

BURDEN ON CAREGIVERS OF PATIENT SUFFERING FROM CANCER

Nisha¹ and Rohini Sharma²

¹Nursing Tutor, Apollo School of Nursing, Indraprastha Apollo Hospital, New Delhi-76, India.

²Vice Principal, Apollo School of Nursing, Indraprastha Apollo Hospital, New Delhi-76, India.

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Corresponding Author

Nisha
Email:- nishabhardwaj475@gmail.com

ABSTRACT

This is a study to assess the burden on caregivers of patient suffering from cancer. Objectives of the study are to assess care givers' burden of patient suffering from cancer; to ascertain relationship between care givers' burden and selected demographic variables like age, gender, socio-economic status etc and to prepare and disseminate pamphlet/guidelines for the caregivers regarding dealing with their burden. A descriptive survey approach and non- experimental design was used, which was conducted on 90 caregivers, selected by purposive sampling technique in Indraprastha Apollo Hospitals, New Delhi.

Key words: Cancer, Care givers, Sampling technique.

INTRODUCTION

Cancer is defined as the unrestrained growth of cells that destroy normal tissue and body parts. Cancer is the number one natural cause of death in India [1].

Cancer affects the entire family, not just the patient. Treating a cancer patient is often an exercise of treating a part if not the whole family of the patient. Northouse¹ and Brown [2] suggest that in addition to causing distress to the patient, it puts financial, personal, social and health stress on family members. If care givers are among the family, as they usually are, stress reduces the quality of care that the patient receives. The amount and type of stress is culturally determined and needs to be evaluated accurately, if strategies are to be developed to combat it. If the stress of the care givers is reduced, then one can expect the patient to benefit.

As patients move through the stages of diagnosis, therapy, remission and relapse, their quality of life (QOL) deteriorates steadily, stated Girgis al. (2013) [3]. During

this, Calman⁴ and Patterson et al. (2013) [4,5] note, daily routines of the family are disrupted, typical duties and activities performed by one member may change or shift onto other family members and there are financial issues. Palliative care should begin right from the stage of diagnosis, but Smith et al [6] observed that it rarely is given at this stage. At least in India, palliative care is mostly used in the end-of-life stage. By this time, the disease has consumed both the victim and the family and both are in need of support. Treating the care givers becomes imperative, since stress erodes the quality of support they can give to the patient, as demonstrated by Ekedahl and Wengström [7], Vrettos et al. [8] Often the disease has severe financial impact on the family that lasts for years after the demise of the patient as shown by Brown et al⁹ Clearly the burden of the disease on care givers needs to be measured and reduced.



NEED OF THE STUDY.

There are nearly 2.5 million cases of cancers in India with almost 900,000 cases diagnosed and 400,000 deaths occurring every year. Age adjusted incidence of cancer in urban areas is estimated to be 106 per 100,000 population in males and 110 per 100,000 population in females. The incidence of cancer in India has kept pace with increasing urbanization and adoption of western lifestyle and dietary practices. However, there has not been a commensurate increase in the number of specialized cancer hospitals. Therefore, a large number of such patients are cared for in homes by the family caregivers.

While providing care and treatment, the entire focus is on the patient and the need and demand of family members and primary caregivers are often overlooked and neglected. The vital role played by such family caregivers is well recognized but burden on them is poorly understood. Caregiver burden is considered a “multi-dimensional biophysical reaction resulting from an imbalance of care demands relative to caregiver's personal time, social roles, physical and emotional states, financial resources and formal care resources given the other roles they fulfill.” Family caregivers experience a multitude of strains, due to the many aspects of life that are affected by cancers, including communication, nursing care, financial concerns, and emotional conflicts. Caregiver burden outcome depends upon a host of variables. Studies done in different countries have shown the association of burden on family caregivers of cancer patients with many socio-demographic factors like age, gender, relationship to the patient, employment, income of caregivers' lack of family and social support, duration of care giving, disruption in daily routine and stage of disease. Assistance in activities of daily living and instrumental activities of daily living in cancer patients also have significant impact on caregivers' burden. Unfortunately, providing care to a seriously ill family member can compromise the caregiver's overall health or physical, psychosocial, and spiritual well-being.

