SYSTEMATIC REVIEW

Burden on caregivers of dementia patients and affecting factors in Turkey: A Systematic Review

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Abstract

Objective: To determine the burden on the caregivers of dementia patients and the factors affecting the perception of it.

Methods: The current systematic review was done in Turkey and comprised a search between October 2019 and March 2020 on Turkish and English indices, including the Turkish Academic Network and Information Center database, Web of Science, PubMed, Education Resources Information Centre, Medline, SocINDEX, Cumulative Index to Nursing and Allied Health Literature, PsycINFO, Google Scholar, Ulusal Tez Merkezi, Dergipark and Turk Medline. The key words used were 'Demans','alzheimer','bakım verenler','hastalık yükü','dementia','alzheimer's','caregivers' and 'burden of illness'. Studies included were those having been conducted from 2010 to 2019 and which used the Personal Information Form, the Zarit Caregiver Burden Scale and the Caregiver Burden Inventory.

Results: Of the 4,182 studies initially found, 502(12%) were accessed using Turkish key words, and 3,680(88%) using English key words. Overall, 16(0.38%) studies met the inclusion criteria and were reviewed. There were 2,060 caregivers and 414 patients in these studies. A high number of variables affected caregiver burden. Patient-related variables reported in multiple studies included time spent on caregiving, dementia stage, patient's age and level of patient's dependence.

Conclusion: The most frequently reported caregiver-related variables which increased caregiver burden were being female, younger age, being unemployed, older age, lower education level.

Keywords: Dementia, Alzheimer's, Caregivers, Burden of illness. (JPMA 72:108; 2022)

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Introduction

Dementia is a progressive disease which starts slowly and gradually gets worse. It is an important public health issue. Based on the changes in daily life activities, the disease presentation can vary from age-related forgetfulness, and from mild cognitive impairment to mild, moderate and severe dementia stages. There are 44.4 million dementia patients in the world. Every year 7.7 million patients are added to this figure and the dementia population is expected to be 75.6 million in 2030 and 135.5 million in 2050.[1,2] In Turkey, the incidence of Alzheimer's dementia is 0.4% between the ages of 65 and 69 years, while it reaches 10% at the age of 90. Its prevalence is 2% between the ages of 65 and 69 years, while it reaches 25% at the age of 90.[3] Dementia patients are usually cared for in their homes by their spouses and immediate family members. Studies show that it can be demanding to provide care to dementia patients, and caregivers' health is adversely affected due to various reasons, including caregiver burden, burnout, social isolation, economic problems etc. Many studies found that stress related diseases, like hypertension and stomach disorders, and mental health problems were higher in caregivers of Alzheimer's patients than those who were not caregivers.[4-9]

Patient's level of dependency, disease stage and duration, cognitive and behavioural symptoms and caregiver burnout are factors affecting the perception of burden by the caregivers. To evaluate caregiver burden for chronic diseases, such as dementia, the Caregiver Burden Scale (CBS) was developed in 1980 and the Turkish version of the scale was developed in 2006.[10] The Caregivers Burden Inventory (CBI) was developed in Canada in 1989, and the Turkish version was developed in 2004.[11] Research on determining caregiver burden is an ongoing process. There are sufficient studies on the subject and it is essential that a systematic review is done to avoid redundant research.[12-19]

The current systematic review was planned to determine the variables that can affect caregiver burden of dementia patients, and to facilitate the introduction of specific measures for the caregivers.

Methods

The current systematic review was done in Turkey and comprised a search between October 2019 and March 2020 on Turkish and English indexes, including the Turkish Academic Network and Information Centre (ULAKBİM) database, Web of Science, PubMed, Education Resources Information Centre (ERIC), Medline, SocINDEX, Cumulative Index to Nursing and Allied Health Literature (CINAHL),

