

Family Caregiver Burden of Elderly with Dementia: A Literature Review

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Abstrak : *The majority of the elderly with dementia living in a community have received care from family caregivers with curious complexity of problems to be identified during the care at home. Caregiver burden conceptualized as multidimensional concept encompassing the emotional, physical, and socioeconomic aspects of the impact of caregiving role. This study aims to review articles and journals about the level of burden and characteristics that have an impact on the burden of elderly caregivers with dementia. A literature review with a search for relevant articles was published between 2015-2020 using databases PubMed, Google Scholar, DOAJ, and Oxford Academic Journals. Keywords used to retrieve literature include caregiver burden and dementia. The results is nineteen articles that met the inclusion criteria and were identified in this literature review. Most family caregivers were identified as having a moderate level of caregiving burden that depends on various factors including characteristics of elderly with dementia, sociodemographic characteristics of caregivers, and characteristics of care itself. The conclusion of this, mostly caregivers reported in this review were more likely to experience a moderate level of caregiving burden with the presence of behavior problems, neuropsychiatric symptoms and dependence on daily care in elderly with dementia are the main characteristics that predict the burden.*

Keywords : *Caregiver Burden, Dementia, Elderly Care, Family Caregiver*

INTRODUCTION

According to the 2019 Alzheimer's Global Report, the incidence of dementia is rapidly increasing, and every three seconds there is one new person in the world suffering from dementia. In 2019, 50 million people worldwide suffering from dementia and with increasing life expectancy and an aging population in 2050 that number is expected to increase to 152 million (Bhatt et al., 2019). The majority of people with dementia (PwD) live in a community and receive care from family members and friends (Prince et al., 2016).

Home care provided to the elderly with dementia is a complex phenomenon (Lethin et al., 2020). Despite the many definitions in the literature, caregiver burden conceptualized as a multidimensional concept encompassing the emotional, physical, and socioeconomic aspects of caregiving role, which is unique for each caregiver. Some family members find meaning in their new role as a caregiver but on the other hand, more than 50% of family caregivers worldwide say that their health, work, and social life are disrupted as a result of their caring responsibilities (Bhatt et al., 2019). Current research has shown that caregivers who live and caring for spouses or parents with dementia have higher levels of stress and burden than caregivers of patients with other chronic illnesses (Anand et al., 2016).

Studies associated with caregiver burden have been discussed all over the world. Therefore, the aims of this study to review articles and journals about level of burden and characteristics that affect

the burden on caregivers caring for the elderly with dementia.

METHODS

Search Strategy

A literature review with a search for relevant articles published between 2015-2020 using databases PubMed, Google Scholar, DOAJ and Oxford Academic Journals. A comprehensive search with spesific keywords using the Boolean operators “AND” and “OR” was performed including the MeSH terms.

Table 1. Article Search Keywords

Databases	Keywords	Total
Pubmed	((burden cost [MeSH Terms]) AND (caregivers, family [MeSH Terms])) AND ("dementia"[MeSH Terms])	282
Google Scholar	family burden "caregiver dementia"	350
Oxford Academic Journals	family AND caregiver AND burden AND dementia AND elderly AND home OR house	230
DOAJ	family caregiver burden* OR stress in dementia	153

Inclusion-Exclusion Criteria

The study selection protocol in the literature review uses a PRISMA (Preferred Items for Systematic Review and Meta-Analysis) flowchart describing the conduct of the review by setting out inclusion and exclusion criteria for studies that have been identified and adapted to the topic and subject matter of the literature review with the PEOS (Problem/Population, Exposure/Event, Outcomes, Study Design) framework about family caregiver burden caring for elderly with dementia.

Table 2. PEOS Data Collection Framework

Element	Inclusion Criteria
Population/ Problem	Family caregiver (spousal, relatives, adult child), Informal caregiver taking care of elderly with Dementia/ PwD
Exposure	Dementia giving care
Outcomes	Caregiver burden, caregiver and PwD characteristic
Study Design	Cross-sectional studies, Cohort Study/ , Longitudinal, Quantitative study, Case control study, Preliminary Study

Based on the results of a literature search through four databases Google Scholar, PubMed, Oxford Academic Journals, DOAJ using predetermined keywords and found total of 1,015 articles that matched these keywords, with the number of articles identified by Mendeley Web Importer a total of 986 articles. Then, upon verification of duplication with the Mendeley application, there were 34 duplicate articles, so the articles were excluded and the remaining 934 articles were examined.

