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The Relationship between Strain and Burden among Caregivers of Cancer Survivors

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Abstract

Caregivers play an imperative role in supporting people with cancer at each stage of the illness trajectory. Providing care to cancer survivors may lead to many negative impediments in all aspects of caregiver's life because it's inherently stressful causes strain and burden in their life.

Materials and methods: A descriptive co-relational study was used to find the strain and burden among cancer survivors. The caregiver's strain was assessed by using caregiver's strain index (13 item) and burden was evaluated by Zarit Burden Interview (ZBI), a 22 questionnaire was used to collect the data from the caregivers through the structured interview scheduled.

Results: Regarding the caregiver's strain, the majority (78%) had severe strain, remaining 22% had moderate strain and none of them had mild level of strain. Whereas regarding the burden, the majority (80%) had moderate to severe burden, remaining 20% had severe burden and none of them had little or mild burden. The Pearson correlation coefficient value was $r = 0.58$ ($P=0.001***$). It shows that, when the caregiver's level of strain increases the burden level also increases.

Conclusion: The family caregivers need a unique attention regarding the physical and psychological issues and their concerns in order to improve the quality of life of caregivers and as well as cancer survivors.

Keywords: caregivers, strain, burden, quality of life and cancer survivors

1. Introduction

Cancer has become one of the ten leading causes of death in India and second highest cause of death among adults. The global community can expect an increase of incidence of about 1% each year, with larger increase in China, Russia and India. In 2030, incidence may increase to 20-26 million with around 13-17 million mortality. Cancer cases doubled globally between 1975 and 2000, will double again by 2020 and triple by 2030. According to GLOBOCAN 2012 report, in worldwide the recent 28 types of cancer in 184 countries offers a comprehensive overview of the global cancer burden [1]. The diagnosis of cancer itself makes the survivors to be threatened in all aspects, and also interrupts the different aspects in their caregivers' life. But the advanced medical technologies has increased survivors chances of cure or remission and has also prolonged the life span even in final stage makes shortened hospital stays and increased use of outpatient services for cancer management [2].

Now, the medical policies have turned their focus of care from professionals to non-professionals which needs an earlier discharge of cancer survivors from hospital. The longer survival and the trend to accommodate patients' desire to be cared for at home, families are supported, or have no option than, to become primary caregivers during treatment, advanced illness, and hospice care [3]. In result, family caregivers (FCs) have a vital role in providing care for these survivors. Hence, they are involved in all aspects of patient care, leads to lifestyle changes throughout the process to meet the demands of their new role makes lot of changes including physical, emotional, social, financial, and spiritual aspects which are considered as a cancer care burden [4].

The family caregivers may experience a host of problems, such as depression, anxiety, anger, lack of sleep, severe fatigue, physical problems and financial problems [5]. They may also experience primary stressors that stem from the patients' daily needs (e.g., bathing, dressing feeding, taking medication, and managing finances) and secondary stressors like providing psycho social support, transportation to clinics, and concern regarding monitoring symptoms in the patients. Family care giving may also lead, to feelings of anger and resentment end up in poor quality of life of caregivers [6]. In studies with large population-based samples, about one third of caregivers reported that neither strain nor negative health effects. Particularly in the early stages of care giving, negative effects may not occur. Even when care giving demands become more intense that results in high levels of distress and depression [7].

Need for the study

The rapid increase in the global cancer burden represents a real challenge for worldwide health systems and as well as to the cancer survivors.

Caregiver's are healthcare assets yet they take care in the chronic stage even at home; but in the health care team members are focus solely on patients, caregiver's needs may not be recognized. The participation of the family caregiver in the health care team might have an important role in improving the patient's health and Quality of life. Family caregiver's provides unexpected care that is physically, emotionally, socially, and financially demanding and might result in the neglect of their own needs. (8) As patients move through the cancer trajectory, and as disease progresses, the needs of patients and their carers increase exponentially. The role of the cancer carer has been transformed from the simple provision of custodial care into a multifaceted role with responsibilities that can be complex and burdensome. Therefore, Carers are essential for ensuring treatment compliance, continuity of care, social support and assisting the healthcare system in achieving the patient's treatment goals (9). In response to these health concerns, researchers had an interest to identify the determinants of caregivers strain and burden. Furthermore, assessing the cancer care burden on family caregivers is essential for establishing any care programs aimed to increase the quality of life among these caregivers.