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PsycINFO, Google Scholar, Ulusal Tez Merkezi, Dergipark and Turk Medline. The key words used were 'Demans', 'alzheimer', 'bakım verenler', 'hastalık yükü', 'dementia', 'alzheimer's', 'caregivers' and 'burden of illness'. Further search was done using alternative English words, 'Dementia disease', 'dementia patients', 'Alzheimer's disease', 'Alzheimer's patients', 'caregiver', 'caregiving', 'primary caregiver', 'family caregiver', 'family', 'patient relatives', 'caregiver burden', 'care burden', 'burden', 'burden of care', 'Turkey', and alternative Turkish words 'Demans hastalığı', 'demans hastaları', 'alzheimer hastalığı', 'alzheimer hastaları', 'bakım verici', 'bakıcı', 'bakım verme', 'birincil bakım verici', 'aile bakım vericisi', 'aile', 'hasta yakını', 'bakım verici yükü', 'bakım yükü' and 'yük, bakımın yükü'.The studies included were cross-sectional studies conducted in Turkey between 2009 and 2018 and published from 2010 to 2019 with caregivers of dementia patients and compared caregiver burden and other characteristics of caregivers using personal information forms (PIFs) as well as the CBS and CBI tools, and of which full text could be accessed. References of the studies included were used to find other studies. Interventional studies, methodological studies, traditional reviews, systematic reviews and meta-analyses were excluded.

Two researchers independently identified and selected the studies, and any disagreement was discussed to reach consensus.

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guideline were used to develop the review framework.[20] The eligibility criteria for the studies to be included was defined by the Patient-Intervention-Comparison-Outcomes-Study design (PICOS) method, according to which, P = caregivers of dementia patients; I = no intervention; C = comparison of personal characteristics and caregiver burden; O = caregiver burden, related variables; and S = descriptive, cross-sectional, observational.[21]

Methodological quality of the studies was evaluated by one researcher and checked by the other. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist comprising 22 items was used to evaluate the quality of the studies.[22]

Other than PIFs, the Turkish version of CBS, which is a valid and reliable tool,10 was used. Also, CBI11 was used to measure the effect of caregiving on the caregivers.

Since the collected data was not homogenous, no meta-analysis could be performed.

Results

Of the 4,182 studies initially found, 502(12%) were accessed using Turkish key words, and 3,680(88%) using English key words. Overall, 16(0.38%) studies met the inclusion criteria and were reviewed (Figure). Mean STROBE score of the studies was 15.73±2.47 (range: 12-20).

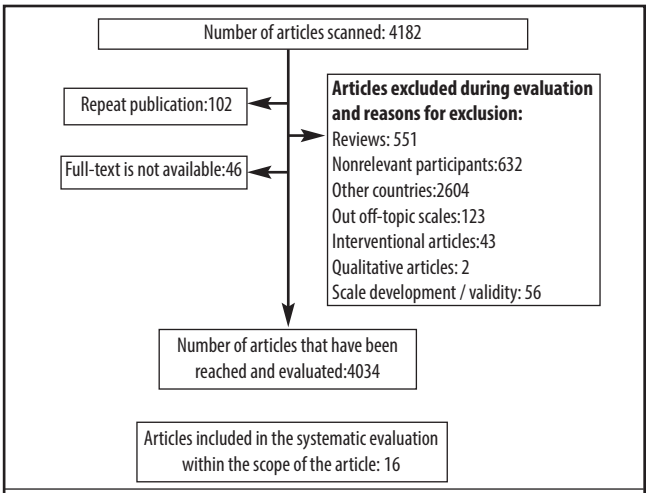

Figure: Flow-chart of the systematic review.

Of the 16 studies, 12(75%%) were articles and 4(25%) were theses. Besides, 6(37.5%) were in English and 10(62.5%) were in Turkish language. The mean time between data collection and publication of the studies was 1.69±1.178" years. However, 3(18.75%) studies did not report the years of data-collection. There were 2060 caregivers and 414 patients in these studies. The studies were conducted in 5 different cities in 4 different regions of Turkey: Aegean 2(12.5%), Marmara 4(49%), Central Anatolia 1(6.25%) and Black Sea 3(18.75%) regions. However, 6(37.5%) studies did not mention the location/city in which the studies were conducted. Research data was collected in hospitals and associations and the sampling size ranged between 82 and 610 (Table 1).

Socio-demographic data of both the patients and the caregivers in the 16 studies was tabulated (Figure 2). Patient-related variables reported in multiple studies included time spent on caregiving, dementia stage, patient's age and level of patient's dependence (Table 2). A high number of variables affected caregiver burden (Table 2).

