

CONTEMPLATING CAREGIVER BURDEN AMONG FAMILY CAREGIVERS OF CANCER PATIENTS: AN INTEGRATIVE REVIEW

Author's Name: Dr Anjana Williams¹, Yaiphakonbi Contractor², Divya Upreti³,
Kaliyamoorthy Rajeswari⁴, Dr Mudakappa P Chavadannavar (HC)⁵,
B Y Tippesh⁶, Shefali Latesh⁷, Dr. Melisa Leo Fernandes⁸,
Chingangbam Anju Chanu⁹

Affiliation:

1. Himalaya College of Nursing, Sparsh Himalaya University, Dehradun, Uttarakhand, India.
dranjanawilliams@gmail.com
2. Krishna School of Nursing, KPGU, Varnama, Vodadara, Gujarat, India. riyalai28@gmail.com
3. Assistant Professor, Sharda School of Nursing Science and Research, Sharda University, India. divyaupreti85@gmail.com
4. Nursing Tutor Gr-II, College of nursing Madras Medical College Chennai, India.
krajitut@gmail.com
5. Assistant Professor, Vigneshwar Institute Of Nursing Science Hubballi, India.
muttumgmgdg@gmail.com
6. Senior Nursing Officer, ESIC Medical College, PGIMSR And Model Hospital, Rajajinagar, Bangalore, Karnataka, India. tippu1983@gmail.com
7. Professor, Pragyan College of Nursing, Bhopal, India. shefalilatesh40@gmail.com
8. Professor, SMBT, Institute of Nursing, Dhamangaon, Nashik, India.
melisafernandes31@gmail.com
9. PhD scholar, Mata Gujri college of nursing, Kishanganj, India. chanju9188@gmail.com

Corresponding Author Name and Email ID: Dr Anjana Williams,

dranjanawilliams@gmail.com

ABSTRACT

This research paper provides a thorough examination of caregiver burden, a critical aspect of healthcare that affects individuals providing care to their loved ones, particularly in the context of chronic illnesses and aging populations. The study delves into the multifaceted dimensions of caregiver burden, encompassing physical, emotional, financial, and social aspects. The paper also scrutinizes coping mechanisms adopted by caregivers to manage the challenges posed by their caregiving role. It delineates between problem-focused coping, which involves practical strategies to address the stressor, and emotion-focused coping, which centers on managing the emotional impact of caregiving. The study emphasizes the importance of recognizing and addressing caregiver burden, as it not only impacts the well-being of caregivers but also has repercussions on the quality of care provided to the care recipient. Furthermore, this research offers insights into potential interventions and support systems that can alleviate caregiver burden. It highlights the significance of psychosocial support for caregivers, including motivational interviewing, to mitigate the emotional distress and burden they experience. Additionally, the paper explores the influence of cultural and religious factors on caregiver burden, shedding light on their potential role as protective or exacerbating factors in the caregiving experience.

Keywords: Caregiver burden, Multifaceted dimensions, Coping mechanisms

INTRODUCTION

The stress experienced by caregivers in home care situations, known as caregiver burden, is a crucial factor influencing the well-being of both the caregivers and the individuals they are caring for. Family members and caregivers of cancer patients play a vital role throughout the entire cancer journey, from diagnosis to survivorship or end of life. While the importance of family caregivers in supporting terminally ill cancer patients is widely acknowledged, there is a lack of understanding regarding the extent of the burden and economic impact they face.

Taking care of a cancer patient can have adverse effects on the caregiver's own health. This uncompensated care demands significant time and energy, involving tasks that are physically, emotionally, socially, and spiritually demanding. Caregivers are at risk of experiencing psychological challenges such as anxiety, depression, and feelings of hopelessness, as well as physical complications including increased mortality, cardiovascular problems, weakened immune functioning, and difficulties with sleep.

