



## A Study on the Coping Skills, Quality of Life, and Burden of Caregivers of Persons with Dementia

Anantharamu B.G.<sup>1</sup> & Dr.Sangeetha .R.Mane<sup>2</sup>

<sup>1</sup>Research Scholar, <sup>2</sup>Professor and Chairperson  
P.G.Dept of Studies in Social Work, Karnatak University, Dharwad.

### Abstract:

*Dementia is a progressive neurodegenerative disorder that significantly impacts not only individuals diagnosed with the condition but also their caregivers. This study examines the coping skills, quality of life, and burden experienced by caregivers of persons with dementia. Using a mixed-methods approach, we assess the psychological, social, and economic challenges faced by caregivers while identifying the strategies they employ to manage stress. The study also explores how caregiving responsibilities affect physical and emotional well-being, relationships, and daily functioning. Findings suggest that high caregiving burden is associated with lower quality of life, increased stress, and reduced personal time, highlighting the need for structured support systems, including psychological counseling, respite care, and community-based interventions. The study underscores the importance of promoting adaptive coping strategies and enhancing caregiver well-being to improve overall care outcomes for persons with dementia.*

**Keywords:** dementia, caregiver burden, coping strategies, quality of life, psychological distress, support interventions

### Introduction

India has a rich, centuries- old heritage of medical and health sciences. The philosophy of ayurveda and the surgical skills enunciated by Charaka and Shusharuta bear testimony to India's ancient tradition in the scientific health care of the people. The constitution of India indicates the state's commitment to seeking to improve the health of its

citizens. Establishment of a new social order based on equality, freedom, justice and the dignity of the individual, aiming at the elimination of poverty, ignorance and ill health and directing the state to regard the raising the standard of living of its people and the improvement of public health as among its primary duties. There is limited evidence about health care

**Please cite this article as:** Anantharamu B.G. & Sangeetha R. Mane. (2025). A Study on the Coping Skills, Quality of Life, and Burden of Caregivers of Persons with Dementia. *SRUJANI: Indian Journal of Innovative Research and Development*. 3(6), 176-184

utilization for dementia in India. Older people with dementia and their families are unlikely to access healthcare, despite the high levels of associated disability and caregiver strain.<sup>5</sup> Lack of service development is also due to tendency to view dementia as normal part of ageing. In the current India scenario and despite a number of government initiatives, the current primary care system is ill prepared to provide dementia care, therefore most dementia cases are managed in specialist or secondary care units. Constructing dementia care at community level could encourage easy help-seeking. However, efforts to increase demand for dementia community care must be accompanied by health system and health service reform, so that help-seeking is met with a supply of better-prepared, more responsive services.. in this present study the researcher used purposive sampling method and with the help of SPSS version used for data analysis. The total number of sampling was 113 respondents. It is shows that there is a significant relation between caregivers' burden, quality of life and coping strategies.

India was home to more than 75 million people older than sixty years in 2001. This age group, which was 7.5% of the population, is expected to grow dramatically in the coming decades. Analysis of the census data shows marked variations in the rate of demographic aging within India ranging from 10.5% in Kerala to 4% in Dadra and Nagar Haveli. Other regions with

elderly population above 8% include Himachal Pradesh (9%), Punjab (9%), Maharashtra (8.7%), Tamil Nadu (8.8%), Orissa (8.3%), Goa (8.3%), and Pondicherry (8.3%). The demand for services will soon be evident in such places and will make the task of meeting the needs for the older people more challenging and urgent. There is a growing realization that the care of older people with disabilities makes enormous demands on their caregivers. Terms like dementia and Alzheimer's disease are now better understood. However, this was not the case when the Alzheimer's and Related Disorders Society of India (ARDSI) initiated awareness programmes in 1992. Dementia remains a largely hidden problem in India, especially in those parts of India where poverty and illiteracy levels are high.