Next, the researcher screened the appropriate first stage articles based on the title and abstract (n = 57) and the second stage of the screening of relevant full-text articles (n = 19) met the criteria and objectives of the literature review identified by the researchers.

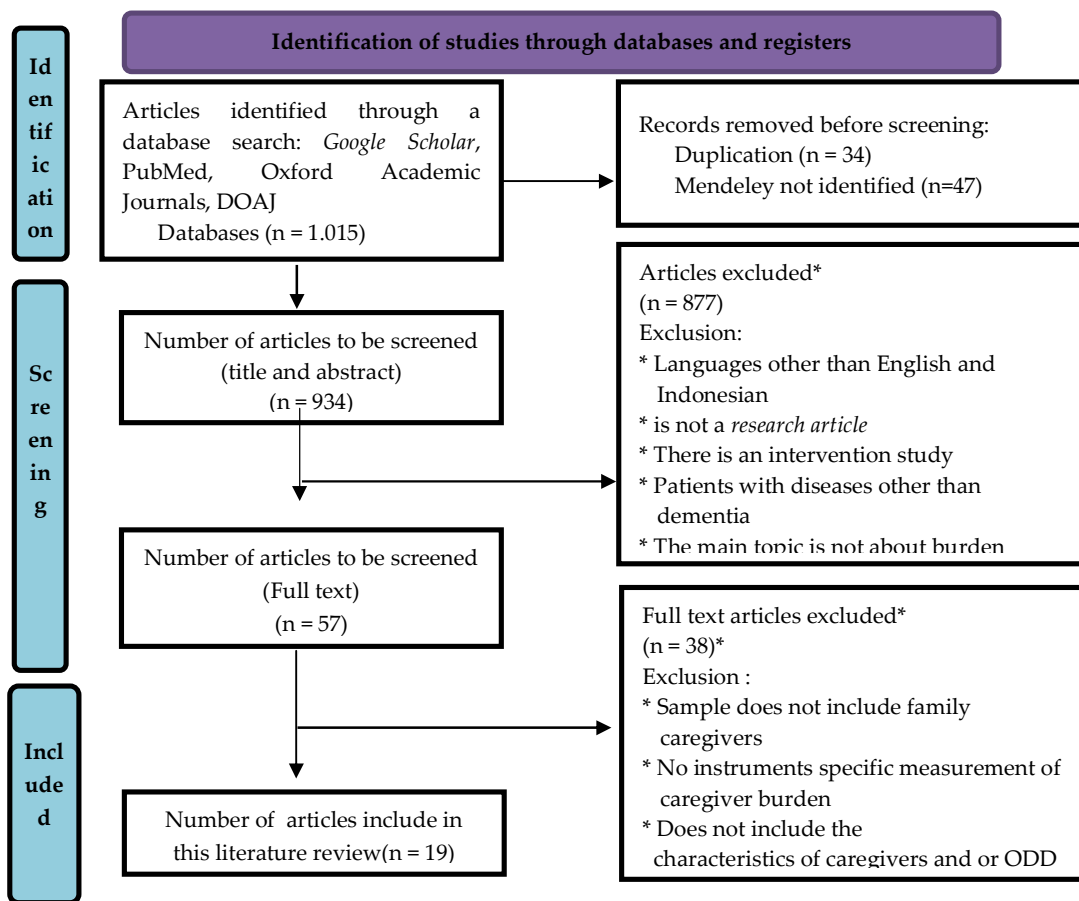


Chart 1. Research Article Selection Flow Diagram

RESULTS

Among the 19 corresponding articles identified in this literature review, 16 articles had a cross-sectional study design and three articles had a longitudinal cohort study. In addition, among 19 studies, Zarit Burden Interview (ZBI) was used by majority in 13 studies with several language version (English and Chinese), four studies used Caregiver Burden Inventory (CBI) and one studies used Relatives Stress Scale (RSS) for the outcome measurement of caregiver burden. The results of this literature review are described by highlighting the findings of several studies from relevant articles and then being resumed according to the results obtained from this review. The results of review in this study is presented in table 3 and Table 4.