Zarit, an American gerontologist, initially characterized the burden of care as "the distress felt by the primary caregiver of an elderly family member, encompassing the caregiver's physical health, mental well-being, financial situation, and social life." Since that time, there has been substantial evidence regarding the challenges of providing care for the elderly population.¹

The concept of burden has generally been approached from three different perspectives. First, it has been described as "the level of tasks and responsibilities, measured by the variety and quantity of care duties undertaken (such as aiding with household chores, managing finances, or personal care) and/or the amount of time spent on these tasks." Secondly, it has also been defined as "the caregiver's personal assessment of the stress or challenges associated with performing these caregiving responsibilities." Thirdly, burden has been further characterized as "the perceived impact of this workload on the caregiver's overall life." The difference between these definitions lies in whether burden is viewed objectively or subjectively in terms of demand. For this study, the third definition of burden is employed.²⁻³

Research has shown varying rates of depression and anxiety among caregivers, with some studies indicating higher rates than those observed in the patient population. For instance, depression rates among caregivers range from 12% to 59%, and anxiety rates range from 30% to 50%, compared to depression rates of 10% to 25% and anxiety rates of 19% to 34% in the patient population. Additionally, a significant percentage of cancer caregivers (between 40% and 76%) report clinically significant symptoms of insomnia, which have detrimental effects on their mental and physical well-being. These symptoms are often chronic and can hinder the grieving process in bereaved caregivers, potentially increasing their risk for chronic illnesses like cardiovascular disease and cancer. **Seo and Park 2019,**

Ahmad Zubaidi et.al. 2019, Fang et.al 2022 studies reported positive correlation between depression and caregiver burden is established in various number of studies.

Moreover, caregiver burden has the potential to negatively influence the quality of care provided to patients, subsequently affecting their health outcomes. Given these challenges, caregivers of cancer patients are in urgent need of psychosocial support.

NEED OF THE STUDY

While there is substantial evidence indicating that caregivers of cancer patients often experience caregiver burden and related symptoms, there is limited knowledge about the various types of psychological interventions that can effectively alleviate their emotional distress and burden.

Caregivers have their own emotional reactions to the diagnoses and prognoses of patients, and they may benefit from specific coaching and emotional support tailored to their needs, separate from what is provided to the patients themselves. The roles and burden of caregivers are significantly influenced by factors such as a patient's prognosis, stage of illness, and care goals. Current research on family caregivers of cancer patients primarily focuses on their adjustment during the acute survivorship phase, spanning from the time of diagnosis to two years post-diagnosis.

FACTORS INFLUENCING CAREGIVER BURDEN

The research examined various sociodemographic factors and identified that the caregiver's familial relationship as a child or grandchild of a cancer patient was the only factor significantly associated with caregiver burden. This correlation remained significant even after considering other influencing variables in the comprehensive analysis.

Wolff and Kasper⁶ highlighted that nearly 80% of informal caregivers for older adults are either spouses or adult children, a trend that was reflected in this study where spouses and offspring constituted 85.9% of all caregivers. Spouses typically take on the primary caregiving role, being the initial source of care for an ailing older adult. Adult children usually step in as secondary caregivers when spouses are unavailable. Previous studies have indicated that spousal caregivers often experience a higher burden compared to adult children caregivers. However, in contrast, some studies have found that adult children caregivers may face higher levels of depressive symptoms and feelings of abandonment, which are elements of caregiver burden, particularly when caring for terminally ill cancer patients.

The study found a connection between the caregiver's relationship with cancer patients and caregiver burden. Interestingly, it revealed that offspring caregivers of cancer patients were notably less likely to experience caregiver burden compared to caregivers who were not related to the patients. Importantly, there was no significant difference in burden between caregivers who were spouses of the patients and

those who were not, which contradicted earlier research findings. This absence of a link between spousal caregiving and caregiver burden in this study may be due to the relatively small sample size and the use of a non-random sampling method.

There are a few potential reasons why adult children caring for cancer patients might experience lower levels of burden compared to other caregiver groups. Firstly, most adult children caregivers typically serve as secondary caregivers, in contrast to spouses who usually take on the primary caregiver role. This results in lower expectations and workloads for adult children, making them less vulnerable to the physical and psychological strains of caregiving.