Needs and demands of patient vary at different points in the trajectory of the disease, and so does the caregiver's burden. Given the magnitude of services provided and the sacrifices made by family caregivers, the adverse consequences of care giving have emerged as a major public-health concern. So the researcher decided to conduct a study to assess the burden on caregivers of patients suffering from cancer.

MATERIALS AND METHODS

The study was conducted in November 2017. The research was an exploratory study. Non- experimental design was used to assess the burden on caregivers of patient suffering from cancer. The data was collected from 90 caregivers of oncology ward in Indraprastha Apollo Hospitals, New Delhi through interview. Subjects were selected by purposive sampling technique. Tool consists of two sections: Demographic Proforma which includes age, sex, socio-economic status etc. of patient & caregiver and Modified Caregiver Strain Index (M- CSI) which is a standardized tool developed by Lisa L. Onega, PhD, RN in 2013. This tool is used to assess the burden on caregiver of the patient suffering from cancer. Content validity of data collection tool was determined by the experts' opinion. The scoring criteria to check of a caregiver is on burden or not: Maximum score is 26, M-CSI Score > 16 implies Burden on care giver. Five types of burden are assessed in the study financial, personal, psychological, social, and physical.

RESULTS

The data was analyzed by descriptive and inferential statistics. Figure 1-4 show the distribution of background information of the caregivers. Out of 90 caregivers 41(45.6) were in the age group of 30-40 years; majority of the care giver 36(40) were doing either private or government job, 32(35.6) were having family income above 40 thousand; 35(38.9) were caring the patient from 1-6 months, it was found 27(30%) were caring the patient since 6 months-1 year.

Table 1 and figure 5 shows the item wise frequency and percentage distribution of M-CSI. The mean CSI score was 14.11, median 15 and standard deviation was 5.148 of patient suffering from cancer.

Table 2 and figure 6 shows the item wise Frequency and percentage distribution of Caregivers burden scores. The burden score depicts that maximum care givers having Psychological burden.

Table 3 showing that χ^2 for df 3 is 7.82 at $p \leq 0.05$. The mean score of duration of care giving was found statistically significant (9.925). Hence, it can be concluded that only the duration of care giving has influence burden on care givers.

Table 1. Mean, Median and Standard Deviation of M-CSI of Caregivers

	MEAN	MEDIAN	STANDARD DEVIATION
M- CSI	14.11	15	5.148

Table 2. Frequency and percentage distribution of Caregivers burden scores

BURDEN	FREQUENCY (F)	PERCENTAGE (%)
Physical burden	2.91	48.5



Personal burden	2.14	53.5
Social burden	2.32	58
Psychological burden	3.99	49.9
Financial burden	2.7	67.5

Table 3. Relationship between Caregivers' Burden and Selected Variables

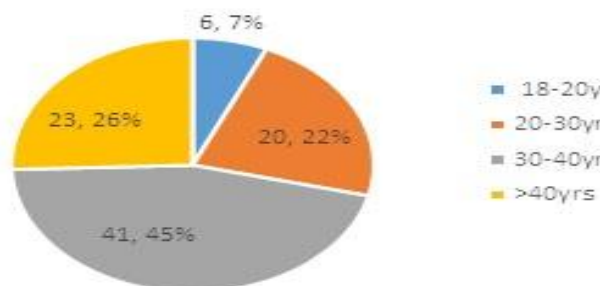
S. No.	Demo variables	AM	BM	Cal.X ²	Tab.X ²	Df
1.	AGE a) 18-20 b) 20-30 c) 30-40 d) >40	3 10 22 12	3 10 19 11	0.09	7.82	3
2.	GENDER a) Male b) Female	27 20	25 18	0.0038	3.84	1
3.	EMPLOYMENT STATUS a) Unempl. b) Job c) Business d) Retired or ex-service	10 21 15 1	8 15 18 2	3.369	7.82	3
4.	MARITAL STATUS a) Unmarried b) Married c) Divorced d) Separated	11 36 0 0	12 31 0 0	3.303	7.82	3
5.	FAMILY INCOME a) <10,000 b) 10,000-20,000 c) 20,000-30,000 d) >40,000	11 8 16 12	5 5 13 20	5.07	7.82	3
6.	DURATION OF CAREGIVING a) <1 month b) 1-6 months c) 6months-1yr d) >1yr	3 25 9 10	5 10 18 10	9.925	7.82*	3