Statement of problem:

A study to evaluate the relationship between caregiver's strain and burden among cancer survivors

3. Objectives

1. To assess the level of caregiver's strain and burden among cancer survivors.
2. To correlate the caregiver's strain and burden among cancer survivors
3. To associate caregiver's strain and burden with selected demographic variables and malignancy related variables among cancer survivors

4. Materials and Methods

The necessary Permission and ethical approval was obtained to conduct this study. A convenient sampling technique was employed to select the sixty samples from Oncology outpatient clinic, in selected hospital, chennai-02. Informed consent was obtained from the participants. The structured interview method was used to collect data from the participants of 15 – 20 minutes without having any possible interaction with other participants.

4.1 Tools and techniques

Caregiver's strain was assessed by using caregiver's strain index developed by Robinson. B. The total item was 13 and for the answer 'Yes' given '1' score and 'No' given '0' score. The interpretation of the score is 0-6 mild, 7-9 moderate and 10-13 severe. The Zarit Burden Interview (ZBI), a 22 questionnaire, 5-point Likert scale (never = 0, nearly always = 4) used widely to evaluate caregiver's burden. The total e scores in the range of 0 to 88, higher scores indicating greater burden. The interpretation of the score is 0 - 21 little or no burden, 21 - 40 mild to moderate burden, 41 - 60 moderate to severe burden and 61 - 88 severe burden .

4.2 Criteria for the sample selection

Inclusion criteria

- The caregivers who were,
- Closely related to cancer survivors (Family members- person who provide the most assistance like spouse, children, parents and siblings).
 - Involved in the care of cancer patients(at least 2-3 hours per day)
 - Aged > 18 years and including both genders
 - Know the language of Tamil or English
 - Willing to participate

Exclusion criteria

- The caregivers who were,
- Under the treatment of Psychiatric illness
 - Not willing to participate.
 - Not known the language of Tamil or English

5. Results and Discussion

The collected data were analyzed by using descriptive & inferential statistics and based on objectives discussed as follows,

5.1 To assess the level of Caregiver's strain and burden among cancer survivors

Among the sixty samples, all the caregiver's had physical strain, frequent changes in personal plan and 93% felt that it's convenient to give care for the cancer survivors. The majority (85%) had sleep disturbances and financial strain. The overall findings shown in table 1, the majority (78%) had severe strain, remaining 22% had moderate strain and none of them had mild level of strain .The similar study findings supported the present study, the Iranian primary family caregivers of hematologic cancer patients experience many strains in physical, psychological, and financial aspects of their life (3). The Payne and colleagues found that 84% of FCs of patients with advanced cancer reported high levels of psychological distress and lack of sleep, 41% experienced high levels of strain, and 10% reported life restrictions and limited support (10).

Table 1: shows the level of caregiver's strain among cancer survivors

	No. of caregivers	Percentage
Mild	0	0.0%
Moderate	13	21.7%
Severe	47	78.3%
Total	60	100.0%

Whereas regarding the burden, the majority (66%) had financial burden and seeking for the better job in caring for cancer survivors. The 60% of the caregivers are supporting alone to deliver the care and have afraid about their future. The overall findings shown in table 2 reveals that, the majority (80%) had moderate to severe burden, remaining 20% had severe burden and none of them had little or mild burden. The other studies have been reported that, the effects of cancer care on financial status, and the job return (11).

Table 2: shows the level of caregiver's burden among cancer survivors

	No. of caregivers	Percentage
Little or no burden	0	0.0%
Mild to moderate burden	0	0.0%
Moderate to severe burden	48	80.0%
Severe burden	12	20.0%
Total	60	100.0%

5.2 Regarding correlation between the caregiver's strain and burden score among cancer survivors.

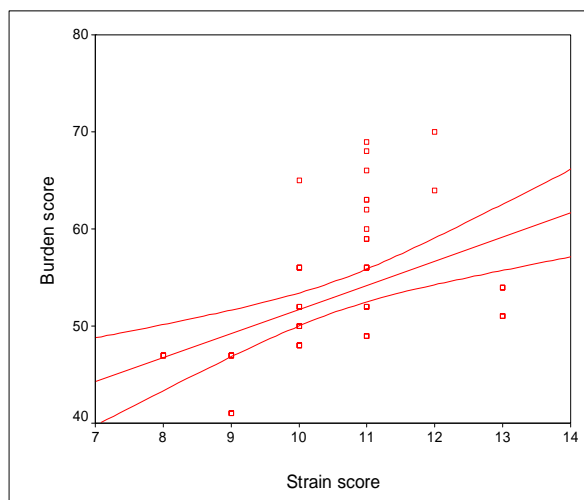


Fig 1: shows the Scatter diagram with regression estimate shows the positive, moderate correlation between strain score and burden score (r=0.58 p=0.001)

Table 1: shows, the correlation co-efficient of caregiver's strain and burden score among cancer survivors.

