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Research article

A COMPARATIVE STUDY OF CAREGIVER BURDEN IN CANCER CERVIX AND CANCER BREAST ILLNESSES

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ABSTRACT

Background: Caregivers of individuals suffering from cancer illnesses are at risk of having subjected to mental health consequences. There is a paucity of data comparing the caregiver burden of cancer breast and cancer cervix patients. **Aim:** The aim of the present study is to compare the caregiver burden of cancer breast and cancer cervix patients. To study the association of caregiver burden with demographic factors like age, gender, duration of caregiving etc. **Materials & Methods:** This Cross sectional study is performed on the key relatives of patients of 31 cancer cervix and 31 cancer breast patients. Burden assessment schedule was used. **Results:** Our findings suggest burden is more in male caregivers of breast cancer patients. It is not so in caregivers of cancer cervix patients. Whenever the caregiver is closely related to the patients the burden is high in both groups. Whenever the burden scores were high the depression scores were also high. Treatment modalities as a whole correlates with burden scores in caregivers of breast cancer patients but not in cancer cervix patients. **Conclusion:** Caregivers with breast and cervical cancer patients are vulnerable if the caregiver is male, from low socioeconomical background, more closely related and when the patients received poor treatment modalities.

Keywords: Burden, caregiver, cancer breast, cancer cervix.

INTRODUCTION

Two important organs of women are uterus and breast. They are associated with female image and are also vital for reproduction and mothering. Both the organs are prone to cancer and their loss is associated with psychological and social consequences. A diagnosis of cancer affects not only the patients but also their significant others, especially when a lot of care tasks are involved. Some care givers perceive the care as a burden, while others consider it as a challenge.^[1] Care givers of individuals suffering from cancer illnesses are at risk of being subjected to mental health consequences. The care giver burden can be quantified into objective and subjective domains. There is a paucity of data comparing the

caregiver burden of cancer cervix and cancer breast patients.^[2] The term caregiver refers to anyone who provides assistance to someone else who is in some degree incapacitated and needs help.^[3] An informal caregiver is an individual such as a family member, friend or neighbour who provides unpaid care. A formal caregiver is a volunteer or a paid care provider associated with a service system.^[4] Objective burden denotes the effects of caregiving on finances well being, health activities of caregivers while subjective burden denotes of depression, anxiety and somatic symptoms associated with the caregiving role. In India very few studies have been conducted in the

areas of family burden and the social support systems of different kinds of cancer patients.

Most of the notable community based studies provide that 18-47% of caregivers land in depression⁵. A widely accepted notion within developing country societies of the family as endlessly supporting caregivers may not be true.⁶ Even where care is exemplary, it is essential that the impact of providing care on the family and on the wider community be quantified.⁷

Aims and objectives

1. To compare the care giver burden in breast cancer patients and cervix cancer patients.
2. To study the association of caregiver burden with demographic factors like age, gender duration of care giving and other variables.

METHODOLOGY

Study design: This cross sectional study is performed on the key relatives of patients of cancer cervix and cancer breast.

Grouping: Group I consist of caregivers of breast cancer patients and group-II consists of care givers of cancer cervix patients. The Patients were recruited from Arignar Anna Cancer Institute, Karapettai, Kanchipuram. It is a large regional centre for all types' cancer diseases. The study was conducted during Dec. 2010 to May 2011.

Sample size: The study involved two groups of care givers each of 31 members.

Ethics Approval: The institutional ethical committee clearance has obtained. Informed oral consent from all the caregivers and the patients were obtained.

A semi-structured interview proforma was used to record the following details Demographic and personal data of both patients and caregivers, clinical diagnosis and details of the type, grading, duration of illness, and duration of the care by caregivers etc.,

Inclusion criteria: 1) Age between 18 to 65 (both inclusive for caregivers). 2) Confirmed primary

diagnosis of cancer breast and cancer cervix for the patients.

Exclusion criteria: caregivers without severe physical illnesses

The following scales were administered.

