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# Caregivers' awareness regarding the care of dementia and the coping strategies among the caregivers of people with dementia: a cross-sectional study in Udupi District, Karnataka

**Original article**

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**Abstract:** **Objectives:** To assess the awareness and coping skills of the informal and formal caregivers of people living with dementia (PLWD). Dementia is a condition, which leads to memory loss and gradual deterioration of cognitive abilities in the affected person. The lack of awareness regarding the care of people with dementia and the caregivers' poor coping strategies can negatively impact caregivers' experiences.

**Methods:** A cross-sectional survey was conducted among the 80 caregivers of PLWD from the psychiatric units of the selected hospitals of Udupi district, Karnataka, India. The baseline data were collected by a self-reported sociodemographic questionnaire. The "Dementia Knowledge Assessment Scale" was used to gauge participants' awareness of the care of people with dementia, while the "Brief COPE inventory," a 28-item questionnaire, was used to gauge carers' coping mechanisms. Descriptive and inferential statistics were used for the data analysis using Jamovi (2.3.24), a graphical user interface for R programming, and Microsoft Excel.

**Results:** Most of the caregivers (n = 68, 85%) had lesser awareness regarding the care of people with dementia. The mean coping strategies score was $60.9 \pm 7.71$. There was a positive correlation between the awareness and the coping strategies scores among the caregivers ($r = 0.659$, $P < 0.05$).

**Conclusions:** The caregivers of people with dementia often lack awareness about dementia and hence experience poor coping due to their high workload and stress. The frontline healthcare professionals and nurses need to provide appropriate interventions to the caregivers to improve their awareness about dementia and its care.

**Keywords:** *awareness • caregiver • coping • coping strategies • dementia care • dementia • knowledge*



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# 1. Introduction

Dementia is the collective term for a progressive decline in memory, thinking ability, or the capacity to make decisions that affect a person's everyday activities.[1] It happens due to various illnesses and damages that either directly or indirectly impact the brain such as Alzheimer's disease. According to the World Health Organization (WHO), >55 million people worldwide have dementia, and there are about 10 million new cases every year.[2] Being the seventh top source of death among all other diseases and being one of the major causes of disability and reliance among the elderly, it has physical, psychological, social, and economic impacts, not only on the person affected but also on their caregivers, family, and society.[2]

For progressive illnesses such as dementia, family carers need to respond to complex and palliative care needs.[3] Since they require special care based on their level of dementia, the majority of them will be looked after by their family or relatives.[4] Care for older persons with chronic illnesses is often provided by close relatives.[5] Family caregivers of people living with dementia (PLWD) often have poor awareness about the underlying disease or dementia progress.[6] Due to this, there is stigmatization and a hurdle toward early detection and care.[2] Understanding dementia is crucial for the early recognition of signs and symptoms, reducing the strain of caregiving, and planning education for the general public and caregivers.[7] In the coming decades, there will be an increase in the rates of dementia worldwide resulting in a high demand for awareness and skilled dementia caregivers across the globe.[8]

Caregivers of PLWD hold a vital role in providing support and full-time care to the person living with the disease.[9] They often have poor understanding of what dementia is, and lack an understanding of the care aspects with deficient skills according to the patient's needs.[10–14] A caregiver's inability to make a reasonable decision for the care recipient is a commonly encountered problem with their limited awareness of the prevalence, causes, symptoms of dementia, and person-centered approaches to be adopted in the care of these patients. Being a spouse caregiver and having a low level of education were major risk factors for knowledge deficiencies identified.[13,15–17]

In terms of coping among caregivers, the dysfunctional ways of thinking and coping when giving care were associated with the caregiver's advanced cardiovascular health. A significant negative relationship between caregivers' awareness about dementia and systolic blood pressure mediated by caregivers' dysfunctional thoughts and experiential avoidance was noted.[18]

Information about the early signs of dementia was extremely poor among the older adults and caregivers of PLWD.[19] The majority of the caregivers of PLWD needs support and more information about the disease to reduce their strain and to improve their caregiving and quality of life.[20] Having adequate awareness and attitude about dementia care are the key factors in providing excellent care for individuals living with dementia.[21] Hence, this study aimed to assess the knowledge and coping strategies among the caregivers of PLWD and their coping strategies and to find the correlation between knowledge and coping strategies if any.