Discussion

It is possible to reach to some general conclusions based on the findings of the studies included in the current systematic review about the burden on the caregivers of dementia patients and its related factors. Many variables which affect caregiver burden were found in the review. Among patient-related variables, time spent on caregiving, dementia stage, patient's age, and level of patient's dependence were reported in multiple studies (Table 1).

Table-1: Studies included in the systematic review.

Author (Publication Year)	Study Design	Data collection tools	City	Year	Study location	Sampling size	Results
1.Akpınar B., Küçükgüçlü Ö., Yener G. (2011)[23]	Comparative descriptive	Questionnaire Form, Mini-Mental State Examination, Caregiver Burden Inventory, Neuropsychiatric Inventory	Izmir	2009	Hospital, association	192	Women have higher caregiver burden than men Female caregivers have higher time-dependent developmental, physical and social burden.
2. Yacı Ö. (Supervisor: Işın Baral Kulaksızoğu) (2011)[24]	Cross-sectional	For caregivers: Questionnaire Form, Zarit Burden Interview, Beck Depression Inventory For Patients: Neuropsychiatric Inventory, Modified Activities of Daily Living/Instrumental Activities of Daily Living Scale	Istanbul	2010	Hospital	90 caregivers	Caregiver burden increases with advancing stages of Alzheimer's disease. Dependency to perform daily living activities, increased number of neuropsychiatric symptoms, increased intensity of care and daily hours spent on caregiving are factors in the increase in caregiver burden.
3.Çetınkaya F., Karadakovan A. (2012)[25]	Cross-sectional	Caregiver Data Form, Patient Data Form, Caregiver Burden Inventory	–	2008	Hospital, association	305 patients, 305 caregivers	The younger the caregiver is, the higher the caregiver burden. Being a woman, marital status, relationship degree with the patients, occupation, children, time spent on caregiving; patient's gender, age group, disease diagnosis, disease duration, disease stage increase caregiver burden.
4.Çinar E. (Supervisor: Servet Arıoğul) (2012)[31]	–	**For patients:** Mini-Mental State Examination, Clinical Dementia Rating Scale, Modified Activities of Daily Living/Instrumental Activities of Daily Living Scale, Disability Assessment for Dementia Scale, Neuropsychiatric Inventory **For caregivers:** Zarit Burden Interview, Beck Depression Inventory, Beck Anxiety Inventory, Neuropsychiatric Inventory, Symptom Check List-90	Ankara	–	Hospital	60 patients 60 caregivers	With the increase in caregiver burden, anxiety and depression increases. Caregiver burden increases with increasing the level dependency of patients and dementia.
5.Yurtsever S., Özge A., Kara A., Yandım A.,Kalav S., Yeşil P. (2013)[37]	Cross-sectional	Questionnaire Form, Barthel Index, Lawton-Brody index, Multidimensional Scale of Perceived Social Support and Zarit Burden Interview	–	2010	Hospital	107	Married women over 50 years old with a low education level have higher caregiver burden Caregiver burden is higher if the patient is the spouse and dependent on the caregiver
6.Özel-Kızıl E., Altıntaş H. Ö., Baştuğ G., Durmaz N., Altunöz U. (2014)[46]	–	For patients: Mini-Mental State Examination, Cornell Scale for Depression in Dementia For Caregivers: Cohen-Mansfield Agitation Inventory, Informant Questionnaire of Cognitive Decline in the Elderly and Zarit Burden Interview	–	–	–	49 patients 49 caregivers	Agitation frequency is the main factor determining subjective caregiver burden.

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Table-1: *Continued from previous page.*