1) **Hospital Anxiety and Depression Scale (HADS)**^[8] has been established as a much applied and convenient self rating instrument for anxiety and depression in patients with both somatic and mental problems and with equally good sensitivity and specificity as other commonly used self rating screening instruments.^{[9],[10]}

2) **Burden Assessment Schedule (BAS)**^[11] This is a structured instrument with 40 items measuring both subjective and objective burden. Each item is rated on a 3 point scale. (Not at all, to some extent, very much) Interrater reliability is good (Kappa 0.80) regarding validity the reported co-efficient of Correlation is 0.82. It assesses nine categories of burden. (It is relevant for many chronic illnesses.)

3) **Presumptive Stressful Life Event Scale** by Gurmeet Singh et al. (PSLES)^[12]. The PSLES is formulated by Singh et al to evaluate the life event (that occurred within one year prior to illness). This is a schedule which was standardized on Indian population and has 51 items assessing various life event experiences by the subject and the time frame for assessing the occurrence of life events, in the year proceeding the examination.

Care givers were included if they satisfied the following criteria.

- 1) Healthy adults of 18 years and above.
- 2) Care givers who were continuously caring for the last one year and spent a lot of time and emotions caring the patients. Patients diagnosed for at least one year and had received relevant treatments (surgery/chemotherapy/radiotherapy etc.) and were now attending the OPD or undergoing treatment. They were in stable clinical condition at the time of interview.

RESULTS

Table 1: Classification of caregivers based on the demographic, economic and other patient related variables

AGE GROUP	BREAST CA		CERVIX CA	
	NO.	%	NO.	%
20-30	13	41.9	9	29.0
30-40	5	16.1	11	35.5
40-50	3	9.7	3	9.7
50-0	6	19.4	3	9.7
60& ABOVE	4	12.9	5	16.1
SEX				
MALE	17	54.8	13	41.9
FEMALE	14	45.2	18	58.1
MARITAL STATUS				
MARRIED	24	77.4	23	74.2
SINGLE	7	22.6	8	25.8
EDUCATION				
ILLETERATE	4	12.9	8	25.8
HIGH SCHOOL	19	61.3	16	51.6
HR.SEC	5	16.1	4	12.9
DIPLOMA	0	0.0	2	6.5
DEGREE	3	9.7	0	0.0
PG	0	0.0	1	3.2
OCCUPATION				
Daily wages	10	32.3	14	45.2
Self employed	7	22.6	4	12.9
Private	4	12.9	4	12.9
Government	1	3.2	0	0.0
Housewife	7	22.6	8	25.8
Student	2	6.5	1	3.2
Income				
BELOW 1000	0	0.0	3	9.7
1000-3000	9	29.0	13	41.9
3000-5000	10	32.3	10	32.3
5000-7000	8	25.8	4	12.9
7000-10000	3	9.7	1	3.2
ABOVE 10000	1	3.2	0	0.0
RELIGION				
HINDU	27	87.1	26	83.9
CHRISTIAN	0	0.0	5	16.1
MUSLIM	4	12.9	0	0.0
OTHERS	0	0.0	0	0.0
FAMILY SYSTEM				
NUCLEAR	20	64.5	23	74.2
JOINT	11	35.5	8	25.8
LIVING TYPE				
Hut	0	0.0	2	6.5
Mud house	0	0.0	0	0.0
Thatched, Sheet, Lightroof	18	58.1	19	61.3
Brick used	13	41.9	10	32.3

Table 2: Classification of caregivers based on the Duration of illness, Hospitalization, treatment