Secondly, the urbanization of Asian societies and the resulting shift towards smaller, nuclear families may impact how adult children perceive their caregiving obligations. In nuclear families, married couples often live separately from their parents. This can result in adult children providing care from a distance, relying on other family members or formal nursing services. As a result, distance caregivers with ample social support may experience a reduced direct burden in their caregiving role.

However, it is important to acknowledge that even distance adult children caregivers may still grapple with psychological distress, particularly when they lack social support due to their numerous responsibilities such as raising children, managing household tasks, holding full-time jobs, and handling financial obligations.

Thirdly, the cultural principle of filial piety, which underscores the responsibility of children to care for their aging parents, may have a significant impact in alleviating caregiver burden among adult children caregivers. In many Asian cultures, there is a strong expectation for children to care for their parents, especially when they are dealing with chronic illnesses..⁹

Numerous studies have demonstrated the positive effects of filial piety on caregiver appraisal and subsequently on caregiver burden. Filial piety is even considered a protective factor against caregiver burden. Offspring caregivers who strongly identify with filial piety are more likely to view caregiving tasks as positive, beneficial, and not burdensome, ultimately reducing their subjective sense of burden. Another critical factor associated with caregiver burden in this study was the presence of depression in cancer caregivers. This relationship aligns with findings from other caregiver studies, supporting the significant link between these two variables. The relationship between caregiver burden and depression is complex and can be bidirectional. Caregiver depression is often viewed as a consequence of the caregiving process, with high caregiver burden contributing to depression, and vice versa.

However, Stommel¹⁰ has suggested an alternative perspective, proposing that caregiver depression may actually predict caregiver burden. In this view, depressed caregivers are more likely to experience high levels of burden. The authors argue that depression, being a relatively stable condition, can significantly

influence caregivers' perceptions and therefore explain variations in perceived burdens.

Aside from a direct connection, caregiver depression could also indirectly contribute to caregiver burden through the feelings of hopelessness, a significant component of depression. However, due to the relatively small sample size and the cross-sectional design of this study, the exact cause-and-effect relationship between caregiver burden and depression was not firmly established.

Nevertheless, the study did discover that a high reliance on negative religious coping (NRC), but not positive religious coping (PRC), was linked with increased caregiver burden. This corresponds with earlier research associating NRC with psychological distress or mental health outcomes. It is posited that individuals who grapple with their religious beliefs may find it challenging to use their faith as a coping mechanism, perceiving their faith as distant and feeble.

These findings may be clarified by the presence of multiple simultaneous stressors, such as lower socioeconomic status, a lack of caregiving resources or support, and the severity of the cancer diagnosis, which could overshadow the protective effects of religiosity and PRC. Interestingly, PRC might even be linked with higher caregiver burden, as it could potentially lead caregivers to take on a greater number of challenging caregiving tasks out of a sense of religious obligation. Additionally, those experiencing higher levels of burden may be more inclined to turn to religion as a means of coping.

In summary, the study's findings indicate that the influence of religiosity and religious coping on caregiver burden is still not well-understood and can be inconsistent. However, this does not negate the potential value or positive role of religious factors in the caregiving process. More local research is needed, ideally using comprehensive and standardized measures, to fully explore the multidimensional aspects of religiosity and religious coping. The study examined various sociodemographic factors, and it was found that the caregiver's relationship as the child or grandchild of a cancer patient was the only factor significantly linked to caregiver burden. This association remained significant even after accounting for other influencing variables in the multivariate analysis. However, when it came to the relationship between spousal caregiving and caregiver burden, no significant level of association was observed.

FACTORS CONTRIBUTING TO SUBJECTIVE CAREGIVER BURDEN IN CANCER CARE

- **Physical Demands:** Cancer caregiving often involves assisting with daily activities, managing medications, and accompanying patients to medical appointments. This can be physically exhausting and challenging for caregivers, especially if the patient's condition is severe or requires intensive treatment.
- **Emotional Distress:** Witnessing a loved one battle cancer can lead to a range of emotions, including fear, anxiety, sadness, and grief. Caregivers may also experience a sense of powerlessness in the face of the disease.

