

Family Caregivers' Burden of Patients Undergoing Oncological Surgery

Kperlang Syrti,* Hepsi Raju**

*B.Sc (N)., Christian Medical College, Vellore, South India

** M.Sc (N)., Reader, College of Nursing, Christian Medical College, Vellore, Tamil Nadu, India

Abstract: ***Background:** Cancer has a great effect on human life not only physically but also mentally. In the journey of a patient with cancer, the family members play an important role. Caring responsibilities can be stressful and many of the families experience care-giving burden. **Methods:** A descriptive study to assess the burden among family caregivers of patients undergoing oncological surgery in surgical wards was conducted. Thirty family caregivers of patients undergoing oncological surgery, who are above 18 years of age were included by consecutive sampling. Zarit burden interview was used to assess the level of care-giving burden. **Results:** Majority of the subjects (66.52%) experienced mild burden while 32.26% had minimal level of burden and 3.23% had moderate burden. There was a significant association between burden of caregivers and the gender of the patient and the number of days of hospitalization. **Conclusion:** Family care-givers experience care giving burden while caring for patients hospitalized for oncological surgeries. Nurses need to be aware of and develop interventions to reduce this care-giving burden.*

Keywords: Burden, Caregivers, Patients undergoing oncological surgery

1. Introduction

Cancer is a life threatening disease that impacts both the patients and their family members. Family caregivers play an important role in caring for patients with cancer. From diagnosis till the end of care, patients are dependent on family caregivers. Family caregivers can be affected physically, emotionally and financially. Studies have reported that care givers experience negative psychological, behavioural and physiological effects on their day-to-day life and health. (Bevans & Sternberg, 2012). Caregiver burden is the distress that a caregiver feels as a result of providing care. Caregivers of patients with cancers in general have a higher level of burden and distress throughout the course of treatment (Kim & Schulz, 2008); (Palos et al., 2011).

Many factors influence the burden experienced by the caregivers. Patients and caregivers need to make adjustments in routines and activities. It was found that patients' dependency in tasks of daily living had a direct effect on the burden experienced by family members. A lack of social and financial support is reported to increase the level of burden (Suwankhong & Liamputtong, 2016).

Various socio-demographic characteristics of the caregiver like female spousal caregivers, caregiver's social functioning, abandonment and impact on schedule and, patient-related variables such as self-efficacy, sleep disturbance, and social support were reported to be associated with care-giving burden. (Li, Mak, & Loke, 2013); (Kurtz, Kurtz, Given & Given, 2004). In addition, marital status, education and type of family of caregivers, occupation of cancer patients and type of treatment facility were found to be predictors of burden (Lukhmana, Bhasin, Chhabra, & Bhatia, 2015).

Therefore, this study was done to assess the family caregivers' burden while caring for patients undergoing oncological surgeries.

The objectives of the study were to

- Assess the care-giving burden among family caregivers of patients undergoing oncological surgery.
- To determine the relationship between the burden of family caregivers and selected demographic and clinical variables of patients and caregivers.

2. Methods

A descriptive study was conducted among thirty one subjects who were family care-givers above 18 years of age and were caring for their patients in a tertiary hospital in south India. The subjects were included by consecutive sampling. Data were collected using Zarit burden interview (ZBI) after obtaining consent by the investigator. The ZBI is a standard, validated tool (Cronbach's alpha = 0.92) to assess care giver's burden. It is a 22-item likert scale. Higher score indicates higher caregiver distress (Zarit, Reever, & Bach-Peterson, 1980).

Each item was scored on a five-point likert scale ranging from 0-never, 2-sometimes, 3-quite frequently, and 4-nearly always. The total score ranges from 0 to 88. The obtained score was interpreted as 0-20-minimal; 21-40-mild; 41-60- moderate; 61-88-severe burden. Data were analysed using SPSS version 15. A p value of <0.05 was considered significant for statistical analysis.

3. Results

The mean age of the patients was 45 years (SD-14.2) with a male preponderance (71%). The mean duration of illness was 17.3 weeks (SD-12.9) and the mean hospitalized days was 8.7 days (SD-5.7). A majority of the patients had done their schooling (58.1%) and 25.8% were professionals. A major proportion of them (64.5%) had a monthly income of less than Rs. 10,000, about half of the patient population (54.8%) belonged to joint family and 90.3% were married.

The mean age of the family care-givers was 39.4 years (SD-11.7). Majority (51.6%) of the caregivers were graduates, and 35.50% were unemployed while an equal proportion (35.50%) were into own business. 74.20% of them were married. The mean time spent by them in the hospital was 14.1 hours (SD-4.5).

Majority of the family caregivers (65%) experienced mild level of burden while 32% had minimal burden and 3% had moderate level of burden as seen in figure 1. In this study, no subjects reported severe care-giving burden. Similar findings were reported by Yildiz et al., (2017) which revealed a moderate burden of caregivers of patients with cancer. The findings of this study is also supported by studies in India by Lukhmana, Bhasin, Chhabra, and Bhatia (2015) where 56.5% caregivers reported no or minimal burden while 37.5% caregivers reported mild to moderate burden and 1% reported severe burden.

