive function of the care recipient explained perceived caregiver burden among all three caregiver categories studied, i.e., spouse, daughter and mother. High quality of support given by close ones and by society was associated with the lower burden. Thus, it can be speculated that the frailer the care recipient, the stronger should be the societal support.

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Table 1. Characteristics of female and male caregivers (CG) who are either spouses, adult children or parents of the care recipient.

Variable	Spousal CG		Adult child CG		Parental CG	
	Female, n=422 mean (SD)	Male, n=238 mean (SD)	Female, n=109 mean (SD)	Male, n=34 mean (SD)	Female, n=229 mean (SD)	Male, n=30 mean (SD)
Age of caregiver ¹	72 (8.6)	75 (9.2)**	58 (9.7)	55 (9.7)	53 (13.1)	59 (14.4)*
Years of education ¹	10.4 (3.4)	9.5 (3.7)**	12.9 (3.4)	12.4 (4.3)	13.5 (4.0)	12.4 (5.2)
Years of caregiving ¹	6.9 (5.0)	6.0 (3.9)*	5.3 (3.5)	4.2 (2.2)	13.1 (12.5)	8.5 (8.2)*
Number of services ¹						
Used services	2.5 (2.1)	2.6 (2.4)	2.5 (1.7)	2.9 (2.1)	2.6 (2.0)	2.5 (2.1)
Used, more needed	0.8 (1.4)	0.8 (1.6)	0.7 (1.4)	0.3 (0.7)	0.9 (1.3)	0.8 (1.5)
Not used, perceived necessary	1.9 (2.8)	1.6 (2.5)	2.1 (3.0)	1.2 (2.3)	1.8 (2.0)	1.4 (2.3)
COPE Index ¹						
Negative impact (7-28)	15.0 (4.4)	13.9 (3.9)**	14.0 (3.8)	12.5 (4.1)	13.7 (3.8)	12.7 (4.5)
Quality of support (5-20)	12.4 (3.3)	12.5 (3.3)	11.8 (3.0)	12.8 (3.6)	11.7 (3.1)	12.3 (2.9)
Positive value (3-12)	9.6 (1.7)	10.2 (1.6)**	9.7 (1.7)	10.5 (1.1)	10.3 (1.3)	10.6 (1.4)
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Occupational status ³						
Fulltime/part time work	33 (7.8)	11 (4.6)	39 (35.8)	13 (38.2)	125 (54.8)	8 (26.7)**
Retired or other nonworking	389(92.2)	227 (95.4)	70 (64.2)	21 (61.8)	103 (45.2)	22 (73.3)
Living area ²						
Large city	112 (26.5)	63(26.5)	22 (20.2)	5 (14.7)	80 (34.9)	9 (30.0)
Small city	177 (41.9)	116 (48.7)	44 (40.4)	10 (29.4)	89 (38.9)	16 (53.3)
Rural	126 (29.9)	57 (23.9)	42 (38.5)	19 (55.9)	59 (25.8)	5 (16.7)
Not available	7 (1.7)	2 (0.8)	1 (0.9)	-	1 (0.4)	-
Caregiver's perceived health ²						
Very good	8 (1.9)	4 (1.7)	4 (3.7)	4 (11.8)	23 (10.0)	2 (6.7)
Good	65 (15.4)	36 (15.1)	45 (41.3)	11 (32.4)	97 (42.4)	11 (36.7)
Fair	282 (66.8)	163 (68.5)	54 (49.5)	16 (47.1)	89 (38.9)	13 (43.3)
Poor or very poor	67 (15.9)	35 (14.7)	6 (5.5)	3 (8.8)	20 (8.7)	4 (13.3)
Signs of depression ³						
Yes	209 (49.5)	79 (33.2)**	43 (39.4)	11 (32.4)	74 (32.3)	9 (30.0)
No	213 (50.5)	159 (66.8)	66 (60.6)	23 (67.6)	155 (67.7)	21 (70.0)
Lack of interest ³						
Yes	201 (47.6)	79 (33.2)**	36 (33.0)	7 (20.6)	65 (28.4)	8 (26.7)
No	221 (52.4)	159 (66.8)	73 (67.0)	27 (79.4)	164 (71.6)	22 (73.3)
Hours of caregiving/24h ²						
0-4 h	20 (4.7)	15 (6.3)*	27 (24.8)	8 (23.5)	14 (6.1)	6 (20.0)
5-6 h	27 (6.4)	19 (8.0)	12 (11.0)	3 (8.8)	16 (7.0)	1 (3.0)
7-12 h	58 (13.7)	45 (18.9)	22 (20.2)	6 (17.6)	48 (21.0)	2 (7.0)
13-24 h	317 (75.1)	159 (66.8)	48 (44.0)	17 (50.0)	151 (65.9)	21 (70.0)

Gender differences were tested between caregivers within each caregiver group, *p < .05; **p < .01 using the t-test for continuous variables¹, Mann-Whitney test for ordinal variables² and χ^2 -test for categorical variables³.

