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To cite this article: Clarita Shynal Martis, Rajeshkrishna Panambur Bhandary, Ramesh Chandrababu, Vani Lakshmi R, Panambur Venkataraya Bhandary, Judith Angelitta Noronha, Jyothi Chakrabarty, Debbie Tolson & Elsa Sanatombi Devi (08 Jan 2024): Caring burden and quality of life among the caregivers of people living with dementia – a cross-sectional study in Udupi district of Karnataka, Home Health Care Services Quarterly, DOI: [10.1080/01621424.2023.2301417](https://doi.org/10.1080/01621424.2023.2301417)

To link to this article: <https://doi.org/10.1080/01621424.2023.2301417>



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Published online: 08 Jan 2024.



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Caring burden and quality of life among the caregivers of people living with dementia – a cross-sectional study in Udupi district of Karnataka

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ABSTRACT

Dementia is a chronic disorder of the brain that affects cognitive performance. The caregivers of individuals with dementia experience a greater burden that affects their Quality of Life (QoL). This cross-sectional study conducted in India was designed to assess the caring burden and QoL among the caregivers of people with dementia, as well as to ascertain the relationship between QoL scores and burden. Our sample included 80 caregivers of people with dementia. Most of the caregivers ($n = 59, 73.8\%$) had a higher level of caregiver burden. There was a negative correlation between caregiver burden scores and QoL. A higher level of caregiver stress and low QoL were experienced by caregivers of dementia patients. In developing countries like India, counseling, and education on home health care for people with dementia should be provided to reduce the burden and enhance the QoL of caregivers.

KEYWORDS

Dementia; caregivers; caregiver burden; quality of life

Introduction

A decline in a person's cognitive ability, memory, or decision-making that interferes with a person's day-to-day activities is collectively termed

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Key messages: Caregiving for an individual living with dementia is linked to the caregiver burden and low QOL. To improve the quality of life for caregivers, appropriate programmes to lessen caregiver load or stress should be provided such as continuous education focused on home health care of people with dementia.

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dementia. It refers to a range of conditions that cause abnormal changes in the brain rather than a single disease (Su et al., 2019, 2020; World Health Organization, 2023). Currently, dementia is the seventh most common cause of death among all diseases and a major contributor to disability and dependency among the older people as there are more than 55 million individuals with dementia, and every year, there are about 10 million new cases (Centers for Disease Control and Prevention, 2023; World Health Organization, 2023).

The People Living with Dementia (PLWD) experience effects on their physical, psychological, social, and economic well-being along with family, society, and caregivers. Most older people with chronic illnesses are cared for by their close relatives (Duggleby et al., 2016). When an illness worsens, it necessitates a higher level of care, primarily provided by family members, which results in high medical costs, psychological stress, bad health, social isolation, and financial difficulty (Zacharopoulou, Zacharopoulou, & Lazakidou, 2015). Since they require thorough care depending on the stage of dementia, most of them will be looked after by their family or relatives (Brodaty & Donkin, 2009). It takes at least five hours a day for family caregivers to provide care for a person with dementia, which can be devastating emotionally, physically, and financially and cause stress in both families and carers (World Health Organization, 2023). Reduced execution of daily living tasks by the care recipients is a sign that the caregivers of PLWD are under more stress than before (Kim, Chang, Rose, & Kim, 2011). This leads to poor health of the caregivers' and early institutionalization of PLWD (Etters, Goodall, & Harrison, 2008). Additionally, the caregiver burden is recognized to accompany it among those who provide care (Seidel & Thyrian, 2019).

The caregivers of PLWD bear a heavier strain than other caregivers (Chen et al., 2023; Hu et al., 2023; Lin et al., 2019; Liu et al., 2022). Caregiver burden or stress is an unnoticeable, neglected and untreated or neglected health risk causing bad significance for both carers and individuals with dementia, comprising augmented illness and figures of mortality (Zwerling, Cohen, & Verghese, 2016). Most of them are older women who are also caretakers (Mondal, Tandon, & Dasgupta, 2021). The PLWD w are also impacted by this heavy burden of caregiving on the caretakers. The COVID-19 pandemic caused a greater caregiving load for informal caregivers of PLWD (Otobe et al., 2022).