# 2. Methods

## 2.1. Design and setting

A descriptive cross-sectional survey design was adopted for this study. All the study participants were recruited from the Out Patient Departments (OPDs) of the selected hospitals in Udupi district. The period of data collection was 16 months, from January 2021 to May 2022. Before recruiting study participants, administrative approval was sought from the medical superintendent, department heads, and administrative officials. This paper discusses the baseline findings of secondary outcome variables of an interventional study directed at caregivers of PLWD aiming on the caregivers' and their quality of life (QOL).

## 2.2. Study participants

The inclusion criteria for study participants were (i) male and female formal and informal caregivers of PLWD from the selected hospitals of the Udupi district (ii) between 18 years and 70 years, (iii) who can read, understand, read, and write Kannada or English language, (iv) caregivers who have been with the person living with dementia by giving care for >3 months.

The exclusion criteria were (i) the caregivers caring for a person with dementia for <3 months, (ii) <18 years and >70 years of age, (iii) residing outside the Udupi district, and (iv) those who were not willing to provide consent for the study.

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 knowledge and coping strategies, among caregivers of PLWD is 71.

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

## 2.3. Study variables

This study included age, sex, educational qualification, current occupation, family income per month, presence of any illness, years of care, and hours of care per day. The baseline clinical details of the individuals living with dementia were collected by a structured baseline clinical pro forma (Table 1). Details such as age, sex, educational qualification, previous occupation, final diagnosis, presence of any comorbidities, and history of traumatic brain injury were collected after obtaining consent from the legal authoritative representative of the individual living with dementia. The research variables were knowledge and coping strategies.

The caregivers' awareness of dementia was evaluated using the "Dementia Knowledge Assessment Scale (DKAS)," a standardized scale with 25 items. The DKAS is a reliable, valid measure of dementia awareness assessment with a ($r$ = 0.85) reliability score.[22] It is a 5-point Likert scale with responses as (a) true, (b) probably true, (c) false, (d) probably false, and (e) I do not know. This scale has 4 subdomains (i) causes and characteristics, (ii) communication and behavior, (iii) care considerations, and (iv) risk and health promotion. Based on Bloom's Taxonomy, the knowledge scores were categorized as low level (0%–59%; scores 0–29), moderate level (60%–79%; scores 30–39), and high level (80%–100%; scores 40–50).[23]

The coping strategies were assessed using the Coping Orientation to Problems Experienced Inventory (Brief COPE Inventory) developed by Carver in 1997. This standardized Likert scale contains 28 items with responses as (1) I have not been doing this at all, (2) I have been doing this a little bit, (3) I have been doing this a medium amount, and (4) I have been doing this a lot. The scale is divided into 3 domains: (i) emotion-focused coping—10 items, (ii) problem-focused coping—6 items, and (iii) dysfunctional coping—12 items. The total score of the Brief COPE inventory is 112. The range of scores for the domain emotion-focused coping was 10–40, problem-focused coping was 6–24, and dysfunctional coping was 12–48.[24,25] The Brief COPE had a 0.71 reliability score. The permission to use DKAS and Brief COPE was obtained from appropriate authorities. All the questionnaires were translated into Kannada (local) language for those caregivers who did not follow English.

| Baseline characteristics and category | Frequency (f) | Percentage (%) |
|---|---|---|
| *Age (years)* | | |
| <70 | 23 | 28.8 |
| >70 | 57 | 71.2 |
| *Gender* | | |
| Women | 48 | 60 |
| Men | 32 | 40 |
| *Years of dementia* | | |
| ≤5 | 62 | 77.5 |
| >5 | 18 | 22.5 |
| *Type of dementia* | | |
| Alzheimer's disease | 39 | 48.8 |
| Vascular dementia | 3 | 3.8 |
| Fronto-temporal lobe dementia | 1 | 1.2 |
| Alcoholic dementia | 3 | 3.8 |
| Moderate dementia | 8 | 10 |
| Advanced dementia | 14 | 17.5 |
| Others | 12 | 15 |
| *Habits* | | |
| Alcohol consumption | 16 | 20 |
| Tobacco chewing | 5 | 6.2 |
| Smoking | 14 | 17.5 |
| *History of past surgeries* | | |
| Past surgeries | 22 | 27.5 |
| Head injury | 5 | 6.2 |

*Note*: PLWD, people living with dementia.