Socio-Demographic Characteristics of Caregivers

Respondents in the study were family caregivers who cared for the elderly with dementia. The average age of the caregiver in the research study was 60 years which was classified as older adults with the average age of the elderly with dementia was 75 years. Gender characteristics of family caregivers are predominantly female. The majority of female caregivers were found from all 19 articles reviewed by researchers with an average percentage of female caregivers was 68.70%.

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In eight research studies, it was found that most of the family caregivers lived in the same house or lived close together. The family caregivers are usually spousal (husband/wife), adult children, and other (brother/sister, daughter-in-law, and other relatives). Caregivers who were children of the elderly with dementia became the majority in ten studies. Spousal caregivers also dominated with average percentage of more than 50% in eight studies.

Conditions of the Elderly with Dementia

The elderly in the studies had been diagnosed with dementia for many years, with an average duration of dementia was more than five years (Kowalska et al., 2017; Zhang et al., 2018) and some of them were affected on average within four years. (Besser and Galvin, 2019; Liew et al., 2018). Alzheimer's disease is the most common type of dementia with the highest percentage (Abreu et al., 2020; Connors et al., 2020; Kawano et al., 2020; Win et al., 2017).

The CDR (Clinical Dementia Rating) score used to measure the severity of dementia in the elderly was identified in seven research studies and several looked at the cognitive status through measures of MMSE (Mini Mental State Examination). The average severity of dementia experienced by the elderly in several studies was found to be in the mild to moderate level of dementia (Kawano et al., 2020; Liew et al., 2018; Win et al., 2017). Meanwhile, behavioral problems and neuropsychiatric symptoms experienced by PwD were reported from 10 research studies.

Caregiving Duration

Caregivers have been involved in their roles for an average of 3.6 years with time spent on caregiving is over 70 hours a week (Mougias et al., 2015). Meanwhile, in several studies, it has been observed that caregiving has been provided for more than 4 years (Kowalska et al., 2017; Lou et al., 2015).

Approximately 79.7% of elderly with dementia live with their family caregivers and 18.7% of caregivers perform their caregiving role for at least 17 hours a day (Park et al., 2015). In a study conducted in China, it was also found that caregivers stayed with PwD for more than 8 hours/day (56 hours/week), and more than 90% of the family caregivers lived with the patient (Lou et al., 2015).

Family Caregiver Burden Score and Levels

Overall, out of the 17 cross-sectional studies identified, 12 studies used the ZBI instrument with the majority of the seven research studies reporting burden level score in the moderate range, four studies reporting the burden in the mild range and one study reporting the severe burden. Then, using the CBI (Caregiver Burden Inventory) measurement, it was found that two research studies reported a moderate level of burden and one study reported a high burden. Meanwhile, with measurements of CBS (Caregiver Burden Scale) and RSS (Relatives Stress Scale), each study reported a moderate level of caregiver burden.

Furthermore, in two longitudinal research studies using ZBI and CBI measurements, both reported moderate caregiving burdens with higher burden scores during the research study (Ransmayr et al., 2018; Connors et al., 2020). Therefore, from all the research studies identified in this

literature review, most of these studies reported a moderate level of caregiving burden on family caregivers caring for the elderly with dementia.

Factors Affecting Burden

Characteristic Factors In The Elderly With Dementia

The severity of dementia in the elderly was found to have a relationship with the burden of care (Win et al., 2017; Ransmayr et al., 2018; Liew et al., 2019) with functional and cognitive status has a statistically significant impact with lower levels of cognitive function leading to higher caregiver burden scores (Park et al., 2015; Yu et al., 2015; Connors et al., 2020). In addition, the presence of behavioral and psychological symptoms of dementia has been found to be one of the main contributors to the variance in caregiver burden. (Yu et al., 2015; Park et al., 2015; Svendsboe et al., 2016; Raggi et al., 2015).

The caregiver burden score increases with the increase in the total NPI score, which is associated with specific deficits in neuropsychological tests (Torrise et al., 2017; Ransmayr et al., 2018). In another study among major stressors, higher functional dependence on performing ADLs was identified as being associated with impaired cognitive function in PwD which also increases the burden (Yu et al., 2015; Win et al., 2017). In addition to dementia-related factors, it was also found that comorbidity in the elderly with dementia also contributed to an increase in caregiver burden (Raggi et al., 2015; Leite et al., 2017). A study in Korea significantly reported higher burden scores experienced by caregivers who cared for the elderly with more comorbidities (Park et al., 2015).