The underlying cause of dementia affects the strain of providing care as well (Huang, Chang, Wang, & Jhang, 2022). As a result of caring for a person living with dementia, caregivers are more likely to cut back on their free time and interests, spend less time with their loved ones, and even quit their jobs. They frequently refrain themselves off from social interaction and as a result, feel lonely (Brodaty & Hadzi-Pavlovic, 1990). Caregiver health issues are

frequently associated with a significant risk of developing weakened immunity, cardiovascular issues, and chronic diseases including diabetes, hypertension, anemia, arthritis, etc (Brodaty & Donkin, 2009).

Females were shown to have the highest association with caregiver load (Chiari et al., 2021). Giving care to a family member who has dementia is linked to higher caregiving load, depression, and finally poor QoL for the caregiver. There is a strong negative correlation between higher burden in caregiving and lower QoL of PLWD caregivers (Karg, Graessel, Randzio, & Pendergrass, 2018; Romero-Mas, Ramon-Aribau, de Souza, Cox, & Gómez-Zúñiga, 2021). One of the most important factors is the carers' QoL because they care for family members who have dementia and informal caregivers of PLWD have low health-related QoL (Garzón-Maldonado et al., 2017; Hazzan et al., 2022). Caregiving is strongly connected with negative effects on the caregivers' QoL, which is negatively impacted by depressed symptoms. This effect is most frequently noticed when the condition is advanced when the caregiver must provide a great deal of care by closely monitoring the patient, spending a great deal of money on the PLWD medical bills, and is also impacted by the caregiver's chronic sickness (Andreakou, Papadopoulos, Panagiotakos, & Niakas, 2016).

Poor QoL arises from caring for a loved one who has dementia. Female caregivers, older caregivers, and caregivers with the presence of any sort of medical conditions or co-morbidities are additional risk factors for poor QoL of the caregivers (Andreakou, Papadopoulos, Panagiotakos, & Niakas, 2016). When compared with younger informal carers, older PLWD caregivers had a lower QoL (Conrad, Alltag, Matschinger, Kilian, & Riedel-Heller, 2018). This may be caused by concerns about the future, the progression of the disease, the stress and illness of the patient, and it may be influenced by several factors affecting both the carers and care recipients (Vellone, Piras, Talucci, & Cohen, 2008; Vun, Cheah, & Helmy, 2020). This paper discusses the baseline findings of an interventional study directed at caregivers of PLWD focusing on the caregiver and their QOL.

Objectives

The objectives of the study were: (i) to assess the caring burden and QoL among those who provide care for PLWD, (ii) to find the correlation between the caregiver burden and the QoL among the caregivers of PLWD, (iii) and to find the association between caregiver burden and the baseline demographic variables among the caregivers of PLWD.

Participants and methods

To determine the caregiver burden and QoL among carers of PLWD, a descriptive cross-sectional study design was used. The Head of the Institution, Medical Superintendent, Medical Director, and Administrative Officer of the chosen institutions provided administrative permits for the study's execution, and the caregivers provided written informed consent. The ethics committee gave their approval (IEC 776/2019) to the study protocol, which is also listed with the Clinical Trial Registry of India CTRI/2020/02/023362.

The sample size was determined at a 5% level of significance with suitable adjustments to facilitate multiple comparisons, 80% power and an anticipated correlation of 0.4, the minimum sample size required for the study to explore the relationship between the caregiver burden and QoL among caregivers of PLWD is 71.

$$n = \left(\frac{Z_{(1-\frac{\alpha}{2})} + Z_{(1-\beta)}}{0.5 * \ln\left(\frac{1+r}{1-r}\right)} \right)^2 + 3$$

The researcher developed a baseline demographic questionnaire. It included information about the age, gender of the caregiver, their relationship to the patient, and the duration of care they had given. The Zarit Burden Interview (ZBI) – 22, a 22-item Likert scale scoring from 0 to 4 with 0 Never, 1-rarely, 2-sometimes, 3-quite regularly, and 4-Near always, was used to quantify the burden of the caregiver. The ZBI-22 is further separated into two domains: role strain (2, 3, 6, 11–13) and personal strain (1, 4, 5, 8, 9, 14, 16–21). No domain included items 7, 10, 15, and 22. Greater caregiving stress in the study is indicated by higher scores. They were divided into four levels based on the participant's score. The scores between 0 and 21 were categorized as little or no burden, 22 to 40 as mild to moderate burden, 41 to 60 as moderate to severe burden, and 61 to 88 as severe profound burden. It has a good reliability with Cronbach's alpha of 0.92 For ZBI-22, there is one additional category for total scoring. Scores of 0 to 21 indicate no burden, while 22 to 80 indicate the presence of a burden (Lin, Ku, & Pakpour, 2017; Tripathi, Srivastava, Tiwari, Singh, & Tripathi, 2016).