**Table 1.** Baseline characteristics of PLWD (N = 80).

## 2.4. Data collection procedure

Since most of the caregivers visit the psychiatry outpatient department for the consultation and follow-up of their relative living with dementia, the caregivers were selected from the selected hospitals. Before recruiting study participants, administrative approval was sought from the medical superintendent, department heads, and administrative officials. After identifying caregivers from the psychiatry OPD of the selected hospitals, the investigator collected information regarding caregivers visiting OPD for consultation or follow-up. The investigator explained the study procedure to the participants and provided a participant information sheet (PIS). A PIS containing detailed information about the study was given to the study participants before including them in this study. This PIS consisted of details regarding the study, title, objectives, name of the principal investigator, duration of the study, questionnaires used, and any risks or benefits. Only after obtaining written informed consent from the study participants, the participants were selected for this study. The anonymity and confidentiality of the study participants were maintained throughout the study process.

## 2.5. Data analysis

Descriptive statistics with frequency tables and percentages were utilized to define the baseline demographics

of PLWD caregivers. Spearman's correlation analysis was performed to determine the correlation between the DKAS and the Brief COPE scores. The chi-squared test was performed to investigate the association between baseline demographic factors and caregivers' awareness of dementia. The statistical analysis was carried out using Jamovi (2.3.24), a graphical user interface for R programming, and Microsoft Excel.

### 2.6. Ethical considerations

The study has received approval from the institutional ethics and research committees and is listed with the Clinical Trial Registry of India (CTRI/2020/02/023362). This study was approved by the ethics committee of Kasturba Medical College and Kasturba Hospital Institutional Ethics Committee (KMC & KH IEC; IEC approval number: 776/2019). All the research investigators complied with the ethical considerations of the Declaration of Helsinki.

## 3. Results

Out of 110 caregivers, 80 met the inclusion criteria. Among the 80 caregivers, 79 were females. The mean age of the caregivers was 46 ± 12.7 years. Most of the caregivers had up to XII grade educational level (n = 44, 55%) and majority were homemakers (n = 66, 82.5%), had family income of rupees 30,000/month (n = 46, 57.5%) and were giving care to their in-laws (n = 46, 57.5%), giving active patient care for 2–4 h/day (n = 48, 60%), and living in rural region (n = 53, 66.3%; Table 2).

Among the PLWD, the majority were women (n = 48, 60%), aged >70 years (n = 57, 71.3%), with Alzheimer's disease (n = 39, 48.8%); were chronic alcoholic (n = 16, 20%); were chronic smokers (n = 14, 17.5%); and were tobacco chewers (n = 5, 6.3%; Table 1).

The domain-wise knowledge scores and coping scores are described in Table 3. The mean knowledge score was 19.59 ± 6.77, while the mean coping score was 60.90 ± 7.70. The mean score for emotion-focused coping was 23.0 ± 4.99, the mean score for problem-focused coping was 12.60 ± 5.94, and the mean score for dysfunctional coping was 25.30 ± 4.10. Majority (n = 68, 85%) of the caregivers had a low level of awareness of dementia, whereas a few (n = 12, 15%) had a moderate level of awareness of dementia (Figure 1). Based on Bloom's Taxonomy, the DKAS scores were categorized as low level (0%–59%; 0–29), moderate level (60%–79%; 30–39), and high level (80%–100%; 40–50).

A statistically significant positive correlation was observed between the knowledge and the coping strategies scores ($r$ = 0.659, $P$ < 0.05; Table 4).

Based on the Mann–Whitney $U$ test at the 5% level of significance, we found that there is a statistically significant difference in knowledge scores across two levels of hours of care. A similar comparable phenomenon is the context of coping (Table 5).