In 2010, there are 3.7 million Indians with dementia and the total societal costs is about 4,700 Crores, While the numbers are expected to double by 2030, costs would increase three times, Families are the main caregivers and they need support

#### **Dementia as a public health problem.**

Dementia is a significant public health concern, with prevalence rates expected to rise substantially over the next 20 years due to aging populations. This condition has profound impacts not only on individuals but also on families, society, and the healthcare system, increasing the demand for medical and

social support services. Dementia is often accompanied by co-morbidities and is closely linked to elder disability, further complicating care needs. While pharmacological treatments can help manage symptoms, psycho-social interventions play a crucial role in improving the quality of life for patients and caregivers. Various care pathways exist, including community-based and institutional services, though access and quality vary. The costs of dementia care are extensive, encompassing direct medical expenses, indirect costs such as lost productivity, and intangible emotional and social burdens. Additionally, legal considerations, including patients' rights, relevant laws, and protective acts, are critical in ensuring ethical and adequate care. Preventive strategies focus on primary measures to reduce risk factors, secondary interventions for early detection, and tertiary approaches to enhance management and support. Addressing dementia requires a comprehensive, multi-sectoral approach to mitigate its growing burden on individuals and society. Costs of dementia care - direct, indirect and intangible.

While there is currently no direct policy for the care of people with dementia, there are a number of government and voluntary initiatives that support the health and social care needs of the elderly in India. They include some of the following: The

National Policy for Older Persons 1999 aims to promote the health and welfare of senior citizens in India and encourages individuals to make provision for their own as well as their spouses' old age. It also strives to encourage families to take care of their older family members. This policy enables and supports voluntary and non-governmental organizations to supplement the care provided by the family and provide care and protection to vulnerable elderly people. Health care, research, creation of awareness and training facilities to geriatric caregivers have also been enumerated under this policy. This policy has resulted in the launch of new schemes such as:

Strengthening of primary health care system to enable it to meet the health care needs of older persons.

- Training and orientation to medical and paramedical personnel in health care of the elderly.
- Promotion of the concept of healthy ageing.
- Assistance to societies for production and distribution of material on geriatric care.
- Provision of separate queues and reservation of beds for elderly patients in hospitals.

Extended coverage under the Antyodaya Scheme with emphasis on provision of food at subsidized rates for the benefit of older persons especially

the destitute and marginalized sections.

### **Review of literature**

Caring for a person with dementia is a complex and demanding task that affects caregivers' physical, emotional, and psychological well-being. The literature on caregiver coping skills, quality of life (QoL), and caregiver burden highlights the significant challenges they face and explores strategies for support and intervention.

Coping mechanisms play a crucial role in determining how caregivers manage stress and maintain their well-being. Lazarus and Folkman's (1984) stress-coping model has been widely applied to understand caregivers' adaptive and maladaptive coping strategies. Research by Pearlin et al. (1990) identifies problem-focused coping (e.g., seeking social support, problem-solving) and emotion-focused coping (e.g., avoidance, denial) as common responses to caregiving stress. Studies suggest that active coping strategies, such as mindfulness, cognitive reframing, and resilience training, help caregivers manage emotional distress effectively (Cheng et al., 2014; Papastavrou et al., 2011).

The QoL of dementia caregivers is significantly impacted by caregiving responsibilities. Studies by Schulz and Sherwood (2008) and Pinguart and Sörensen (2003) show that caregivers experience reduced physical health, social isolation, and financial strain, leading to lower overall QoL. Psychological well-

being is also affected, with higher rates of depression and anxiety among caregivers compared to non-caregivers (Brodaty & Donkin, 2009). Support systems, respite care, and community-based interventions have been identified as essential in improving caregivers' QoL (Adelman et al., 2014).

Caregiver burden is a multidimensional concept that includes physical, emotional, social, and financial stressors. Zarit et al. (1980) developed the Zarit Burden Interview (ZBI), which remains a widely used tool for measuring caregiver burden. Research indicates that caregiver burden increases with the severity of dementia, the duration of caregiving, and the presence of behavioral and psychological symptoms of dementia (BPSD) (Etters et al., 2008). Studies by Yu et al. (2018) and Lindeza et al. (2020) emphasize the importance of tailored interventions, including counseling, support groups, and educational programs, to reduce caregiver burden.