The standard World Health Organisation Quality of Life Brief Version (WHOQOL BREF) questionnaire, which has 26 items, was used to measure the overall QoL. It has four domains namely the physical health domain, psychological health, social relationships, and environmental domain. This tool has a good test-retest reliability of 0.66–0.84 for each of the four domains (Lin et al., 2019; Lin, Li, Lin, & Chen, 2016; Tripathi, Srivastava, Tiwari, Singh, & Tripathi, 2016). Both tools were offered in English and the regional language Kannada. The necessary authorities granted permission for the usage of the

tools in both the local Kannada language and English. Permission to use ZBI-22 was obtained online from MAPI trust and permission to use the WHOQOLBREF scale was obtained from the WHO site. The ZBI and WHOQOL-BREF were extensively utilized in studies on caregivers of dementia patients to evaluate their burden and QoL. As a result, the researcher decided to use the same scales. Both Kannada and English versions of the data collecting tools were given, based on the interests of the study participants.

The formal and informal caregivers between the ages of 18 and 70 who understood Kannada or English were recruited from selected hospitals in the Udupi District. Before recruiting the study participants, administrative approval was sought from the medical superintendent, department heads, and administrative officials. The institutional research committee and institutional ethics committee gave their approval to the project.

The caregivers were selected from the designated hospitals since most of them visit the psychiatric OPD for follow-up and consultation with their relatives suffering from dementia. After screening the caregivers to meet the inclusion criteria, the Principal Investigator explained the study procedure to the caregivers and obtained the informed consent. Before being enrolled in the study, participants were given a Participant Information Sheet with comprehensive information about the investigation. Details about the study, including its title, goals, lead investigator's name, length of the trial, questionnaires utilized potential hazards and benefits, etc., were included on this participant information sheet. The study's subjects were only chosen after providing written consent. The study's participants' privacy and confidentiality were always maintained.

Data analysis

To establish the baseline demographics of the caregivers of dementia patients, descriptive statistics using frequency tables and percentages were used. Spearman's correlation analysis was performed to determine the correlation between the ZBI and QoL scores. The Chi-square test was performed to investigate the association between baseline demographic factors and caregiver burden. Jamovi (2.3.24), a graphical user interface for R programming and Microsoft Excel were used to conduct the statistical analysis.

Results

Eighty caregivers out of 110 met the requirements for inclusion. There was only one male caregiver out of the total participants recruited. The average age of the caregivers was 46 ± 12.7 . Most of the carers ($n = 44$, 55%) were home-makers ($n = 66$, 82.5%), provided care for 2–4 hours each day ($n = 48$, 60%),

Table 1. Baseline characteristics of caregivers of PLWD n = 80.

<i>Baseline characteristics of caregivers of PLWD</i>			
Baseline characteristics	Category	(n)	(%)
Age in years	Up to 45 years	45	56.2
	More than 45 years	35	43.8
Sex	Male	1	1.20
	Female	79	98.8
Caregivers' education	Below graduation	44	55.0
	Graduation & above	36	45.0
Occupation	Homemaker	66	82.5
	Private sector work	2	2.50
	Owning business	12	15.0
Monthly family income	≤30000 INR	46	57.5
	Above 30,000 INR	34	42.5
Marital status	Married	73	91.2
	Unmarried	2	2.50
Relationship to the person with dementia	Widow/widower	5	6.2
	Spouse	15	18.8
	Daughters in law	46	57.5
	Daughter	15	18.8
	Son	1	1.20
Area of living	Others	3	3.75
	Urban	8	10
	Semi-urban	19	23.8
	Rural	53	66.2
Duration of care giving in years	Up to 4 years	45	56.2
	Above 4 years	35	43.8
Hours of active care per day	Up to 2 hours	32	40.0
	2–4 hours	48	60.0
Presence of chronic illness in caregiver	Present	37	46.2
	Absent	43	53.8
Receiving support in giving care	Supported	44	55.0
	Not supported	36	45.0

n – total number; (%) = percentage; PLWD – people living with Dementia.