Table 2. Characteristics of care recipients (CR) whose care is provided by spouse, adult child or parent.

Variable	Spouse as caregiver for the care recipient		Adult child as caregiver for the care recipient		Parent as caregiver for the care recipient	
	Female n=422 Mean (SD)	Male n=238 Mean (SD)	Female n=109 Mean (SD)	Male n=34 Mean (SD)	Female n=229 Mean (SD)	Male n=30 Mean (SD)
Age of care recipient	76 (9.1)	74 (10.5)**	86 (8.3)	83 (9.6)*	23.6 (14.3)	25.3 (14.7)
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Disability of CR³						
Physical weakness	83 (19.7)	49 (20.6)	38 (34.9)	11 (32.4)	4 (1.7)	3 (10.0)
Physical impairment or illness	157 (37.2)	87 (36.6)	28 (25.7)	7 (20.6)	48 (21.0)	4 (13.3)
Dementia	83 (19.7)	57 (23.9)	19 (17.4)	9 (26.5)	1 (0.4)	-
Dementia and other disability	84 (19.9)	32 (13.4)	20 (18.3)	6 (17.6)	1 (0.4)	1 (3.3)
Developmental or psychiatric disability	15 (3.6)	13 (5.5)	4 (3.7)	1 (2.9)	175 (76.4)	22 (73.3)
Physical mobility of CR²						
No difficulties	69 (16.4)	32 (13.4)	8 (7.3)	1 (2.9)	131 (57.2)	17 (56.7)
Some difficulties	105 (24.9)	54 (22.7)	39 (35.8)	14 (41.2)	35 (15.3)	2 (6.7)
Many difficulties	150 (35.5)	93 (39.1)	42 (38.5)	7 (20.6)	37 (16.2)	8 (26.7)
No independent mobility	62 (14.7)	42 (17.6)	16 (14.7)	9 (26.5)	10 (4.4)	-
Completely immobile or bedridden	36 (8.5)	17 (7.1)	4 (3.7)	3 (8.8)	16 (7.0)	3 (10.0)
Cognitive functioning of CR²						
No difficulties	75 (17.8)	45 (18.9)	16 (14.7)	5 (14.7)	60 (26.2)	9 (30.0)
Small difficulties	127 (30.1)	72 (30.3)	36 (33.0)	9 (26.5)	53 (23.1)	11 (36.7)
Difficulties	78 (18.5)	51 (21.4)	26 (23.9)	10 (29.4)	37 (16.2)	4 (13.3)
Many difficulties	88 (20.9)	44 (18.5)	22 (20.2)	4 (11.8)	37 (16.2)	3 (10.0)
No logical thinking	54 (12.8)	26 (10.9)	9 (8.3)	6 (17.6)	42 (18.3)	3 (10.0)

Gender differences tested within each caregiver group, *p < .05; **p < .01 using Mann-Whitney test for ordinal variables² and χ^2 -test for categorical variables³.

Table 3. Regression coefficients, standard errors, p-values and partial eta-squared from a general linear model for caregiver burden of spousal caregivers.