- **Financial Strain:** The costs associated with cancer treatment, including medical bills, medications, and potential loss of income due to caregiving responsibilities, can create significant financial stress for the family.
- **Social Isolation:** The demanding nature of caregiving can lead to social isolation as caregivers may have limited time and energy for social interactions outside of their caregiving role.
- **Uncertainty and Anticipation of Loss:** The unpredictable nature of cancer can lead to anticipatory grief, where caregivers may experience sadness and anxiety about the future, even before the loss of their loved one.

COPING STRATEGIES TO ALLEVIATE CARE GIVER BURDEN

Folkman, Lazarus perceived 'coping' as a process that explains how an individual (caregiver) responds during increased exposure to stress and when experiencing stressful stimuli (appraisal of burden). Coping strategies were categorized as problem-focused and emotion-focused coping strategies. While emotion-focused coping strategies involve effortful strategies (interpretation of burden) that caregivers adopt to mitigate the adverse emotional outcomes instigated by stressful events, problem-focused coping strategies on the other hand, are aimed at ameliorating the negative impact of the burden using problem-solving mechanisms or eliminating the sources of stress by building up positive/negative coping such as adaptive or maladaptive coping strategies. In advanced cancer caregiving, caregivers use both adaptive and maladaptive coping strategies which can affect families' caregiving outcomes.¹³⁻¹⁵

Emotion-focused coping pertains to the regulation of one's emotions in response to a stressful situation. This type of coping is typically employed when an individual perceives that there are limited options for directly altering the stressor. Examples of emotion-focused strategies encompass wishful thinking, downplaying the issue, or attempting to avoid it altogether.

Some strategies such as seeking social support serve both emotional and problem-focused functions. Neither of the two forms of coping is inherently adaptive or maladaptive, thus in stressful situations individuals may use a combination. The key to successful coping is the use of coping flexibility. Coping flexibility involves ability to change, and adapt coping strategies over time and across different stressful conditions as different strategies work effectively than others depending on circumstances.¹⁶⁻¹⁷

INTERVENTIONS

Because of the significant role that caregiver burden plays in the caregiving process, it is essential to create strategies to alleviate this burden and evaluate their impact. Effective interventions should be accessible to a wide range of caregivers. As Elmar Gräßel¹⁸ puts it, The value of an intervention is

determined by its effectiveness and utilization." Thus, it is crucial to not only design interventions but also enhance awareness and promote the utilization of these strategies.

Interventions aimed at relieving caregivers should take into account four key elements:

- Provision of information and training
- Access to professional assistance
- Facilitation of effective communication
- Provision of public and financial backing

IMPLICATIONS

1. It is important to increase awareness of measures aimed at enhancing and expanding informal caregiving services.
2. Efforts should be made to enhance the availability of support services at the regional level.
3. The effectiveness of relief strategies can be improved by implementing case management services.
4. Greater accessibility to public financial support should be provided.
5. The fundamental conditions for caregiving should allow for a balance between caring responsibilities and employment. Employment conditions should be adapted to ensure caregivers do not face disadvantages if they reduce their working hours or temporarily leave their jobs.
6. Efforts should be made to minimize language barriers, and support services in information, counselling, and assistance should be culturally sensitive and easily accessible.
7. The scope of internet-based support should be expanded.
8. There is a need for more high-quality empirical studies to assess the impact of relief interventions. Evidence-based research in health services should focus on this aspect.¹⁹

CONCLUSION

Subjective caregiver burden refers to the individual caregiver's perception of the stress, emotional strain, and disruption of daily life resulting from their caregiving responsibilities. It is important to recognize that this burden is subjective, varying from person to person based on their unique circumstances, coping mechanisms, and support networks.

Subjective caregiver burden in the context of cancer care is a multifaceted and complex issue that significantly impacts both the caregiver and the family unit. Recognizing and addressing this burden is crucial for providing holistic support to both the patient and their caregiver. By offering resources, respite care, and emotional support, healthcare professionals and communities can help alleviate the subjective caregiver burden and improve the overall well-being of families affected by cancer.