| Baseline characteristics and category | Frequency (f) | Percentage (%) |
|---|---|---|
| *Age (years)* | | |
| <45 | 45 | 56.2 |
| >45 | 35 | 43.8 |
| *Gender* | | |
| Male | 1 | 1.2 |
| Female | 79 | 98.8 |
| *Educational background* | | |
| Up to XII grade | 44 | 55 |
| Above XII grade | 36 | 45 |
| *Current occupation* | | |
| Homemaker | 66 | 82.5 |
| Private service | 2 | 2.5 |
| Own business | 12 | 15 |
| *Family income per month (rupees)* | | |
| Up to 30,000 | 46 | 57.5 |
| >30,000 | 34 | 42.5 |
| *Marital status* | | |
| Married | 73 | 91.2 |
| Unmarried | 2 | 2.5 |
| Widow/widower | 5 | 6.2 |
| *Relationship to the care recipient* | | |
| Wife | 15 | 18.8 |
| Daughters-in-law | 46 | 57.5 |
| Daughter | 15 | 18.8 |
| Son | 1 | 1.2 |
| Others | 3 | 3.75 |
| *Place of living* | | |
| Urban | 8 | 10 |
| Semi-urban | 19 | 23.8 |
| Rural | 53 | 66.2 |
| *Years of caring* | | |
| <4 | 45 | 56.2 |
| >4 | 35 | 43.8 |
| *Duration of caring per day* | | |
| Up to 2 h | 32 | 40 |
| 2–4 h | 48 | 60 |
| *Suffering from chronic illness* | | |
| Yes | 37 | 46.2 |
| No | 43 | 53.8 |
| *Support in giving care* | | |
| Given support in caring | 44 | 55 |
| Not given support in caring | 36 | 45 |

*Note*: PLWD, people living with dementia.

**Table 2.** Baseline characteristics of caregivers and PLWD (N = 80).

# 4. Discussion

A condition like dementia deserves person-centered care. Family caregivers are often unaware of the sort of

| Domain | Mean | SD | Minimum score | Maximum score |
|---|---|---|---|---|
| *Knowledge domain scores* | | | | |
| Causes and characteristics (0–14) | 6.80 | 2.78 | 2 | 14 |
| Communication and behavior (0–12) | 3.85 | 2.49 | 0 | 10 |
| Care considerations (0–12) | 4.34 | 2.31 | 0 | 10 |
| Risk and health promotion (0–12) | 4.60 | 2.67 | 0 | 12 |
| Overall knowledge scores (0–50) | 19.59 | 6.77 | 10 | 36 |
| *Coping strategies scores* | 23 | 4.99 | 16 | 34 |
| Emotion-focused coping (10–40) | | | | |
| Problem-focused coping (6–24) | 12.60 | 5.94 | 6 | 24 |
| Dysfunctional coping (12–48) | 25.30 | 4.10 | 18 | 33 |
| Total scores (28–112) | 60.90 | 7.70 | 48 | 80 |

*Note*: DKAS, Dementia knowledge Assessment Scale; PLWD, people living with dementia; SD, standard deviation.

**Table 3.** Knowledge scores and coping strategies scores of the caregivers of PLWD (N = 80).

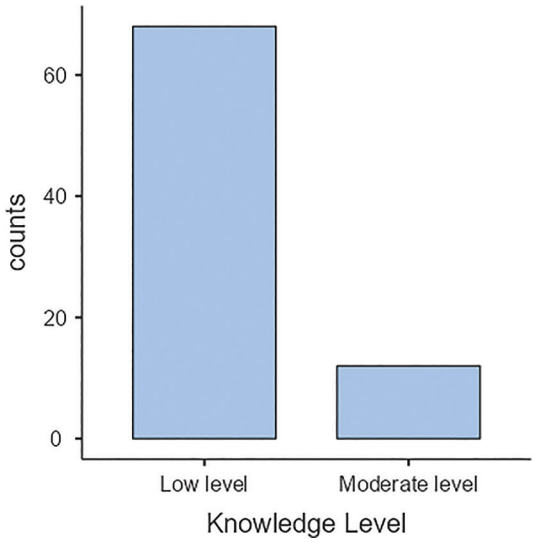


**Figure 1.** Knowledge level among the caregivers (N = 80).

| Variables | Knowledge | Coping |
|---|---|---|
| Knowledge | - | |
| Coping | 0.659* | - |

*Note*: PLWD, people living with dementia;
*Statistically significant at $\alpha = 5\%$.