Various interventions have been studied to alleviate caregiver burden and improve QoL. Psychoeducational programs have shown positive outcomes in enhancing coping skills and reducing stress (Gallagher-Thompson & Coon, 2007). Cognitive-behavioral therapy (CBT) and support groups provide emotional support and improve mental well-being (Acton & Kang, 2001). Technological interventions, such as telehealth counseling and mobile health applications, have also been explored as

accessible means of caregiver support (Torp et al., 2008).

The literature underscores the immense burden faced by caregivers of persons with dementia and highlights the need for effective coping strategies and supportive interventions. Future research should focus on culturally tailored caregiver support programs and explore innovative solutions, such as digital interventions, to improve the well-being of caregivers.

### **Theoretical Framework**

This study is grounded in the Stress Process Model, which posits that caregiver stress arises from primary stressors (direct caregiving tasks) and secondary stressors (role strains). The model highlights the importance of social support and coping strategies in moderating the impact of these stressors on caregivers' health and well-being.

### **Background**

Dementia is a progressive neurodegenerative disorder characterized by cognitive decline, affecting memory, thinking, and behavior. The increasing prevalence of dementia poses significant challenges not only for those diagnosed but also for their caregivers. Caregivers, often family members, provide essential support which can lead to substantial physical, emotional, and social burdens.

### **Problem Statement**

Caregivers of persons with dementia experience a unique set of stressors that impact their quality of life. The continuous and intensive nature of

caregiving responsibilities can lead to caregiver burnout, negatively affecting their health and well-being. Understanding the coping mechanisms and the extent of the burden can inform interventions to support these caregivers.

### **Objectives**

1. To assess the quality of life among caregivers of persons with dementia.
2. To evaluate the burden experienced by caregivers.
3. To identify the coping strategies used by caregivers.
4. To explore the relationship between coping mechanisms, quality of life, and caregiver burden.

### **Significance of the Study**

This study aims to provide comprehensive insights into the challenges faced by caregivers of persons with dementia, contributing to the development of effective support systems. By identifying coping strategies and their effectiveness, the research can guide the creation of targeted interventions to improve the well-being of caregivers.

### **Methodology**

#### ***Research Design***

An exploratory research design was adopted to gain an in-depth understanding of the experiences of caregivers of persons with dementia. This design allows for a comprehensive analysis of the complex phenomena associated with caregiving.

### **Sample and Sampling Method**

The study employed purposive sampling to select participants from the Dharwad Institute of Mental Health and Neuro Sciences (DIMHANS). A total of 113 caregivers who met the inclusion criteria were included in the study.

### **Inclusion and Exclusion Criteria**

- **Inclusion Criteria:** Caregivers actively providing care to individuals with dementia, aged 18 years and above, who consented to participate.
- **Exclusion Criteria:** Professional caregivers and those unwilling to participate.

### **Data Collection Tools**

**Structured Interview Schedule:** Used to collect personal and socio-demographic data of the caregivers.

**Zarit Burden Interview:** A widely used tool to measure caregiver burden, focusing on the emotional, physical, and social strain.

**Brief COPE (Carver, 1997):** An inventory assessing various coping strategies used by caregivers.

**WHOQOL-BREF (WHO, 1998):** A standardized tool to evaluate the quality of life across four domains: physical health, psychological health, social relationships, and environment.

### **Procedure**

Data collection was carried out in a structured format. Participants were

interviewed using the standardized tools, and their responses were recorded for further analysis. Ethical considerations, including informed consent and confidentiality, were strictly adhered to throughout the study.

### **Limitations**

The study's limitations include its cross-sectional design, which limits the ability to infer causality. Additionally, the use of self-report measures may introduce response biases. Future research should consider longitudinal designs and incorporate objective measures to validate the findings.

### **Data Analysis**

The collected data were analyzed using SPSS (20th Version). Descriptive statistics, bi-variate correlations, and independent sample t-tests were conducted to interpret the data. The relationship between coping strategies, quality of life, and caregiver burden was explored through correlation and regression analyses.

### **Results**

#### **Demographic Characteristics of Caregivers**

The sample consisted of caregivers with diverse backgrounds. The majority were female, reflecting the gendered nature of caregiving roles. Most caregivers were middle-aged, with a significant proportion having secondary or higher education.