DURATION OF ILLNESS	BREAST CA		CERVIX CA	
	No.	%	No.	%
BELOW 1 M	0	0.0	0	0.0
1-6 M	11	35.5	15	48.4
6-12 M	9	29.0	10	32.3
12-18 M	6	19.4	4	12.9
18-24 M	1	3.2	0	0.0
24-30 M	0	0.0	0	0.0
ABOVE 30 M	4	12.9	2	6.5
HOSPITALISATION				
1 TIME	4	12.9	10	32.3
2 TIMES	11	35.5	10	32.3
3 TIMES	5	16.1	4	12.9
4 TIMES	1	3.2	5	16.1
5 TIMES	2	6.5	2	6.5
6 TIMES	5	16.1	0	0.0
7 TIMES	1	3.2	0	0.0
8 TIMES	1	3.2	0	0.0
9 TIMES	1	3.2	0	0.0
Duration of treatment				
BELOW 1 M	0	0.0	1	3.2
1-6 M	12	38.7	23	74.2
6-12 M	10	32.3	4	12.9
12-18 M	4	12.9	2	6.5
18-24 M	1	3.2	0	0.0
24-30 M	0	0.0	0	0.0
ABOVE 30 M	4	12.9	1	3.2
Mode of treatment				
SURGERY	0	0.0	0	0.0
SURGERY + CHEMOTHERAPY	10	32.3	10	32.3
CHEMOTHERAPY	7	22.6	7	22.6
RADIOTHERAPY	0	0.0	0	0.0
CHEMOTHERAPY + RT	1	3.2	1	3.2
SURGERY +RT	2	6.5	2	6.5
SURGERY + RT +CHEMOTHERAPY	11	35.5	11	35.5
Time spent per week				
< 8 HOURS	0	0.0	1	3.2
9-16 HOURS	1	3.2	1	3.2
17-32 HOURS	3	9.7	3	9.7
>32 HOURS	27	87.1	26	83.9
Relationship				
PARENT	1	3.2	3	9.7
SPOUSE	10	32.3	8	25.8
DAUGHTER	5	16.1	11	35.5
SON	5	16.1	3	9.7
DAUGHTER IN LAW	5	16.1	2	6.5
SIBLING	2	6.5	2	6.5
OTHER RELATION	3	9.7	2	6.5

Table : 3 Difference between the caregiver burden of breast and cervix cancer patients

Breast	Cervix	P value
66.77±9.639	70.77±10.1	0.116

The mean caregiver burden scores of breast cancer and that of cervix cancer were compared using ‘t’ test.

Overall caregivers burden without breakdown for cancer breast and cervix were worked out The burden score for caregivers of cancer cervix is more by 4. But the difference ‘4’ is not statistically significant as $p(0.116)$ as $p(0.116) > 0.05$. Hence we conclude that the difference ‘4’ is due to chance.

Table 4: Burden between male and female caregivers of breast & Cervix cancer patients:

	Male	Female	P value
Breast	70.6±9.079	62.79±9.04	0.0341
Cervix	72.92±12.55	69.22±7.93	0.3224

Among 31 care givers, 17 male & 14 female reported for Breast cancer cases. As the difference of score between Male and Female is significant i.e., $P(0.034) < 0.05$, we conclude that male caregiver burden score is significantly more when compared to female.

A test for comparison of burden score for cervix cancer to find out if any gender difference was correlated and the difference is insignificant as $P = 0.3224, > 0.05$. Hence we have no claim to record that there is a difference in the burden score between male & female caregivers.

Table 5: Education

burden score of cervix cancer		burden score of breast cancer	
r value	-0.167	r value	-0.158
P value (two-tailed)	0.3687	P value (two-tailed)	0.3961

As the correlation between education and burden score were not significant in both groups of care givers i.e. $p=0.3687$ and $p =0.3961$ respectively for cancer cervix group and cancer breast group, we conclude that education does not influence the burden. The ‘r’ values are seen closed to ‘0’.

Table 6: Occupation :

burden score of cervix cancer		burden score of breast cancer	
r value	-0.0516	r value	-0.27
P value (two-tailed)	0.7826	P value (two-tailed)	0.1418

The correlation co-efficient ‘r’ = -0.05 and -0.27 leads to say that there is no relationship between occupational and caregiver burden in both groups of care givers. It is also seen that ‘r’ value are not significant as $p = 0.7826$ and $P=0.1418$ for cervix and breast groups.

Table 7: Anxiety

burden score of cervix cancer		burden score of breast cancer	
r value	0.2982	r value	0.1465
P value (two-tailed)	0.1032	P value (two-tailed)	0.4315

The correlation co-efficient ‘r’ = 0.2982 and 0.1465 leads to say that there is no relationship between Anxiety and caregiver burden in both groups of care givers. It is also seen that ‘r’ value are not significant as $p = 0.1032$ and $P=0.4315$ for cervix and breast groups.