Caregiving Factors And Characteristics Of Family Caregivers

Younger caregiver age independently predicts an increased caregiving burden and older caregiver age is associated with lower overall burden (Mougias et al., 2015; Zhang et al., 2018). Moreover, several studies have obtained different results, that there is no significant relationship between caregiver burden scores and caregiver age (Lou et al., 2015; Ransmayr et al., 2018). Greater total CB scores were found among family caregivers who were spouses and reported a significantly higher burden than other family members (Park, et al., 2015; Lou et al., 2015; Win et al., 2017; Zhang et al., 2018; Ku et al., 2019; Connors et al., 2020).

In five research studies it was found that compared to male caregivers, higher burdens were reported on female caregivers (Park et al., 2015; Svendsboe et al., 2016; Ku et al., 2019; Raggi et al., 2015; Besser and Galvin, 2019). The variable duration of caregiving hours is also obtained directly positively related to CBI scores (Yu et al., 2015). In addition, among families with elderly dementia, the better economic status of caregivers (having a lot of money) was found to be the most significant for the lower caregiver burden (Ku et al., 2019) and higher stress and burden were found in the lower income group. (Zhang et al., 2018).

Table 3. The Study Articles Included

No	Authors,Year	Location	Sample	Aim	Design and CB Measures
1	(Zhang <i>et al.</i> , 2018)	China	212 family caregivers of PwD	To find out the level of strain among Chinese caregivers of pwd and that correlation between subjective burden.	Cross-sectional study ZBI
2	(Ransmayr <i>et al.</i> , 2018)	Austria	585 persons caring for PwD	To analyze the burden felt by PwD caregivers in Austria while providing care at home.	Cohort study (Multicenter longitudinal) CBI
3	(Win <i>et al.</i> , 2017)	Singapore	458 Family caregivers	To investigate burden patterns and characteristics of CDOO (Caregivers of Dementia in Oldest Old)	Cross-sectional study ZBI
	(Yu <i>et al.</i> , 2015)	China	200 patients with mild AD , caregivers	To evaluate the direct or indirect factors of the characteristics of PwD or caregivers on CB.	Cross-sectional study CBI
5	(Park <i>et al.</i> , 2015)	South Korea	1133 elderly with AD and their caregivers	To define the major contributors to burden on caregivers of PwD.	Cross-sectional study ZBI
6	(Kowalska <i>et al.</i> , 2017)	Poland	The study group consisted of 58 caregivers	To analyze burden-related factors and determine estimate CB levels of caregivers of PwD.	Cross-sectional study ZBI
7	(Torrise <i>et al.</i> , 2017)	Italy	27 PwD and their caregivers	To know specifically the behavioral and psychological symptoms of dementia that can greatly affect the burden.	Cross-sectional study ZBI
8	(Lou <i>et al.</i> , 2015)	China	310 PwD and their caregivers	To discuss the relationship among caregiver and patient characteristics with CB, depression and anxiety.	Cross-sectional study ZBI
9	(Mougias <i>et al.</i> , 2015)	Greece	161 primary caregivers of PwD	To know the association of patients and caregiver factors with level of CB	Cross-sectional study ZBI
10	(Leite <i>et al.</i> , 2017)	Brazil	92 informal caregivers	Analyzing the socio-demographic characteristics of caregivers and their relationship to the burden.	Cross-sectional study ZBI
11	(Kawano <i>et al.</i> , 2020)	Japan	337 family caregivers of PwD	Investigated the factors influencing the burden to clarify whether positive aspects of the patient had an effect on CB.	Cross-sectional study ZBI
12	(Svendsboe <i>et al.</i> , 2016)	Norway	186 PwD included with their aregivers	To find out the specific challenges of treating people with Dementia with Lewy Body (DLB) and AD.	Cross-sectional study, RSS
13	(Raggi <i>et al.</i> , 2015)	Italy	73 PwD with their caregivers	To identify the coping strategies adopted by family caregivers and the factors that contribute to the burden of PwD.	Cross-sectional study CBI
14	(Connors <i>et al.</i> , 2020)	Australia	720 patients with their caregivers	To identify predictors of burden and describe the burden of long-term care over a 3-year period.	Cohort study (Three year longitudinal) ZBI
15	(Besser and Galvin, 2019)	USA	674 FTD caregivers	To determine the characteristics of caregivers and patients that are related to the care burden domain in FTD.	Cross-sectional study ZBI
16	(Vaingankar <i>et al.</i> , 2016)	Singapore	693 PwD and their informal caregivers	To examine the correlation of caregiver burden and differences based on dementia severity status.	Cross-sectional study ZBI
17	(Abreu <i>et al.</i> , 2020)	Portugal	102 PwD included with their caregiver	To define the correlation between functional dependence of relatives of PwD with psychological distress CB.	Cross-sectional study ZBI
18	(Ku <i>et al.</i> , 2019)	Taiwan	231 PWD Caregiver	To identify variable factors that can ease the burden and compare predictors of cost with care burden.	Cohort study ZBI
19	(Liew <i>et al.</i> , 2019)	Singapore	394 caregivers with	To specify whether there are differences in caregiver burden factors with PDG risk factors.	Cross-sectional study ZBI