and lived in rural areas ($n = 53$, 66.3%). (Table 1). Daughters-in-law were the majority ($n = 46$, 57.5) in terms of relationship to the care recipient whereas there were few other caregivers (Son –1, Cousin 1, Neice-1, Home nurse-1)

The majority of PLWD were females ($n = 48$, 60%), over 70 years old ($n = 57$, 71.3%), were in-laws ($n = 46$, 57.5%) to the caregivers, were suffering from Alzheimer's disease ($n = 39$, 48.8%), were chronic alcoholics ($n = 16$, 20%), chronic smokers ($n = 14$, 17.5%), and tobacco chewers (smokeless tobacco users) ($n = 5$, 6.3%). (Table 2).

Table 3 describes the ZBI and QoL scores split down by domain. While the mean QoL score was 45.9 ± 13.9 , and the mean ZBI score was 63.40 ± 16.99 (Table 3). Most of the carers ($n = 59$, 73.8%) reported feeling extremely burdened when caring for the dementia patient (Figure 1). We discovered a negative correlation ($r = -0.370$, $p < .05$) between caregiver burden and QoL ratings.

Based on the Mann-Whitney U test at a 5% level of significance, we conclude that there is a statistically significant difference in the QoL scores across two levels of hours of care, caregiver burden and two levels of education. A similar phenomenon is also observed in the context of the presence of chronic illness among caregivers as depicted in Table 4.

Table 2. Baseline characteristics of PLWD. *n* = 80.

<i>Baseline characteristics of PLWD</i>			
Baseline characteristics	Category	(<i>n</i>)	(%)
Age	Up to 70 years	23	28.8
	More than 70 years	57	71.2
Sex	Female	48	60
	Male	32	40
Relationship to the caregiver	In-law	46	57.5
	Others	34	42.5
Years of dementia	Up to 5 years	62	77.5
	More than 5 years	18	22.5
Type of Dementia	Alzheimer's Dementia	39	48.8
	Vascular Dementia	3	3.8
	Fronto-temporal lobe Dementia	1	1.2
	Alcoholic Dementia	3	3.8
	Moderate Dementia	3	3.8
	Advanced Dementia	14	17.5
	Others	17	21.2
	Past habit of	Alcohol intake	16
History of	Tobacco eating	5	6.2
	Smoking	14	17.5
	Surgeries in the past	22	27.5
	Past head injury	5	6.2

n – total number; (%) = percentage; PLWD – people living with Dementia.

Table 3. Domain wise caregiver burden scores and quality of life scores of the caregivers of PLWD. *n* = 80.

Domain	Mean	Standard deviation	Minimum score	Maximum Score
ZBI Scores				
Personal Strain (0–48)	34.09	9.43	9	48
Role Strain (0–24)	17.11	5.33	1	24
Total ZBI scores (0–88)	63.40	16.99	14	84
QoL domain scores				
Physical health (0–100)	37.97	15.72	6	81
Psychological (0–100)	46.26	14.66	19	88
Social relationships (0–100)	60.15	14.75	31	100
Environment (0–100)	39.10	17.61	6	81
Total QoL scores	45.9	13.9	20.5	84.5

*ZBI – Zarit Burden Interview; QoL – Quality of life.

Discussion

The purpose of this study was to evaluate the QoL and caregiver burden among PLWD caregivers. Out of 80 samples, there was just one male caregiver in the study. Because men locally who are relatives of PLWD go to work to provide for their families and because their wives, daughters, or daughters-in-law typically take care of their parents, it was not possible to recruit a significant number of male carers for this study. Most of the time, a person's daughter-in-law, wife, or daughter took care of them. The study is contradicted by a Taiwanese study that reported that poor activities of daily living and being a son were associated with a greater level of burden among caregivers (Tsai et al., 2022).