	Female, N=422				Male, N=238			
	B	SE B	p	η_p^2 (%)	B	SE B	p	η_p^2 (%)
Positive value	-.53	.11	<.001	5	-.319	.146	.030	2
Caregiver's perceived health			<.001	5			.591	1
Very good vs. poor	-2.83	1.29	.029	1	-1.58	1.69	.353	0
Good vs. poor	-2.75	.62	<.001	5	-.87	.82	.293	0
Fair vs. poor	-1.62	.46	<.001	3	-.20	.61	.749	0
Signs of depression (not bothered vs. bothered)	-.86	.46	.060	1	-2.52	.60	<.001	8
Lack of interest (not bothered vs. bothered)	-1.92	.45	<.001	4	-.82	.58	.157	1
Cognitive functioning of CR			.011	3			.021	5
No difficulties vs. no logical thinking	-2.05	.64	.001	2	-2.59	.81	.002	4
Small difficulties vs. no logical thinking	-1.54	.56	.006	2	-2.15	.75	.005	4
Difficulties vs. no logical thinking	-1.69	.60	.005	2	-1.38	.77	.077	2
Many difficulties vs. no logical thinking	-.85	.58	.143	0	-1.82	.78	.020	2
Physical mobility of CR			.447	1			.981	0
Without difficulties vs. completely immobile	-.39	.70	.578	0	.04	.97	.965	0
Some difficulties vs. completely immobile	-.59	.66	.368	0	-.33	.89	.711	0
Many difficulties vs. completely immobile	.09	.62	.884	0	-.28	.85	.741	0
No independent mobility vs. Completely immobile	.27	.70	.700	0	-.16	.90	.861	0
Years of education	.18	.05	<.001	3	.05	.06	.333	0
Hours of caregiving/24h			.86	2			.062	3
0-4 h vs. 13-24 h	-1.62	.81	.045	1	-1.00	.87	.262	1
5-6 h vs. 13-24 h	-.34	.71	.630	0	-1.94	.80	.015	3
7-12 h vs. 13-24 h	-.94	.50	.057	1	-.89	.54	.104	1
Quality of support	-.17	.06	.003	2	-.15	.07	.035	2
Services not used, perceived necessary	.17	.06	.006	2	.06	.08	.451	0
Services used, more needed	.04	.13	.761	0	.28	.13	.030	2
Age of Care Recipient	.02	.02	.376	0	-.02	.02	.360	0

η_p^2 , Partial eta-squared

CR, care recipient

Table 4. Regression coefficients, standard errors, p-values and partial eta-squared from a general linear model for caregiver burden of daughter and mother caregivers

	Daughter CG, N=109				Mother CG			
	B	SE B	p	η_p^2 (%)	B	SE B	p	η_p^2 (%)
Positive value	-.29	.21	.185	2	-.77	.16	<.001	11
Caregiver's perceived health			.013	11			.001	7
Very good vs. poor	-6.44	2.24	.005	9	-3.60	1.0	<.001	6
Good vs. poor	-1.54	1.50	.307	1	-1.88	.81	.022	2
Fair vs. poor	-.99	1.46	.499	0	-1.02	.71	.153	1
Signs of depression (not bothered vs. bothered)	-1.73	.84	.044	5	-.16	.63	.805	0
Lack of interest (not bothered vs. bothered)	-1.09	.89	.226	2	-1.05	.63	.098	1
Cognitive functioning of CR			.211	6			.012	6
No difficulties vs. no logical thinking	-2.63	1.39	.061	4	-1.18	.61	.056	2
Small difficulties vs. no logical thinking	-2.53	1.31	.057	4	-.58	.61	.342	0
Difficulties vs. no logical thinking	-2.94	1.40	.039	5	-.85	.67	.204	1
Many difficulties vs. no logical thinking	-1.19	1.25	.345	1	.90	.64	.161	1
Physical mobility			.103	8			.052	4
Without difficulties vs. completely immobile	-.76	2.07	.716	0	-2.22	.76	.004	4
Some difficulties vs. completely immobile	-3.52	1.72	.044	5	-1.77	.86	.041	2
Many difficulties vs. completely immobile	-3.33	1.71	.054	4	-1.50	.84	.074	2
No independent mobility vs. Completely immobile	-3.37	1.78	.062	4	-.94	1.12	.401	0
Years of education	-.07	.10	.456	1	.06	.06	.316	0
Hours for caregiving/24h			.889	1				
0-4 h vs. 13-24 h	-.61	.90	.498	0	-.28	.80	.725	0
5-6 h vs. 13-24 h	-.36	1.07	.741	0	-.47	.76	.539	0
7-12 h vs. 13-24 h	-.53	.84	.527	0	-.42	.48	.374	0
Quality of support	-.23	.12	.044	5	-.22	.07	.002	5
Services not used, perceived necessary	.12	.11	.297	1	.23	.10	.027	2
Services used, more needed	.25	.22	.274	1	.45	.15	.003	4
Age of CR	.04	.04	.286	1	-.02	.02	.195	1

η_p^2 , Partial eta-squared

CR, care recipient