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Relationship Between Quality of Life and Self-Efficacy Among the Caregivers of Palliative Care Patients of Lung and Breast Cancer

KEYWORDS : Breast cancer, Lung Cancer, Palliative care, Quality of Life

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ABSTRACT

Pain is one of the most common and dreaded symptoms associated with cancer during palliative care. An individual who assumes the care of the ill relative is expected by society to provide both physical and emotional support to the patient. This responsibility creates a stressful situation for the caregivers, often evoking symptoms of psychological distress. Such distress begins at the time the chronically ill patient gets into palliative care affecting the Quality of Life and Self-Efficacy of caregivers. The present study examines the relationship between Quality of Life and Self-efficacy among the caregivers of lung and breast cancer patients. The participants were caregivers (n=30 in each group) of lung and breast cancer patients who were in palliative care. The caregivers were with the patient in palliative ward for a minimum period of 30 days. The caregivers completed a measure assessing their Quality of Life and Self-efficacy for helping the patient manage symptoms. Purposive sampling technique was used for the study. T test and Pearson correlation was used to analyze the results. The results revealed that the caregivers of lung cancer patients had poor Quality of Life and low self-efficacy compared to caregivers of breast cancer patients. Scores vary negatively with Quality of Life for the caregivers of Lung cancer patients. Though there is a negative relationship between Self-Efficacy and Quality of Life among the caregivers of breast cancer patients the relationship is not significant.

Introduction:

Patients with oncology disease may complain of pain or discomfort related to the complication of treatment. The primary caregiver is forced to take responsibility for the patient's medical treatment and daily routine. Lung cancer and its treatment impose many demands on family caregivers, which may increase their risk for distress. [1] Studies have revealed that caregivers who rated their self-efficacy as high reported much lower levels of caregiver strain. [2]

Most research on the association between socioeconomic status and caregiver emotional state indicates a positive correlation. Oberst et al., [3] found that caregivers of a low Socio-economic status felt more threatened by the patient's illness. Similarly, financial problems were consistently cited as one of the issues of greatest concern (along with general health, self appraisal, work and condition of family) by caregivers of patient's in chemotherapy treatment. [4]

In the light of the above studies the objective of the present study was:

1. To examine whether there is a significant difference in Quality of Life and Self-Efficacy among the caregivers of Lung Cancer and Breast Cancer patients in palliative care
2. To examine the relationship between Quality of Life and Self-Efficacy among the caregivers of breast and lung cancer patients in palliative care

METHODS:

PARTICIPANTS: The current study has 30 caregivers each of patients with Lung cancer and Breast cancer. The patients of both the group were diagnosed with cancer and were in Palliative care. The patients did not have any other cancer apart from lung and breast cancer. The caregivers of these patients were taken for the study after taking their consent. As is common in the cancer literature, "caregiver" was broadly defined in this study as any friend or family member who provided practical and emotional support to the patient. To identify the primary caregiver the patient was asked to identify the person they relied on for support with things like getting the doctor or going to the doctor, taking medication and other instrumental tasks. They were then asked to identify the main person they relied on for support. This person was identified as the primary caregiver. The person they mentioned as caregiver was cross checked with the doctors and nursing staff.

The inclusion criteria for caregivers to be included were: 1. they do not suffer from major health problems. 2. They lack social and economic support 3. They are in hospital caring for the patient for a minimum period of 40 days. 4. They belong to low socioeconomic group 5.they are living with the patient from past 4 years 6. The caregivers who do not get respite care.

Eighty four caregivers were considered to be included for the study. Of those approached 24 caregivers declined and 60 caregivers consented. The most common reasons for declining included "lack of interest" (8), "How do I benefit" (12), "too busy in taking care of the patient" (4). The caregivers were chosen from the palliative care ward of cancer hospital.

The male caregivers of the study were 12 and women caregivers were 18. Both patients and caregivers were predominantly illiterate. 20 % of the caregivers were husband, 23.33% were wife, 16.66 % were sons, 30% daughters, and 3.33% each were sister, brother and sister-in-law.