P<0.05 level

*=-Significant at df= 3

Fig.1 Pie chart showing age wise percentage Distribution of caregivers

Age wise % of caregivers

**Fig.2 Pie chart showing employment status distribution of caregivers**

% Employment status of caregivers

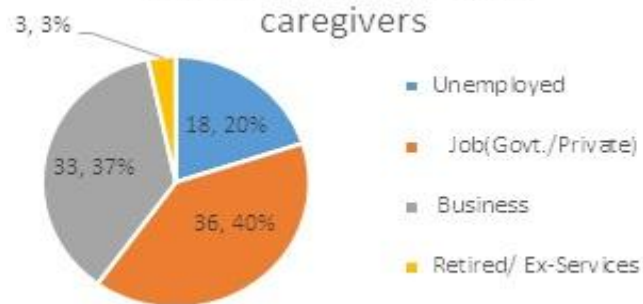
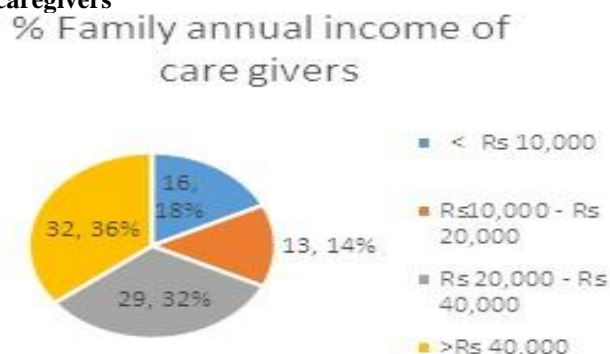
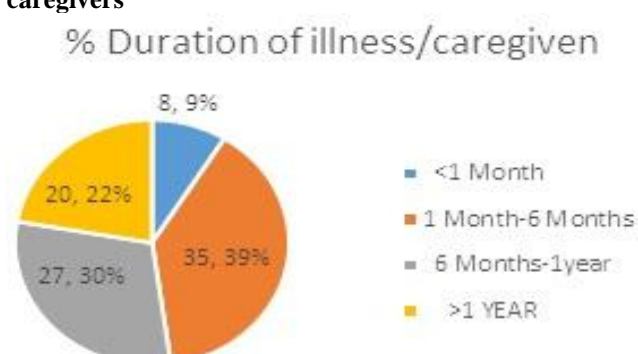
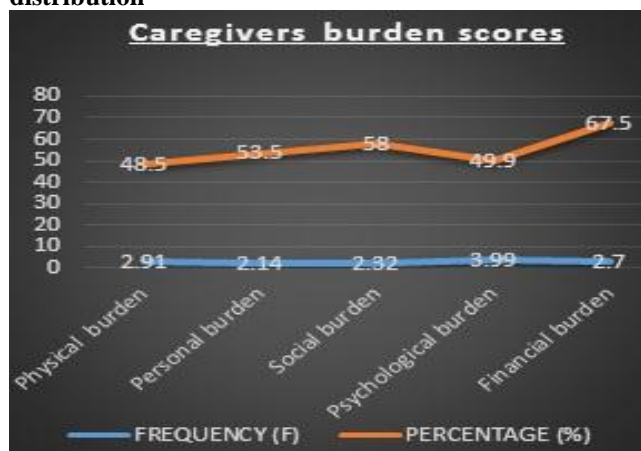