Burden Level of Caregiver Burden

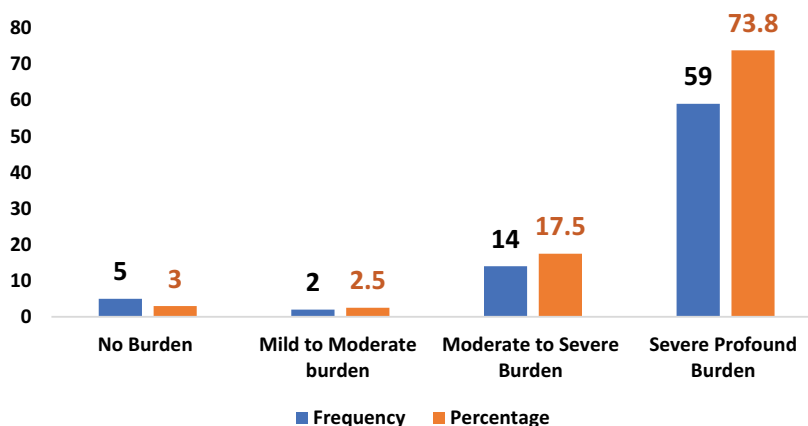


Figure 1. Level of caregiver burden among the caregivers of PLWD.

Table 4. Role of socio-demographic variables on caregiver burden and quality of life of caregivers $n = 80$.

Outcome	Socio-demographic variable	Mean (SD)	Median (IQR)	p-value
Hours of caring per day				
Caregiver burden	Up to 4 hours	58.8 (21.8)	66.5 (32.8)	0.331
	More than 4 hours	66.5 (12.2)	67.0 (11.0)	
⁺ QoL	Up to 4 hours	53.7 (14.8)	54.0 (17.63)	<0.001
	More than 4 hours	40.6 (10.5)	39.1 (5.06)	
Presence of chronic illness among caregivers				
Caregiver burden	Suffering with chronic illness	61.9 (18.8)	66.0 (12.0)	0.553
	Not suffering from chronic illness	65.1 (14.7)	68.0 (16.0)	
[#] QoL	Suffering with chronic illness	49 (15.3)	47 (21.75)	0.027
	Not suffering from chronic illness	42.3 (11.3)	40.8 (6.50)	
Educational qualification among the caregivers				
[#] Caregiver burden	Below Pre university level	67.1 (13.0)	68.0 (14.3)	0.041
	Above Pre university level	58.9 (20.1)	66 (29.3)	
[#] QoL	Below Pre university level	43 (12.8)	40.8 (11.8)	0.044
	Above Pre university level	49.4 (14.5)	43.9 (22.0)	
Habit of tobacco chewing among the caregivers				
Caregiver burden	Tobacco chewing	68.0 (15.1)	67.0 (13.0)	0.426
	Not chewing tobacco	63.1 (17.2)	67.0 (14.5)	
[#] QoL	Tobacco chewing	36.9 (4.56)	40.8 (17.25)	0.004
	Not chewing tobacco	46.5 (14.1)	36.0 (6.50)	
History of past surgeries to the person with dementia				
[#] Caregiver burden	No past surgeries	60.9 (18.6)	66.0 (18.0)	0.005
	Had surgeries previously	70.1 (9.34)	68.5 (12.8)	
QoL	No past surgeries	47.0 (14.2)	40.8 (18.2)	0.348
	Had surgeries previously	42.9 (13.0)	43.0 (15.4)	

⁺- Significant at 5% based on Mann-Whitney U test; SD – Standard deviation; IQR – Inter-Quartile Range; [#] - Significant at 5% based on Welch's t; QoL-Quality of life..

It is noteworthy that daughters-in-law made up the majority of ($n = 46$, 57%) carers for PLWD. This could be a result of Indian tradition, which generally involves parents residing with their offspring, particularly their son and daughter-in-law. Men often provide for their families

through work, therefore the wife, who is typically the daughter-in-law of the individual living with dementia, will be responsible for the family and other domestic duties. As a result, daughters-in-law assume the role of their in-laws' informal caregivers as they get older because most males work to support the family. However, due to changes in the family system, there are some situations where the wife or daughter will provide care (Herat-Gunaratne et al., 2019).

Most ($n = 66$, 82.5%) of the caregivers were homemakers, and two caregivers were working in the private sector where one was a paid caregiver, and the other one was the son who was living and taking care of his mother and the only breadwinner in the family. Along with caring for their loved one with dementia, a small number of caregivers ($n = 12$, 15%) owned businesses that included agriculture, tailoring, and horticulture such as cultivating jasmine flowers, areca nut cultivation, and cultivating coconut plantations where they could add income for their family expenses.

