



CAREGIVERS BURDEN AMONG CAREGIVERS OF CANCER PATIENTS

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ABSTRACT

Introduction: One of the leading causes of morbidity and mortality in the world is cancer. Due to advances in treatment modalities in cancer, there is a higher percentage of people living with assistance of care givers. In care givers, it is producing definite disturbances in the physical as well as psychological well being. **Aim Of The Study:** To analyse the caregivers' burden in caregivers of people suffering from Cancer. **Materials And Methods:** The sample is drawn from female or male Caregivers of these patients of cancer attending the Outpatient Psychiatry department and Radiotherapy department at Government Stanley Hospital, Chennai, including not less than 40 Caregivers of patients with Malignancy. **Results:** In cancer caregivers, depression is high among 40- 60 years. The chronic illness among the caregivers were found to be 67.5%. Majority of the caregivers were female, middle age groups, Married, Nuclear family, urban population and illiterate in educational status. Most of them were employed, supporting their family and cancer patients. Most of the caregivers were their spouses themselves. The major group of caregivers were care giving for less than one year because of the high mortality in the cancer patients. According to Zarit Burden Interview, 33.5% had little burden, 20% had mild burden, 27.5% had moderate burden and 20% had severe burden. **Conclusion:** In caregivers, most of the caregivers were found to be in caregiver burden. Among them, one fifth had severe caregiver burden. Caregiver burden has negative effects on quality of life of caregivers and also patients. Caregiver burden on long term may cause psychiatric comorbidities. To sustain this ever growing pool of caregivers, counselling centre to be suggested to set up in all Cancer care hospitals and appropriate interventions support group to be established so as to help the caregiver cope and deal with miserable multifaceted burden.

KEYWORDS : Caregivers, cancer

INTRODUCTION

One of the leading causes of morbidity and mortality in the world is cancer, with a prevalence of approximately 14 million new cases and 8.2 million cancer related deaths in 2012. The number of new cases expected to rise in next two decades is about 70%. Among men, the most common sites of cancer are lung, prostate, colorectal, stomach and liver. Among women, the most common sites of cancer are breast, colorectal, lung, cervix and stomach cancer.

Cancer causing viral infections, such as HBV/HCV and HPV which is an increasing trend nowadays are responsible for up to 20% of cancer deaths in low and middle income countries. According to WHO cancer research agency and international agency for research on cancer (IARC), ageing is another elemental factor for development of cancer. The incidence of cancer rises dramatically with age, most likely due to development of risk for specific cancer that increases with age.

Due to advances in treatment modalities in cancer, there are higher percentage of people living with assistance of care givers. Because of advancement in palliative care treatment which relieves, rather than cures, symptoms caused by cancer, it poses a burden to care givers by providing long term care for patients' activities of daily living. In care givers, it is producing definite disturbances in the physical as well as psychological well being and thereby affects the emotional and financial needs of family members and their caregivers.

Cancer is potentially a dangerous disease, which can have definite effect in the physical as well as psychological wellbeing of the individual with the cancer and also the caregiver and thereby affects the emotional, socioeconomic needs of the caregivers. The patients who need palliative care, which can have impact on both the patient and the caregivers' physical and psychological wellbeing and increases the caregiver burden. This is due to the more palliative care given in home settings by the caregivers due to short hospital stay practices to decrease the cost bear for

hospitalization. In early stages of cancer, the diagnosis of cancer itself and treatment of cancer is having more impact on psychological morbidity in both patient and the caregiver. In advanced stages of cancer, the physical problems concerning the seriousness of illness, duration of hours of care giving, dependency of patients to caregivers, financial concerns and low social support were causing more distress and increasing the decline in the quality of life and burden to the caregivers.

MATERIALS AND METHODS

Study Setting

The study was conducted at psychiatry and radiotherapy outpatient department at government Stanley medical college hospital, Chennai. It is a tertiary care institute where patients come from northern part of Chennai, Thiruvallur District and southern districts of Andhra Pradesh.

Study Population

The sample is drawn from female or male patients and their Caregivers of these patients of cancer attending the Outpatient Psychiatry department and Radiotherapy department at Government Stanley Hospital, Chennai.

Study, including not less than 40 Caregivers of patients with Malignancy.

Duration Of Study: 6 months.

Inclusion Criteria

1. Participants to be willing to provide informed consent for the interview and assessment.
2. Patients willing to allow Caregivers to be assessed.
3. Caregivers aged from 20- 85 yrs were taken.

Exclusion Criteria

1. Those patients and caregivers who did not give their consent.
2. Refusal to allow spouse to be evaluated.
3. Caregivers with the history of Substance abuse and with the history of suicide attempt/ attempts or previous psychiatric

symptoms and interventions.

4. Caregivers with the family history of psychiatric illness.

Variables Studied

Socio economic variables- Age, Sex, Religion, Family type, Marital status, Education, Occupation, Monthly income.

Clinical Variables- chronic illness, Caregiver Burden.

Study Procedure

1. After obtaining informed consent from patients and their caregivers attending the Psychiatry and Radiotherapy OPD, they will be interviewed and assessed using various scales. Data will be recorded for this purpose.
2. Information is obtained from caregivers.
3. Socio demographic and medical details will be obtained using semi structured questionnaire designed for this study.

Instuments Used

1. A semi structured pro-forma to collect the sociodemographic details, family history details and a semi structured clinical profile of Caregivers.
2. Assessment of Caregivers' burden by Zarit Burden Interview (ZBI).