	Mean	SD	% of mean score	Correlation co-efficient	Interpretation
Strain score	10.5	1.32	1.32	r=0.58 P=0.001***	There is a significant, positive, moderate correlation between strains score and burden score.
Burden score	52.95	6.91	6.91		

Table 3 depicts that, the caregiver's mean and standard deviation of strain score was 10.5 and 1.32. Whereas the caregiver's mean and standard deviation of burden score was 52.95 and 6.91. The Pearson correlation coefficient value was $r=0.58$ ($P=0.001$). It's reveals that, when the caregiver's level of strain increases the burden level also increases.

5.3. Regarding the association of demographic and clinical variables with caregiver's Strain and Burden among cancer survivors.

a. It was found that, the all caregivers (100%) those who are giving care to female cancer survivors had severe strain, but in male it was 71% in severe strain and 29% in moderate level of strain. Whereas, regarding the burden in caring for the female cancer survivors 47 % had severe burden, 53% had moderate to severe burden, but in male only 11 % had severe burden and remaining 89 % had moderate to severe burden. The chi square value of 5.63 and 8.88 was significant at the level of $P=0.02^*$ and 0.01^{**} . It shows that, the caregivers who are caring for the female cancer survivors had more severe strain and burden than the male survivors.

b. Regarding the education, the caregivers who completed their college level had 100% of severe strain than the school level (89%) and not had formal education caregivers. (65%). The chi square value of 7.64 was significant at the level of $P=0.0^{**1}$ but it's not had association with burden score. It denotes that, the caregivers who had higher education try to deliver a quality of care when compare to the other level of education.

c. Regarding the family type, the caregivers who are in the joint family 27 % had severe burden and 73 % had moderate to severe burden where as in nuclear family 100% in moderate to severe burden. The chi square value of 8.65 was significant at the level of $P=0.01^{**}$ but it's not had associated with strain score. It illustrates that, the joint family caregivers had more burden than nuclear family caregivers.

d. Regarding the types of caregivers, the severe strain and burden scores were 100% and 62% in spouse, 84 % and 13 % in children and 50% and 14 % in siblings. The chi square value of 9.60 and 10.42 was significant at the level of $P=0.01^{**}$. It's depicts that, the spouses are had more strain and burden when compare to the other family members. Haj Mohammad *et al* stated that Thirty-four percent of the spousal caregivers who were looking after esophageal cancer survivors reported moderate or high burden.

e. Regarding malignancy related variables, the level of strain and burden score was associated with the stage of malignancy ($X^2=8.70$ and 12.28), functional status of the client ($X^2=8.71$ and 10.53) and duration of treatment ($X^2=15.16$ and 8.68 , $P=0.03^*$) at the level of $P=0.01^{**}$. It's showed that, the caregivers who are caring for stage II, ambulation level and within 1-5 yrs of taking treatment of cancer survivors had less strain and burden than the stage IV, bed ridden and more than 10 yrs taking treatment of cancer survivors.

6. Recommendations

Caregivers are the core of healthcare resources and for the cancer survivors. Therefore, it is essential that caregivers must be included in healthcare transactions and their contributions in care partnering must be made transparent. But still many unanswered questions require further research.

- ✓ Longitudinal studies are needed to establish more clearly the long-term impact of care giving on caregivers of cancer survivors.

- ✓ The care giving burden may vary in different stages; therefore, individual caregivers may need different interventions and strategies that meet their needs in caring for loved ones.
- ✓ The findings depicts that, the family caregivers need special attention regarding the psychological issues and their concerns.
- ✓ Family caregivers also need to have appropriate counseling methods.
- ✓ This study findings, helps to identify the variables leading to improved or increased QOL and wellbeing among caregivers.
- ✓ The result helps to plan for the family centered care in order to improve psychological wellbeing of the caregivers.

7. Conclusion

Cancer causes patients and caregivers to lose control over their lives, has an adverse effect on their personal and social life causes their health and quality of life to deteriorate. Oncology nurses are uniquely positioned to play a vital role in recognizing caregivers strain and burden to intervening to break the cycle of unremitting physical and psychosocial burden. When caregivers don't get the help they need, or if they try to do more than they are able, either physically or financially burnout can occur. Caregivers who are "burned out" may experience fatigue; stress, anxiety, and depression inversely affect their quality of life. This study finding depicts that, additional research should focus on need based intervention helps to reduce the strain and burden and improve their overall health and quality of life of caregivers.

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