In the current study, the majority (73.8%) of the caregivers experienced severe profound burden, while 17.5% experienced moderate to severe burden. This finding is supported by few studies (Liu, Heffernan, & Tan, 2020; Settineri, Rizzo, Liotta, & Mento, 2014; Tsai et al., 2021; Tulek et al., 2020; Zarit, Reever, & Bach-Peterson, 1980). Duration of caring could be one factor leading to burden as the majority ($n = 48$, 60%) of the caregivers spent at least 2–4 hours per day in the patient's activities such as giving a bath, giving back massage, taking the patient for a walk, feeding, etc whereas few ($n = 32$, 40%) of the caregivers spent only up to 2 hours in patient the activities. This study discovered a negative correlation between the WHOQOL-BREF scores and ZBI scores, indicating that as the burden increases, there is a decline in the QOL. The results are corroborated by a prior study done in India that evaluated the caregiver burden and QoL among PLWD carers that and discovered a negative relationship between the Zarit Burden ratings and QoL (Tripathi, Srivastava, Tiwari, Singh, & Tripathi, 2016).

In the current study, the majority ($n = 59$, 73.8%) of the caregivers experienced severe profound burden, while few ($n = 14$, 17.5%) caregivers experienced moderate to severe burden. These findings are supported by a few studies published earlier where caregivers of PLWD experienced a severe burden (Liu, Heffernan, & Tan, 2020; Settineri, Rizzo, Liotta, & Mento, 2014; Tsai et al., 2021, 2022; Tulek et al., 2020; Zarit, Reever, & Bach-Peterson, 1980). Duration of caring could be one factor leading to burden as majority ($n = 48$, 60%) of the caregivers spent at least 2–4 hours per day in patient's activities such as giving a bath, giving back massage, taking the patient for a walk, feeding, etc whereas few ($n = 32$, 40%) of the caregivers spent only up to 2 hours in patient activities. This is also supported by a study done in Spain which reported a negative

correlation between the duration of caring and QoL (Romero-Mas, Ramon-Aribau, de Souza, Cox, & Gómez-Zúñiga, 2021).

This study discovered a negative correlation between the WHOQOL-BREF scores and ZBI scores ($r = -0.370$, $p < .05$), indicating that as the burden increases, the QoL decreases. The results are corroborated by a prior study that evaluated the caregiver burden and QoL among PLWD carers in India and discovered a negative relationship between the Zarit Burden ratings and QoL (Tripathi, Srivastava, Tiwari, Singh, & Tripathi, 2016).

We found a significant association between the caregivers' QoL, and the hours of care given per day to the PLWD. This finding is also supported by a Spanish study that reported a negative correlation between the duration of caring and QoL.

Limitations

Due to the smaller sample size of caregivers of PLWD, the results of this current descriptive cross-sectional study cannot be directly applied to represent a larger population of caregivers of PLWD compared to the previous research studies.

Most of the caregivers in this study were females. Females and males may have different levels of QoL and psychological health. Therefore, the findings could not be generalized to male participants.

Future implications

According to the results of this descriptive cross-sectional survey, caring for a person with dementia can be strenuous. The socio-demographic profile and psychological characteristics of the carer are the key contributors to the burden of caring. Appropriate interventions such as home health care education, awareness camps, self-help groups, and community help groups are recommended to decrease the burden and improve QoL. Research studies with a bigger sample size could be conducted by healthcare professionals, especially nurses, doctors, and counselors for early detection of caregiving stress that could prevent future indications of depression or mental instability among caregivers to reduce caregiver burden and improve the QoL.

Conclusion

The study results reveal a higher caregiving burden and low QoL among caregivers of PLWD. These findings are an eye-opener as they strongly suggest implementing measures to reduce caregiver burden to enhance the QoL of the

caregivers of PLWD. The healthcare providers must periodically evaluate the caregiver burden among those who care for PLWD to provide interventions such as education on home health care of PLWD, stress reduction interventions, awareness programs, and self-help groups, that can lessen the burden and improve the QoL.

Abbreviations

QOL	Quality of life
PLWD	People living with dementia
ZBI	Zarit Burden Interview
OPD	Outpatient departments

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The author(s) reported there is no funding associated with the work featured in this article.

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