Table 4. Results of The Study Articles Included

No	Findings
1	The length of care period was related to the level of burden, while the PwD caregivers in Chinese families experienced high levels of strain and moderate levels of burden.
2	At initial assessment the mean total CBI score was 16. Two years later, the CBIss increased to 22 with 37% of caregivers reporting mild CB, 16.8% moderate or severe CB, and 46.2% little CB.
3	The observed trend is that the closeness of the relationship between the partner and the recipient of the care maybe associated with a higher level of burden on the spouses than on the adult child.
4	Longer caregiving duration and level of cognitive function in patients were simultaneously controlled for other variables associated with CB.
5	The most significant factor of 25.6% burden is dementia-related factors then followed by caregiving related factors.
6	There is a percentage of 93% of the sample of the study group who depend on family assistance to care for PwD with most of the caregivers having a moderate burden.
7	The behavior problems of demented patients are related to burden level. and distress. There is a intense correlation between CBI scores and PwD neuropsychiatric symptoms.
8	Caregiver burden, depression and anxiety were notably correlated with another neuropsychiatric symptoms and connected with caregiving duration.
9	It was independently found that the young age and depression of caregivers, high behavioral symptoms of PwD were associated with burden.
10	Fifty percent of caregivers had moderate overburden, 38% exhibited mild overburden and 12% high overburden.
11	There is a significant relationship of positive influence of dementia patients and different types of dementia with CB level.
12	In the early stages of dementia there is an increased risk of psychiatric disorders with caregivers in AD patients (20.2%) and 40% caregivers in DLB sufferers experiencing moderate to high burdens.
13	The higher levels of cognitive, motor, psychological, and behavioral impairment of patients with AD are associated with increased the burden.
14	CB increases over time in the majority of caregivers. Several characteristics such as caregiver gender, clinical characteristics and patient care level appear to be predictors of burden.
15	The increased of role strain experienced by female caregivers. Burden, role strain, personal and overall performance are associated with neuropsychiatric symptoms in PwD.
16	Significant contributors perceived by informal caregivers are related to high care demands, presence of BPSD and severity of dementia in the elderly.
17	Among the most common Alzheimer's sufferers 35.3% showed moderate debility and 45.1% severe weakness with the majority of family caregivers reporting moderate burden (76.5%).
18	Predictors of cost of care differ from predictors of caregiver burden. Functionality was measured by (KATZ'S ADL) associated with total cost and impaired behavior (NPI).
19	The difference between burden and PDG is evidenced by different risk factor profiles. These risk factors include behavioral problems in PwD, advanced stage dementia, primary care roles.

DISCUSSION

The results of the literature review show that the burden is a common problem faced during caregiving, especially among family caregivers. Family caregivers who continuously care for the elderly can create a burden, considering that dementia has not yet had a specific treatment and its

severity occurs progressively (Prabasari, 2020). The burden of providing care for elderly with dementia is related to the high dependence of PwD (People with Dementia) on their caregivers, leading to a variety of long-term problems (Rezaei et al., 2020).

The prevalence of behavioral disorders, the level of neuropsychiatric symptoms and dependence on care in the elderly with dementia are the main characteristics associated with PwD that most contribute to caregiver burden (Lou et al., 2015; Park et al., 2015; Raggi et al., 2015; Yu et al., 2015; Svendsboe et al., 2016; Ransmayr et al., 2018; Ku et al., 2019; Connors et al., 2020). This effect appears to be driven primarily by disruptive behavior as it causes an adverse impact on the emotional relationship between caregiver and care recipient and exacerbates the difficulties in caring for elderly people with dementia (Jhang et al., 2021).