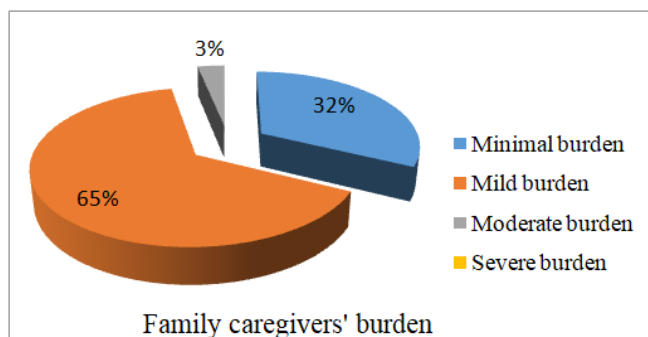


Figure 1: Distribution of Family care-givers based on care-giving burden

This study found a significant association between the family care-givers burden and the gender of the patients ($\chi^2=6.97$; $P=0.03$). This could imply that since a majority of the patients were male and were the bread winners of the family, this could have had serious financial implications on the family which translated to caregivers' burden. Similarly, it has been reported by Suwankhong & Liamputtong (2016) that a lack of social and financial support increases the level of burden. Significant association between the family care-givers burden and the number of hospitalized days of the patients was found ($\chi^2=17.89$; $P=0.006$) implying that longer the hospitalization, more the burden of caring.

A weak negative correlation between family care-givers burden and their age was found although not statistically significant. This could mean that younger caregivers experience more care-giving burden. The study by Given et al., (2004) revealed that caregivers aged 35-44 years reported the strongest sense of abandonment. Caregivers who were the adult children of patients with cancer and were employed reported high levels of depressive symptoms. This study did not find relationship with other socio-demographic variables of the caregivers. This may possibly be due to a small sample size in this study. Nevertheless, similar findings are reported by O'Driscoll et al., (2010) and Johansen et al., (2018) where the burden did not vary by socio-demographic variables. However,

Lukhmana et al., (2015) reported significant association with marital status and type of family whereas Kurtz et al., (2004) and Goldstein et al., (2004) reported association with impact on schedule, restriction on daily activities, social functioning and younger age of care givers.

4. Limitations

The family care-giving burden was self reported and as such socially desirable responses could have affected the results. The sample size was small to do subgroup analysis for association of burden with socio-demographic variables.

Implications for Nursing practice and research

Effect of interventions like counselling on family care-giving burden could be studied with a larger sample size and qualitative studies on aspects resulting in an increased care-giving burden needs to be studied.

5. Conclusion

Family care-givers are the primary source of social and emotional support for patients undergoing oncological surgeries and play a foremost role in the patient coping with the disease and treatment. And as such they frequently experience stress and bear the burden of care-giving, especially while caring for patients with cancer. The results of this study suggest that a majority of family care-givers experience care-giving burden. It would be well within the purview of nursing care to identify caregivers at risk and help them to evaluate factors that increase feeling of care-giving burden. Concern should be directed toward the caregivers' wellbeing, in addition to that of the patients.

References

- [1] Bevans, M. F., & Sternberg, E. M. (2012). Caregiving Burden, Stress, and Health Effects among Family Caregivers of Adult Cancer Patients. *Jama*, 307(4), 398–403.
- [2] Given, B., Wyatt, G., Given, C., Gift, A., Sherwood, P., DeVoss, D., & Rahbar, M. (2004). Burden and Depression Among Caregivers of Patients with Cancer at the End-of-life. *Oncology Nursing Forum*, 31(6), 1105–1117. <https://doi.org/10.1188/04.ONF.1105-1117>
- [3] Goldstein, N. E., Concato, J., Fried, T. R., Kasl, S. V., Johnson-Hurzeler, R., & Bradley, E. H. (2004).
- [4] Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *Journal of Palliative Care*, 20(1), 38–43.
- [5] Johansen, S., Cvancarova, M., & Ruland, C. (2018). The Effect of Cancer Patients' and Their Family Caregivers' Physical and Emotional Symptoms on Caregiver Burden. *Cancer Nursing*, 41(2), 91–99.
- [6] Kim, Y., & Schulz, R. (2008). Family caregivers' strains: comparative analysis of cancer care giving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health*, 20(5), 483–503.

- [7] Kurtz, M. E., Kurtz, J. C., Given, C. W., & Given, B. A. (2004). Depression and physical health among family caregivers of geriatric patients with cancer--a longitudinal view. *Medical Science Monitor: International Medical Journal of Experimental and Clinical Research*, 10(8), CR447-456.
- [8] Li, Q. P., Mak, Y. W., & Loke, A. Y. (2013). Spouses' experience of caregiving for cancer patients: A literature review. *International Nursing Review*, 60(2), 178-187.
- [9] Lukhmana, S., Bhasin, S. K., Chhabra, P., & Bhatia, M. S. (2015). Family caregivers' burden: A hospital based study in 2010 among cancer patients from Delhi. *Indian Journal of Cancer*, 52(1), 146.
- [10] O'Driscoll, D., O'Rorke, M., O'Keefe, L., Conlon, K., Murray, L., & Sharp, L. (2010). Burden on primary caregivers of individuals with pancreatic cancer: results from the all-Ireland PanCAM study. *NCRI cancer conference abstracts*.
- [11] Palos, G. R., Mendoza, T. R., Liao, K.-P., Anderson, K. O., Garcia-Gonzalez, A., Hahn, K.,
- [12] ...Cleeland, C. S. (2011). Caregiver symptom burden: the risk of caring for an underserved patient with advanced cancer. *Cancer*, 117(5), 1070-1079.
- [13] Suwankhong, D., & Liamputtong, P. (2016). Social Support and Women Living With Breast Cancer in the South of Thailand. *Journal of Nursing Scholarship: An Official Publication of Sigma Theta Tau International Honor Society of Nursing*, 48(1), 39-47.
- [14] Yildiz, E., Karakaş, S. A., Güngörmüş, Z., & Cengiz, M. (2017). Levels of Care Burden and Self-efficacy for Informal Caregiver of Patients With Cancer. *Holistic Nursing Practice*, 31(1), 7-15.
- [15] Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates feelings of burden. *The Gerontologist*, 20(6), 649-655.