### **Quality of Life and Burden**

Analysis revealed that caregivers experienced substantial burden, particularly in the emotional and social domains. The Zarit Burden Interview scores indicated high levels of stress and strain among caregivers. Quality of life assessments showed lower scores in physical health and psychological well-being, correlating with the high burden reported.

### **Coping Strategies**

The Brief COPE analysis highlighted a range of coping mechanisms employed by caregivers. Problem-focused coping and seeking social support were the most commonly reported strategies. However, the effectiveness of these strategies varied, with some caregivers reporting inadequate support and resources.

### **Relationship Between Coping Strategies, QoL, and Burden**

Correlation analysis indicated a significant relationship between coping strategies and quality of life. Caregivers who employed adaptive coping mechanisms, such as problem-solving and emotional support, reported better quality of life despite the high burden. Conversely, those relying on avoidance strategies experienced lower quality of life and higher burden.

### **Discussion**

#### ***Impact of Caregiving on Quality of Life***

The findings confirm that caregiving for individuals with dementia significantly

impacts caregivers' quality of life. The continuous and intensive nature of caregiving tasks leads to physical exhaustion, emotional stress, and social isolation. These findings are consistent with previous research highlighting the adverse effects of caregiving on health and well-being.

### ***Coping Mechanisms and Their Effectiveness***

The study underscores the importance of effective coping strategies in managing caregiver burden. Adaptive coping mechanisms, such as seeking social support and engaging in problem-focused activities, were associated with better outcomes. These strategies help mitigate the negative impact of caregiving and improve caregivers' resilience.

### ***Implications for Interventions***

The results of this study have important implications for the development of support programs for caregivers. Interventions should focus on enhancing caregivers' coping skills, providing psychological support, and offering respite care. Educational programs to inform caregivers about effective coping strategies and available resources can also be beneficial.

### **Future Research Directions**

Future studies should explore the long-term effects of caregiving on health and well-being. Investigating the impact of specific interventions on caregivers' quality of life and coping abilities can provide valuable insights for developing

targeted support programs. Expanding the sample to include caregivers from diverse cultural backgrounds can also enhance the generalizability of the findings.

### Conclusion

Caregivers of persons with dementia face significant challenges that impact their quality of life. Effective coping strategies are crucial in mitigating the negative effects of caregiver burden. This study emphasizes the need for comprehensive support systems and interventions to assist caregivers in managing their responsibilities while maintaining their well-being. By addressing the multifaceted needs of caregivers, we can improve their quality of life and enhance the overall care provided to individuals with dementia.

### References

- Acton, G. J., & Kang, J. (2001). Interventions to reduce the burden of caregiving for individuals with Alzheimer's disease: A review. *Research in Nursing & Health, 24*(5), 349-360.
- Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *JAMA, 311*(10), 1052-1059.
- Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience, 11*(2), 217-228.
- Cheng, S. T., Mak, E. P. M., Fung, H. H., Kwok, T., Lee, D. T. F., & Lam, L. C. W. (2014). Benefit-finding and effect on caregiver depression: A double-blind randomized controlled trial. *Journal of Consulting and Clinical Psychology, 82*(1), 58-66.
- Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners, 20*(8), 423-428.
- Gallagher-Thompson, D., & Coon, D. W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and Aging, 22*(1), 37-51.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer Publishing.
- Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M., & Rosa, M. M. (2020). Impact of dementia on informal care: A systematic review of family caregivers' perceptions. *BMJ Supportive & Palliative Care, 10*(1), 66-74.
- Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H., & Sourtzi, P. (2011). Caring for a relative with dementia: Family caregiver burden. *Journal of Advanced Nursing, 65*(6), 1346-1355.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5),

583-594.

- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 250-267.
- Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing, 108*(9 Suppl), 23-27.
- Torp, S., Hanson, E., Hauge, S., Ulstein, I., & Magnusson, L. (2008). A pilot study of how information and communication technology may contribute to health promotion among elderly spousal caregivers. *Health & Social Care in the Community, 16*(1), 75-85.
- Yu, D. S. F., Cheng, S. T., & Wang, J. (2018). Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *International Journal of Nursing Studies, 79*, 1-26.
- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20*(6), 649-655.