Fig.3. Pie chart showing family income Distribution of caregivers**Fig. 4. Pie chart showing duration of care giving of caregivers****Fig.5. line graph showing mean,median and SD of M-CSI.****Fig.6 line graph showing Frequency and percentage distribution**

DISCUSSION AND CONCLUSION

The study was conducted with an aim to assess the burden on caregivers of patient suffering from cancer as well as to identify the areas which can improve the care and to reduce the burden on care givers. Majority of caregivers had financial burden as respective to other burdens. A similar study conducted by Johansen S [1], Cvancarova M and Ruland C depicted that there were significant associations between caregiver burden and the patient-related variables such as self-efficacy ($P = .02$), sleep disturbance ($P = .03$), and social support ($P = .04$). Among FC-related variables depression, fatigue and symptoms were significantly associated with higher caregiver burden. The study reveal that being a female, either as a patient or FC, increased the likelihood of experiencing fatigue and sleep disturbance

A study conducted by S Lukhmana, SK Bhasin, P Chhabra and Ms Bhatia Department of Community Medicine, UCMS and GTB Hospital, Delhi, India (2010) concluded that the study population consisted of 90 (45%) males and 110 (55%) female caregivers aged 18-65 years. 113 (56.5%) caregivers reported no or minimal burden while 75 (37.5%) caregivers reported mild to moderate

burden. According to the study marital status, education and type of family of caregivers, occupation of cancer patients and type of treatment facility were found to be the predictors of burden on caregivers.

In closing, the findings of this review provide a more comprehensive understanding regarding the caregivers' experience, particularly the caregivers who were caring for cancer patients. The first recommendation to practice is related to the importance of a positive perspective of caregiving. The first key to successful development is to perceive the positive aspects of the situation. Positive perception helps the caregivers overcome the negative aspects of the situation. Therefore, nurses and healthcare professionals should be more sensitive regarding positive perceptions, aware of their importance, and enhance the development of these perceptions. The more positive the caregivers are about the situation, the better they cope and the higher chance they will accomplish the ultimate goal of living. However, it is challenging to develop a focus in the healthcare of cancer that assists caregivers in finding positive perspectives of being a caregiver.



REFERENCES

1. Northouse L. (1984) The impact of cancer on the family: An overview. *Int J Psychiatry Med*, 14, 215-42.
2. Brown ML. (1990) The national economic burden of cancer: An update. *J Natl Cancer Inst*, 82, 1811-4.
3. Girgis A, Lambert SD, McElduff P, Bonevski B, Lecathelinais C, Boyes A, *et al.* (2013) Some things change, some things stay the same: A longitudinal analysis of cancer caregivers' unmet supportive care needs. *Psychooncology*, 22, 1557-64.[PUBMED]
4. Calman KC. (1984) Quality of life in cancer patients : An hypothesis. *J Med Ethics*, 10, 124-7.
5. Patterson JM, Rapley T, Carding PN, Wilson JA, McColl E. (2013) Head and neck cancer and dysphagia; caring for carers. *Psychooncology*, 22, 1815-20.
6. Broom AF, Doron A. (2013) Traditional medicines, collective negotiation, and representations of risk in Indian cancer care. *Qual Health Res*, 23, 54-65.
7. Smith TJ, Temin S, Alesi ER, Abernethy AP, Balboni TA, Basch EM, *et al.* (2012) American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care. *J ClinOncol*, 30, 880-7.
8. Ekedahl M, Wengström Y. (2007) Nurses in cancer care : Stress when encountering existential issues. *Eur J OncolNurs*, 11, 228-37.
9. Vrettos I, Kamposioras K, Kontodimopoulos N, Pappa E, Georgiadou E, Haritos D, *et al.* (2012) Comparing health-related quality of life of cancer patients under chemotherapy and of their caregivers. *Scientific World Journal*, 2012, 135-283.