**Table 4.** Correlation between knowledge and coping strategies among the caregivers of PLWD (N = 80).

| Outcome | Sociodemographic variable | Mean (SD) | Median (IQR) | *P*-value |
|---|---|---|---|---|
| Hours of care | | | | |
| | *Knowledge** | | | <0.001 |
| | Up to 4 h | 24 (6.64) | 23.5 (12) | |
| | >4 h | 16.7 (5.13) | 16.0 (8) | |
| | *Coping#* | | | <0.001 |
| | Up to 4 h | 66.9 (7.68) | 67.0 (10.75) | |
| | >4 h | 56.9 (4.42) | 57.5 (5.50) | |
| Caregiver education | | | | |
| | *Knowledge* | | | 0.139 |
| | XII and below | 18.4 (5.98) | 17.0 (7.25) | |
| | Above XII grade | 21.0 (7.47) | 19.5 (12.50) | |
| | *Coping#* | | | 0.006 |
| | XII and below | 58.7 (5.96) | 58.5 (6.50) | |
| | Above XII grade | 63.6 (8.77) | 64.5 (13.50) | |
| Chronic illness among caregivers | | | | |
| | *Knowledge* | | | 0.456 |
| | Chronically ill | 20.2 (7.18) | 18.0 (8.0) | |
| | Not chronically ill | 18.9 (6.31) | 18.0 (9.0) | |
| | *Coping#* | | | <0.001 |
| | Chronically ill | 62.5 (8.01) | 62.0 (12.0) | |
| | Not chronically ill | 59.1 (7.01) | 58.0 (5.0) | |

(*Continued*)

**Table 5.** Continued

| Outcome | Sociodemographic variable | Mean (SD) | Median (IQR) | *P*-value |
|---|---|---|---|---|
| Family income | | | | |
| | *Knowledge* | | | 0.251 |
| | ≤30,000 rupees per month | 18.7 (5.94) | 18.0 (8.75) | |
| | >30,000 rupees per month | 20.8 (7.69) | 19.0 (11.50) | |
| | *Coping#* | | | <0.001 |
| | ≤30,000 rupees per month | 59.0 (6.68) | 58.0 (10.3) | |
| | >30,000 rupees per month | 63.5 (8.31) | 61.5 (12.8) | |
| Brief COPE—Emotion-focused coping | | | | |
| | *Caregivers' education** | | | <0.001 |
| | XII and below | 21.2 (3.84) | 20.0 (6.0) | |
| | Above XII grade | 25.2 (5.37) | 26.0 (8.0) | |
| | *Monthly income** | | | <0.009 |
| | ≤30,000 rupees per month | 21.7 (4.30) | 20.0 (7.50) | |
| | >30,000 rupees per month | 24.8 (5.37) | 26.0 (8.0) | |
| | *Hours of care given per day#* | | | <0.001 |
| | Up to 4 h | 26.9 (4.54) | 28.0 (4.5) | |
| | >4 h | 20.4 (3.27) | 20.0 (4.0) | |
| | *Chronic illness among caregivers** | | | <0.029 |
| | Chronically ill | 24.1 (4.99) | 26.0 (9.0) | |
| | Not chronically ill | 21.7 (4.74) | 20.0 (6.0) | |
| Brief COPE—Problem-focused coping | | | | |
| | *Caregivers' education** | | | 0.004 |
| | XII and below | 10.7 (4.57) | 9.50 (5.25) | |
| | Above XII grade | 14.9 (6.64) | 14.0 (13.75) | |
| | *Hours of care given per day** | | | <0.001 |
| | Up to 4 h | 17.72 (5.78) | 18.0 (8.50) | |
| | >4 h | 9.19 (2.76) | 8.0 (3.25) | |
| | *Chronic illness among caregivers** | | | 0.017 |
| | Chronically ill | 14.1 (6.11) | 14.0 (10.0) | |
| | Not chronically ill | 10.9 (5.31) | 9.0 (4.0) | |
| Brief COPE—Dysfunctional coping | | | | |
| | *Caregivers' education#* | | | <0.001 |
| | XII and below | 26.8 (3.64) | 27.0 (5.25) | |
| | Above XII grade | 23.4 (3.90) | 23.0 (5.25) | |

*Note*: COPE, coping orientation to problems experienced; IQR, inter-quartile range; SD, standard deviation; *Significant at 5% based on Mann–Whitney *U* test; #Significant at 5% based on Welch's *t*.

**Table 5.** Role of sociodemographic variables on knowledge scores and coping strategies scores (N = 80).

care or the level of care they must provide due to a lack of awareness and expertise. In addition, their awareness about community resources is also poor leading to poor health, inadequate and suboptimal utilization of these kinds of resources.[26] Having adequate awareness about dementia and its care aspects is necessary for a caregiver to give quality care to the PLWD. The purpose of this study is to assess the awareness of care for dementia and the coping strategies among caregivers of PLWD, to ascertain the relationship between the awareness of dementia and coping; and to find out the association between the demographic factors among those who provide care for PLWD.