Table 8: Depression

burden score of cervix cancer		burden score of breast cancer	
r value	0.4861	r value	0.4526
P value (two-tailed)	0.0056	P value (two-tailed)	0.0106

It is seen that there is a positive correlation between depression and burden score in both groups of care givers and the correlations are significant. We conclude that whenever the burden score are more the depression is also more.

Table 9: Relationship :

burden score of cervix cancer		burden score of breast cancer	
r value	-0.3963	r value	-0.6546
P value (two-tailed)	0.0273	P value (two-tailed)	$P < 0.0001$

The correlation co-efficient ‘r’ = 0.3963 is significant as $p=0.027 < 0.05$ in cervix group and significantly the ‘r’ = -0.6546 and $P < 0.0001$ in breast group leads to conclude that there is a significant correlation between the relationship and burden score in both groups. We may conclude that there is a big burden when there is a close relationship.

Table 10: Family System :

burden score of cervix cancer		burden score of breast cancer	
r value	0.2434	r value	-0.2383
P value (two-tailed)	0.1871	P value (two-tailed)	0.1967

The family system and burden score do not have much relationship. The correlation coefficient $r=0.2434$ and $r = -0.2383$ are not significant. We conclude that the family system and the burden scores are independent.

Table 11: Type of living :

burden score of cervix cancer		burden score of breast cancer	
r value	-0.32	r value	-0.02113
P value (two-tailed)	0.0793	P value (two-tailed)	0.9102

Type of living and burden score do not have significant relationship as $r = -0.32$ and $r = -0.02$ respectively in cervix group and breast group.

Table12: Treatment modality :

burden score of cervix cancer		burden score of breast cancer	
r value	0.09942	r value	0.389
P value (two-tailed)	0.5946	P value (two-tailed)	0.0305

Treatment modality and burden score have good correlation ' r ' = 0.39 in breast group and it is significant, whereas it is not significant in cervix group.

Table 13: Time spent

burden score of cervix cancer		burden score of breast cancer	
r value	0.3447	r value	0.2654
P value (two-tailed)	0.0576	P value (two-tailed)	0.149

The time spent by caregivers is not significantly correlated to burden score as $p=0.0576$ and $p = 0.149 > 0.05$. We conclude that apart from time spent there are other factors to maximize the burden to the individual caregiver.

Table 14: Duration of illness

burden score of cervix cancer		burden score of breast cancer	
r value	0.117	r value	0.3462
P value (two-tailed)	0.5495	P value (two-tailed)	0.0564

The ' r ' = 0.117 and $r = 0.34$ are not significant as $p = 0.549 > 0.05$ And $p=0.059 > 0.05$. We conclude that duration of illness and burden score are not correlated.

Table 15: Illness

burden score of cervix cancer		burden score of breast cancer	
r value	0.1734	r value	0.2441
P value (two-tailed)	0.3509	P value (two-tailed)	0.1857

The pearson ' r ' = 0.1734 shows that the relationship between the illnesses and the burden score of caregivers certify is positive. It can be concluded that as the illness is more than the burden score is also more but it is insignificant as $p = 0.35 > 0.05$.

Table 16: Income

burden score of cervix cancer		burden score of breast cancer	
r value	-0.2546	r value	-0.1776
P value (two-tailed)	0.1669	P value (two-tailed)	0.3393

No relationship is established between the income level and burdens of the caregivers of cancer cervix as the $p = 0.1669 > 0.05$. But it is seen that as the income becomes low the burden score becomes high and not significant ($r=0.2546$)

DISCUSSION

Caregivers of breast cancer group were of 20-30 age groups, but for cancer cervix it was 30-40 age group. More no.of (54%) male caregivers belong to breast cancer group than for cancer cervix group. Both groups were represented by more number of married people. Majority of caregivers in both groups (61.3%, 51.6%) completed school education. Daily wage earners (32.3%, 45.2%) were more represented in both groups. More no. of caregivers in both groups were with income of below Rs.5000 per month. Majority of them in both groups (87.1%, 83.9%) belonged to Hindu religion. 64.5% of caregivers of cancer breast and 74.2% of caregivers of cancer cervix patients belonged to nuclear family. As far as duration is concerned more no. of cases came under 6 months of caring. More number of patients underwent (35.5%) all the three treatment modalities in both groups. As far as time spent per week by the carers in caregiving activities more than 32 hours (87% in breast cancer and 83% in cancer cervix group) is the largest group in both groups.