Author (Publication Year)	Study Design	Data collection tools	City	Year	Study location	Sampling size	Results
7.Erkuran H. (Supervisor: Birsen Altay) (2015)[40]	Descriptive	Questionnaire Form, Zarit Burden Interview, Stress Coping Scale	Samsun	2014	Hospital	120	Female caregivers, caregivers who are unemployed, who have poor sleeping habits, who feel inadequate when providing care to patients and who say that they do not know, how to meet physical needs of patients, who report that caregiving affects their personal lives have higher caregiver burden.
8.Tezcan S.(Supervisor: Ayşe Yıldız) (2017)[29]	Descriptive	Questionnaire Form, The Alzheimer's Disease Cooperative Study - Activities Of Daily Living, Zarit Burden Interview	Istanbul	2013	Hospital, association	82	Caregiver burden of caregivers who are 40 and younger and who are between the ages of 51 and 60 had higher caregiver burden than the others. Caregiver burden increases with the increasing age and advancing stage of the disease of the patient.
9.Eğilli C.S., Sunal N. (2017)[47]	Descriptive	Personal Information Form and Zarit Burden Interview	Istanbul	2015-2016	Hospital	186	The burden of caregivers of patients who are 80 and older is higher.
10.Küçükgüçlü Ö., Akpınar Söylemez B., Yener G., Demir Barutçu C., Akyol M.A. (2017)[11]	Comparative descriptive	Questionnaire Form, Mini-Mental State Examination, Caregiver Burden Inventory, Neuropsychiatric Inventory, Functional Activities Questionnaire	–	2015-2016	Hospital	134	Time dependence burden of caregivers of frontotemporal dementia patients is more than those of the caregivers of Alzheimer's patients. The two factors affecting the burden the most in both groups are the daily activities and neuropsychiatric symptoms of patients.
11.Altay B., Erkuran H., Aydın Avcı İ. (2018)[16]	Descriptive	Questionnaire Form, Zarit Burden Interview	Samsun	2013-2014	Hospital	87	The longer the time spent on caregiving , the higher caregiver burden is. Burden of female and unemployed caregivers are higher.
12.Onat Kaya H., Çelik Y. (2018)[48]	–	Questionnaire Form, Zarit Burden Interview	–	2015-2016	Hospital	100	Mean burden of female caregivers and caregivers with health problems are higher than that of male caregivers.
13 Şentürk SG., Akyol M.A., Küçükgüçlü Ö. (2018)[49]	Descriptive, cross-sectional	Questionnaire Form, Caregiver Burden Inventory Resilience Scale for Adults, Standardized Mini Mental State Test, Blessed Dementia Scale (Blessed ADL1) and Blessed Orientation-Memory-Concentration Test (Blessed ADL2)	–	2016-2017	Hospital	103	Caregiver burden is related to resilience.
14. Uygun KÜ., Taylan H.H. (2018)[26]	Descriptive and explanatory quantitative	Questionnaire Form, Zarit Caregiver Burden Interview	Sinop	2018	Hospital	108	Social burden of caregivers who are 65 years or older is lower and social burden of caregivers between the ages of 25-44 is higher. Female caregivers have higher developmental, emotional and total caregiver burden. Social burden of unemployed caregivers is higher than other participants. Emotional burden is inversely proportional to income.

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Table-1: *Continued from previous page.*

Author (Publication Year)	Study Design	Data collection tools	City	Year	Study location	Sampling size	Results
							As the duration of illness (years spent on caregiving) increases time-dependence, physical and total burden also increase. As the daily average time spent on caregiving increases time-dependence, developmental, physical and total burden also increase.
15.Yıldızhan E., Ören N., Erdoğan A., Bal F. (2019)[30]	Descriptive	Questionnaire Form, Zarit Burden Interview, Maslach Burnout Inventory	Istanbul	2016	Geriatric care facilities	203	Caregiver burden increases with increasing level of burnout. Caregiver burden scores of people between the ages of 31 and 40 are higher than those between the ages of 20-30. Semiliterate caregivers have a higher level of burden than caregivers with other educational levels.
16.Atak T., Özekes M. (2019)[7]	Relational screening model	Questionnaire Form, Caregiver Burden Inventory, Stress Coping Style Scale, Resilience Scale for Adults, Generalized Perceived Self-Efficacy Scale	Izmir	–	Hospital	134	Coping skills and resilience has a negative relationship with caregiver burden.

Table-2: Patient-related factors that increase caregiver burden.

Variable	Number of Research	Number of participants
Length of maintenance	5 (1,2,3,11,14)	1087
Older age	5 (3,8,9,14,15)	1189
Dementia Stage	4 (2,3,4,8)	902
High dependency level	3 (2,4,5)	317
Being a partner	1 (5)	107
The duration of the disease	1 (14)	108
Numerous neuropsychiatric symptoms	1 (2)	90
Agitation of the patient	1 (6)	98

Table-3: Caregiver-related factors that increase caregiver burden.