ZARIT BURDEN INTERVIEW

The Zarit Burden Interview, is a popular caregiver self report measure employed by many aging agencies. The original version has 29 items of questions which was evolved by Zarit in 1980. The revised version by Bedard in 2000 which contains 22 items. Each item on the interview is an expression in which the caregiver is asked to endorse using a 5 point scale. The response options range from 0(never) to 4(nearly always). The score range from 0 to 68. The score 0 to 21 indicates little or no burden, score 21-40 indicates mild to moderate burden., score 41-60 indicates moderate to severe burden and the score 61-68 indicates severe burden. It is the instrument most commonly used in dementia care giving research and by clinicians in usual practice to measure the change over time resulting from interventions aimed at decreasing the burden. The scale has two factor model, one is personal strain and the other one is role strain. The reliability and validity of this scale was tested by Herbert, Bravo and Previlke in 2000, concluded that it has good internal consistency, reliability, with a cronbach's alpha coefficient of 0.92. They also concluded that the score on this scale were unrelated to age, sex, language, locale, marital status or employment status, indicating the measure is appropriate for use with a variety of population. Scores were also significantly positively associated with behavioural and psychological severity in the older adult patients and depression scores of the caregiver, as studied by Center for Epidemiological studies Depression

Gender	
Male	2(5.0%)
Female	38(95.0%)
Age of the caregiver	
≤ 40 Yrs	14(35.0%)
41-60 Yrs	22(55.0%)
Above 60 Yrs	4(10.0%)
Marital status of care givers	
Unmarried	4(10.0%)
Married	33(82.5%)
Divorced	0(0.0%)
Widowed	3(7.5%)
Type of family	
Nuclear family	28(70.0%)
Joint family	12(30.0%)
Locality	
Rural	16(40.0%)
Urban	24(60.0%)
Educational status of caregivers	

Illiterate	18(45.0%)
Middle school	15(37.5%)
High/Hr sec school	5(12.5%)
Graduates	2(5.0%)
Relationship to the patients	
Siblings	1(2.5%)
Spouse	28(70.0%)
Daughter/Son	6(15.0%)
Daughter/son -in-law	1(2.5%)
Others	4(10.0%)
Duration of caregiver given	
5-10 years	2(5.0%)
1-5 years	14(35.0%)
less than 1 year	24(60.0%)
Degree of burden in ZBI scale of care givers of Cancer patients	
Little/No burden	13(32.5%)
Mild burden	8(20.0%)
Moderate burden	11(27.5%)
Severe burden	8(20.0%)

DISCUSSION:

Sociodemographic Factors

The mean age of caregivers of cancer patients was between 41-60 years. The mean caregiver distribution was matching with previous studies done in cancer caregivers by Susan C MC Millan , the mean age of caregiver in cancer patient was 45- 54 years and in another study by Ioannis Vrettos in same group , it was 48.9±14.3 years. The mean age of caregivers found in other studies such as Covinsky et al and in Australian Bureau of Statistics: disability ageing and carers was 65 years. 95% of the caregivers were female. 82.5% of the caregivers were married.70% of them were from the nuclear family. 60% of the population were from urban area. The analysis on educational status of caregiver shows that illiterates were high among cancer caregivers(45%). Cancer caregivers (37.5%) of them studied middle school education.

A higher proportion (62.5%) of them were employed. The analysis of relationship of caregiver to Cancer patient shows that 70.0% were spouses and 15% were son/daughters. The duration of caregiving less than one year was 60%among caregivers of cancer patients. Duration of care giving 1-5 years and more than 5 years was 35%and 5%respectively. The status of chronic illness was analysed and it was found that 32.5% of caregivers of cancer patients had chronic illness.

The severity of burden in ZBI Scale was 32.5%, 20.0%, 27.5% and 20.0% for little or no burden, mild, moderate and severe burden in cancer caregiver respectively. The caregiver burden in cancer caregivers was similar to study which was done by N Haj Mohammed et al, it was 24.6%.

The results in our study gives information about various factors and domains of care giving role and help them to understand the challenges when caring for the patients influencing their quality of life and leads to the caregiver burden. This can help health care professionals to meet the needs of the caregiver in strain.

Psychological interventions are to be given to them to reduce their caregiver burden and depression. Counselling can be provided to dementia caregivers to help them in coping better with the stress of caregiver burden.

It also provides evidences in order to develop public policies and programmes that are targeted to meet the long term needs of cancer caregivers and prevent the psychological effects. Health care professionals need to exceed the expectations of only saving patients' lives, extending this expectation to saving their caregivers.

LIMITATION

The caregiver sample was taken only from the hospital based patients, so the sample may be an over representation of caregivers than from the general population. Individual differences in caregivers like their personality, attitudes, cultural beliefs and ethnicity were not taken into account. The sample size was small and not community based sample. The pre exposure coping strategies and other domains of caregivers.

CONCLUSION

Cancer is a terminal illness, needs long term care, which were having comparable levels of dependence to family members, especially the primary caregivers. The study was aimed at the analysing caregiver burden among caregivers of cancer patients. Most of the caregivers of cancer patients had caregiver burden. Caregiver Burden has negative effects on quality of life of caregivers and also patients. So assistance, psycho education and early intervention from health care professionals is the key to improve the quality of life of caregivers and hence the patients' quality of life.

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