Sex: As far as breast cancer patient's caregivers are concerned the difference of score between male and female is significant. i.e. $p(0.034) < 0.05$, we

conclude that male caregiver burden score is significantly more when compared to female caregivers. The reason being as explained in a study^[13] men were found to be deeply emotionally engaged but they were hiding it, and were playing protective, reassuring, minimizing role. And it has been found that the coping strategies which husband and wives used were largely independent of one another^[14] Mastectomized wives husbands most of them reported good overall adjustment but a sub group remained distressed and reported adverse effects on their relationship with wives^[15]. Another study^[16] says that breast cancer as an illness gave rise to predominantly negative and dark association among caregivers.

Income: As far as the income is concerned it is seen that as the income becomes low the burden score becomes high. It has been found caregivers with a relatively low socioeconomic state are assumed to report a higher burden and subsequently a poorer health^[17]. In another study^[18] negative relationship between income and caregiver outcomes has been observed for only certain types of caregivers (partners) whereas other types of caregivers as in our study, report no relationships. The financial burden was more problematic than the effect of caring on family routines^[19].

Relationship: Our results show that there is a significant correlation between the relationship and the burden score in both groups (cancer and cervix patient's caregivers). ($p=0.027$, $p < 0.0001$). In the case of family caregivers the burden of caring for their relatives is associated with significant levels of anxiety and depression.^[20]

Duration of caregiving: As far as duration of caregiving is concerned time spent by caregivers is not significantly correlated to burden scores ($p=0.1497 > 0.05$). In a study^[21] among cancer patients and family members no significant effects of the duration of care giving were found on outcome of caregiving^{[22] [23]}.

Treatment modality: We have found that there is a good correlation between treatment modality and caregiver burden scores ($r=0.389$) in breast group and it is significant whereas it is not significant in cervix group caregivers. In studies of spouses of mastectomy patients it was found they were playing a protective, reassuring role.^[13]

Illness of caregivers : Our results show when the physical illness were more in caregivers then the burden scores were also more in both groups. Caregivers physical wellbeing is at greater risk because they have little time to rest, engage in fewer self care behaviour or often fail to seek medical help for themselves when sick.^[24]

Depression: It is seen that there is a positive correlation between depression and burden score in both groups of care givers and the correlations are significant. We conclude that whenever the burden score are more the depression is also more.

Several authorities^{[25] [26] [27] [28][29]} noted that depression is the primary psychological symptom in caregivers of cancer patients.

Anxiety: There is no relationship between anxiety and burden scores in both groups of caregivers. In some of the studies^[30], the authors demonstrated positive experience of giving care rather than negative experiences. They also argued that caregivers who were most intensely involved in care giving might have greater opportunity to derive satisfaction from care giving. This may be the reason why some of the caregivers were not anxious as in our study.

Family System: There were no relationship between the caregiver burden of both groups and the family system.

PSLE score: Mean PSLE score for caregivers of cancer cervix patients is significantly more than the caregivers of breast cancer patients.

CONCLUSION

Male caregiver burden scores were significantly more when compared to female caregivers of both groups. Another finding is seen that as the income becomes low the burden scores become high. And there is a significant correlation between the relationship of the caregiver and the burden score of both groups. There is a good correlation between the type of treatment modality and caregiver's burden scores in breast cancer patients only. Whenever the burden score were high the depression scores were also high. Mean PSLE scores for caregivers of cancer cervix patients were significantly more than the caregivers of breast cancer patients. Hence our findings suggest that the families living with breast and cervical cancer patients are vulnerable if the caregiver is male, from

low socioeconomical background, more closely related and when the patients received poor treatment modalities.

Limitations: Our sample is small. There is no rating scale in vernacular language. We have translated it to our local language. It may be a confounding factor.

Future directions: Patients and caregivers need to be considered as a unit for attention in the clinical setting and clinicians need to invest in the education and support of family caregivers in order to enhance their care giving roles. Patterns of caregiving changes in relation to the course of the patient's illnesses will throw more light about the care giving process.

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