REFERENCES

1. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*. 1980;**20**:649–655.
2. Pinquart M, Sörensen S. Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. *Gerontologist*. 2005;**45**:90–106.
3. Glachen M. Impact of cancer care on caregivers. *J Oncol Nurs* . 2011;**44**:1–4
4. Seo, Ye Ji, and Heeok Park. "Factors influencing caregiver burden in families of hospitalised patients with lung cancer." *Journal of clinical nursing* 28.9-10 (2019): 1979-1989.
5. Fang, Linlin, et al. "Relationships between care burden, resilience, and depressive symptoms among the main family caregivers of stroke patients: A cross-sectional study." *Frontiers in psychiatry* 13 (2022): 960830. Jennifer L. Wolff, Judith D. Kasper, Caregivers of Frail Elders: Updating a National Profile, *The Gerontologist*, Volume 46, Issue 3, June 2006, Pages 344–356, <https://doi.org/10.1093/geront/46.3.344>
6. Lowenstein, A., & Gilbar, O. (2000). The perception of caregiving burden on the part of elderly cancer patients, spouses and adult children. *Families, Systems, & Health*, 18(3), 337–346. <https://doi.org/10.1037/h0091862>
7. Polly Mazanec, Distance Caregiving a Parent With Cancer, *Seminars in Oncology Nursing*, Volume 28, Issue 4, 2012, Pages 271-278, ISSN 0749-2081, <https://doi.org/10.1016/j.soncn.2012.09.010>.
8. Lai, D. W. L. (2010). Filial Piety, Caregiving Appraisal, and Caregiving Burden. *Research on Aging*, 32(2), 200-223. <https://doi.org/10.1177/0164027509351475>
9. Stommel, M., Given, C. W., & Given, B. (1990). Depression as an Overriding Variable Explaining Caregiver Burdens. *Journal of Aging and Health*, 2(1), 81-102. <https://doi.org/10.1177/089826439000200106>
10. Angelica P. Herrera , Jerry W. Lee , Rebecca D. Nanyonjo , Larry E. Laufman & Isabel Torres-Vigil (2009) Religious coping and caregiver well-being in Mexican-American families, *Aging & Mental Health*, 13:1, 84-91, DOI: [10.1080/13607860802154507](https://doi.org/10.1080/13607860802154507)
11. Ng, G.C., Mohamed, S., Sulaiman, A.H. *et al.* Anxiety and Depression in Cancer Patients: The Association with Religiosity and Religious Coping. *J Relig Health* **56**, 575–590 (2017). <https://doi.org/10.1007/s10943-016-0267>.
12. Folkman S, Lazarus RS. An analysis of coping in a middle-aged community sample. *J Health Soc Behav*. 1980;**21**:219–239
13. Lazarus RS, Folkman S. Stress, appraisal, and coping. New York: Springe, 198



14. Rahmani F, Ranjbar F, Hosseinzadeh M, Razavi SS, Dickens GL, Vahidi M. Coping strategies of family caregivers of patients with schizophrenia in Iran: A cross-sectional survey. *Int J Nurs Sci.* 2019;**6**:148–153
15. Manuel, J., Burwell, S., Crawford, S. et al. Young women's perception of coping with breast cancer. *Journal of Cancer Nursing* 2007; 30 (2): 85-94
16. Folkman, S, Lazarus, R.S., Dunkel-Schetter, C. et al. Dynamics of a stressful encounter: Cognitive appraisal, Coping and encounter outcomes. *Journal of Personality and Social Psychology* 1968; 50 992-1003
17. Gräbel E, Adabbo R (30 August 2011). "Perceived burden of informal caregivers of a chronically ill older family member". *Journal of Gerontopsychology and Geriatric Psychiatry.* **24** (3): 143–154.
18. Gräbel E, Behrndt EM (2016). "Belastungen und Entlastungsangebote für pflegende Angehörige." [German book section: Burden and unburdening interventions for caregivers.]. *Pflege-Report.* Stuttgart: Schattauer.