In comparison with gender, we could find only one male caregiver out of 80 participants as most of the caregivers of PLWD were women who were either the wives, daughters, or daughters-in-law of the person with dementia. A similar study conducted in India revealed only 2 male caregivers out of 41 caregivers of PLWD.[27]

Studies in the past have shown that women spent more time in providing care and get engaged more in personal-care tasks when compared with men. Along with this, they also find that women caregivers experience more mental and physical strain, greater caregiver burden, and elevated levels of psychological agony while providing care.[5,28,29] We strongly propose that awareness programs for women at various levels of the community be organized to educate them to adopt the role of a family caregiver.

Among all the other types, Alzheimer's dementia was found to be more prominent (n = 39, 48.8%) among the majority of the PLWD. This is strongly supported by research.[1,2,30]

Among the caregivers, most of them (n = 53, 66.3%) were from rural areas, had education up to 12th grade (n = 44, 55%), and were homemakers (n = 66, 82.5%). This could be the main reason why most caregivers have low awareness of dementia, which is also supported by a study done in China where the available data suggested a correlation between a low level of awareness of dementia and low level of education, and having a rural background probably having limited access to educational facilities.[15]

Most of the caregivers (n = 68, 85%) had a low level of awareness of dementia. These findings are in line with the results of the previous studies conducted in the Netherlands and in the United Kingdom, where the caregivers expressed a lack of understanding about dementia when caring for a person with dementia.[15,31,32]

We found a positive correlation between the scores for DKAS and Brief COPE, which suggests a positive correlation between the awareness of dementia and the coping strategies ($r = 0.659$, $P < 0.05$). The study is supported by a previous study done in the United Kingdom, where the researchers found a significant association between monitoring coping style, service knowledge ($r = 0.38$, $P = 0.04$), and coping knowledge ($r = 0.29$, $P = 0.04$), blunting coping style and service knowledge ($r = 0.37$, $P = 0.01$).[33] However, we did not find any studies supporting this using the DKAS and Brief COPE scales.

We found a statistically significant difference in the knowledge and coping strategies scores across two levels of hours of care given per day ($P < 0.001$). A similar phenomenon was observed in the context of emotion-focused coping and in the other domains of coping across caregivers' educational level, monthly income, hours of care given to the care recipient per day, and the presence of chronic illness among the caregivers. We found one study done among Vietnamese caregivers contradicting our results, which reported that educational qualification was not found to be correlated with any domains of coping strategies.[34]

## 4.1. Strengths

To our knowledge, this is the first cross-sectional study done in South Karnataka, India, to assess the caregivers' dementia care awareness and the coping strategies.

## 4.2. Limitations

Due to the smaller sample size of caregivers of PLWD, the results of this current descriptive cross-sectional study can not be directly applied to represent a larger population of caregivers of PLWD compared to the previous research studies. Females were a majority in number; hence, the results cannot be generalized to male caregivers as male and female caregivers may have different levels of coping strategies.

## 4.3. Future implications

The results of this descriptive cross-sectional survey suggest that caregivers often lack knowledge about dementia and its care aspects. A few of the caregiver characteristics, such as low educational status and residing in a rural area without proper educational and healthcare amenities, are major contributors to poor knowledge leading to poor coping styles. The researchers recommend interventions such as conducting home-based educational programs and awareness programs at various levels of the community to educate caregivers and the general public on dementia.

## 5. Conclusions

There was less awareness of the care of people with dementia. This study suggests educating caregivers about dementia and its care aspect can help in improving their coping strategies when providing care. An educational intervention such as community health programs, home-based care, and awareness programs conducted by healthcare professionals can also improve caregivers' knowledge of dementia. Research studies with the involvement of more frontline health professionals such as nurses, doctors, and counselors are likely to provide more insights for educating the caregivers on dementia thereby and improving their coping strategies. These interventions will certainly alleviate stress levels while providing optimal care and eventually contribute toward improving the quality of life for both PLWD and their caregivers.

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## Ethical approval

The study has received approval from the institutional ethics and research committees and is listed with the Clinical Trial Registry of India (CTRI/2020/02/023362). This study was approved by the ethics committee of Kasturba Medical College and Kasturba Hospital Institutional Ethics Committee (KMC & KH IEC; IEC approval number: 776/2019). This paper discusses the baseline findings of secondary outcome variables of an interventional study directed at caregivers of PLWD aiming at the caregiver and their QOL.

## Conflicts of interest

All contributing authors declare no conflicts of interest.

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