In fact, caring for people with dementia also means managing symptoms that caregivers of people with other illnesses may not face, such as neuropsychiatric symptoms (e.g., anxiety, apathy, and impaired self-control) and severe behavioral problems (Kim et al., 2021). Characteristic factors related to dementia in the elderly, such as the type and severity of dementia and the duration of dementia experienced by the elderly, were found to have a major impact on the caregiving burden experienced during treatment, independently from other factors (Svendsboe et al., 2016; Win et al., 2017; Ransmayr et al., 2018; Liew et al., 2019; Abreu et al., 2020; Kawano et al., 2020). It is important to note that comorbidity in elderly with dementia and caregiver health status have been identified as factors affecting caregiver burden in this literature review (Park et al., 2015; Raggi et al., 2015; Leite et al., 2017). However, research exploring the burden of caregiving related to morbidity is still limited and further research is needed to explore this issue.

In several studies in this literature review, social support and family function were reported as mediator variables among other factors that influence the burden (Yu et al., 2015; Kowalska et al., 2017). These results demonstrate the importance of providing support to family caregivers as an important step in the care of the elderly community with dementia and can support a more positive caregiving experience.

In addition, findings from the existing literature review also showed that caregiver characteristics were also related to burden of care, specifically the socio-demographic characteristics of caregivers including age, gender, family relationships and co-residence with PwD (Raggi et al., 2015; Lou et al., 2015; Mougias et al., 2015; Park et al., 2015; Svendsboe et al., 2016; Win et al., 2017; Zhang et al., 2018; Ransmayr et al., 2018; Ku et al., 2019; Besser and Galvin, 2019; Connors et al., 2020). Conflicting results for caregiver age with regard to burden were also identified showing that age may not be linearly related to burden but rather to perceptions of caregiving related to other age-influenced factors.

On the other side, it can be seen the kinship relationship between caregivers and the elderly reported in this literature review with the majority of caregivers being adult children, then caregivers who are spouses of the elderly with a higher level of burden are reported (Park, et al., 2015; Lou et al., 2015; Win et al., 2017; Zhang et al., 2018; Ku et al., 2019; Connors et al., 2020). Female caregivers with higher burden were also associated with the tendency for women to spend more time caring for them, taking more care, and taking care of household tasks and activities (Alzheimer's Association, Centers for Disease Control and Prevention, 2020).

While the relationship with the financial burden experienced by family caregivers in this literature review, although family economic status was identified as one of the significant predictors of burden on caregivers (Zhang et al., 2018; Ku et al., 2019). However, further studies are needed in the future to explore more in terms of potential economic factors for families who carry out dementia care for their relatives at home.

Several longitudinal studies included in this review reported an increase in burden over time, that caregivers gradually became overwhelmed by the ongoing care burden with increasing demands on care and time with the development of dementia and severe neuropsychiatric symptoms (Ransmayr et al., 2018; Connors et al., 2020). Longitudinal findings were more mixed for the overall burden trajectory, using baseline and follow-up data for elderly dementia and their caregivers allowing for better evidence of potential predictors of future caregiver burden.

This review has limitations, the first were not critically appraised the 19 included study articles by using any specific instrument and treating all evidence as equally valid. The second limitation concerns with some of the concept of 'burden' was not clearly defined, for example some of the examination using ZBI instrument to measure another variable such as 'stress' and 'depression' and it was difficult to analyze and differed the key outcome when screening process. The characteristics of limitations in this review also include the limitations of each previously published study where the adequacy of the studies included according to the inclusion/exclusion criteria in the methodological procedures described by the researcher.

CONCLUSION

Furthermore, at last the existing literature reveals that the level of caregiver burden can be influenced by various factors. Mostly caregivers reported in this review were more likely to experience a moderate level of caregiving burden with the presence of behavior problems, neuropsychiatric symptoms and dependence on daily care in elderly with dementia are the main characteristics that predict the burden.

The results of this review show that the characteristics of the elderly with dementia (severity and type of dementia, behavioral disorders, neuropsychiatric symptoms, level of dependence on treatment, comorbid illnesses), socio-demographic characteristics of caregivers (age, gender, economic status, status of family relationships and co-residence), and characteristics of care (duration and intensity of care) are factors that affect the caregivers burden. In addition, social support and family function were identified as mediator variables that influence the caregiver's perceived burden.

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