Variable	Number of Research	Number of participants
Being a woman	6 (1,3,5,7,11,12)	1216
Young age	4 (3,8,14)	800
Not working	3 (7,11,14)	315
Older age	2 (5,8,15)	392
Low education	2 (5,15)	310
Presence of a health problem	1 (12)	100
Weakness of psychological resilience	1 (13)	103
Poor sleep quality	1 (7)	120
Feeling inadequate	1 (7)	120
Think that it affects your life	1 (7)	120
Being married	1 (5)	107
High anxiety	1 (4)	120
Having depression	1 (4)	120
Low income	1 (14)	108
High level of burnout	1 (15)	203
Low coping skills	1 (16)	134

Based on our review, reported that time/hours spent on care increased the burden perceived by the caregivers.[16,23-26] There are studies showing that the length of the care period increases the burden of care.[18,19,27,28] The relationship between caregiver burden and time spent on care found in the studies conducted in Turkey and included in our systematic review shows similarities with international studies.

Also, studies in the current review reported that older age in dementia patients, increased caregiver burden.[25,26,29,30] which is also reported by other studies.[15,17,28] This is thought to be caused by the presence of other concomitant chronic diseases, and decreasing physical fitness with age.

Some studies in the review reported that advancing stage of dementia increased caregiver burden.[24,25,29,31] This was similar to studies in literature.[28,32-35] Fong et al.[4] found that delirium increases the burden of care in elderly adults with Alzheimer's disease, while Mukherjee et al.[36] stated that dementia level affects caregiver distress. Therefore, we may conclude that there are similarities between the findings of the current review and literature. This could be explained by deteriorating cognitive impairment, leading to more communication and motor disorders in the advanced stages of dementia.

In the current review, studies emphasised that higher dependency level increased caregiver burden.[24,25,37] In international literature, some studies found that dependence level of the patient had an effect.[6,15,17,38,39]

The most frequently reported caregiver-related variables which increased caregiver burden in the studies included in the systematic review were being female, younger age, being unemployed, older age, lower education level.

Some studies reported that female caregivers had higher caregiver burden.[16,23,25,37,40] Similarly, Campos-Puente et al. 41 and Yeager et al.[42] reported that gender had an effect on caregiver burden, while other studies emphasised that female caregivers had a higher burden of care.[13,14,18,19] Almost in all societies women assume the role of caregiver because of their social roles that include patient care in addition to care of other family members at home. Therefore, the burden of women who provide care in addition to housework and child care would be higher than that of men, and this will increase their perceived burden.

Also, some studies reported that relatively young groups had higher burden level, and one study emphasised that caregivers who were themselves old as well as caregivers who were aged <40 years had higher burden.[25,26,29] On the other hand, some studies reported that older caregivers had higher caregiver burden.[29,30] In international literature, a study found that younger caregivers had higher caregiver burden.[43] The differences between the studies in the literature and the studies in the current review are thought to be caused by different perception of burden due to different socio-demographic, health and cultural characteristics of the groups.

A couple of studies reported that people with lower education levels perceived higher caregiver burden.[30,37] In international literature, a study[44] found that lower education level was a factor that increased caregiver burden, while another study[45] found that caregivers with higher education level perceived lower level of caregiver burden.[45] Based on these findings, it was concluded that low education level may cause problems in efficient caregiving, problem-solving and coping strategies.

In the current review, some studies found that caregiver burden of unemployed people was high.[16,26,40] No similar finding was found in global literature. However, one study[5] suggested that higher caregiver burden is associated with reduced work productivity. Unemployed caregivers spend a majority of their days with the people they provide care for, and, therefore, this finding is something that should be expected.

The current review has limitations. The research articles included had sample size as low as <150. Additionally, the review only covered studies done with specific inclusion criteria and published in either Turkish or English language. Reports and books on the subject in Turkey, if any, were not included in the current review.

Conclusion

The systematic review found several variables that affect caregiver burden. The most important of these variables include time spent on caregiving, stage of dementia, younger age of patients, higher dependence level, being female caregivers, being a young/old caregiver, being unemployed and having low education level. Based on these findings, protective measures for caregivers are need to reduce the risk.

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