MEASURES:

Interview schedule: A semi-structured interview schedule was used to elicit more information from the caregiver apart from the one covered in the questionnaires. The schedule elicited greater information about the caregiver profession, family relationship, family structure and emotional turmoil they were experiencing.

Socio demographic details: The socio demographic detail was required to know about the caregivers profession, monthly income, type of family, geographical region they live in, age, SES, and economic coverage { government scheme (Below poverty line) or private scheme coverage}.

The socio demographic details of the patient was also taken like cancer stage, year or month of diagnosis, current treatment, food and other habits of the patient and frequency of habits.

The Quality of Life of caregivers of cancer: The QOL questionnaire consists of 35 items with 5 dimensions namely, Burden, Disruption, Positive Adaptation, Finance and Others. The Burden dimension consists of -10 items, Disruption 7 items, Positive adaptation 7, Financial 3 items and others 8 items. This scale was developed by Weitzner (1999). It has the psychometric properties of internal correlation and coefficient of .90 and .94

Self-Efficacy scale: Self –Efficacy scale of caregivers was developed by Porter (2007). It consists of 16 items with 3 subscales namely, managing pain, symptoms and function. Caregivers were asked to rate how confident they are that they can help the patient manage symptoms. Caregivers rated 16 items regarding their perceived ability to manage a variety of symptoms on a scale of 10 (not at all certain) to 100 (certain). The 3 subscales are highly correlated with each other (.80 to .86). The possible range for the total score is 0 to 100 with higher scores indicating greater Self-Efficacy. Cronbach alpha for the total subscale was .96.

Ethics: the protocol or procedure followed were in accordance with the ethical committee of the hospital

Statistical Analysis:
Firstly, 't' test were calculated to test the significance of difference between the two groups of caregivers that is caregivers of Lung Cancer and Breast Cancer patients on Quality Of Life

Secondly,'t' test were calculated to test for significance of difference between the caregivers of Lung Cancer and Breast Cancer patients on Self-Efficacy scale

Thirdly, Pearson correlation was used to examine the relationship between Self-Efficacy and Quality Of Life among the caregivers of Lung Cancer patients.

Fourthly, to know the relationship between Self-Efficacy and Quality Of Life for caregivers of Breast Cancer patients Pearson correlation was used.

Results:
Descriptive Analysis:

Table 1: indicating t test for significance of difference between the caregivers of two groups on QOL

	Group	n	M	SD	SEM	t	Sig. (2-tailed)
Burden	lung cancer caregivers	30	28.0667	7.82539	1.42871	2.327(*)	.023
	breast cancer caregivers	30	23.5000	7.37072	1.34570		
Disruption	lung cancer caregivers	30	20.4333	5.15072	.94039	2.353(*)	.022
	breast cancer caregivers	30	17.3333	5.05373	.92268		
Positive Adaptation	lung cancer caregivers	30	15.4333	4.06570	.74229	1.891	.064
	breast cancer caregivers	30	13.7333	2.77841	.50727		
Financial Concern	lung cancer caregivers	30	11.6333	4.78131	.87294	.916	.363
	breast cancer caregivers	30	10.7000	2.87858	.52555		
Other	lung cancer caregivers	30	19.0667	4.82045	.88009	1.078	.285
	breast cancer caregivers	30	17.7333	4.75564	.86826		
Total QOL	lung cancer caregivers	30	94.5667	16.88640	3.08302	2.815(**)	.007
	breast cancer caregivers	30	82.0333	17.59405	3.21222		

Note: df = 58
** t value is significant at the 0.01 level (2-tailed).
* t value is significant at the 0.05 level (2-tailed).

The mean score on the subscale of Burden for Lung cancer caregiver is 28.06 and Breast cancer caregivers is 23.50.The Lung cancer caregivers show higher degree of Burden as compared to Breast cancer caregivers. The difference between the two groups of caregivers was significant on Burden sub scale (t=2.327, df=58, **P<0.01).

On the subscale of Disruption greater disruption was seen in Breast cancer caregivers as compared to Lung cancer caregivers where the mean is 20.433 and 17.33 respectively. The difference between the two groups was significant (t=2.353, df=58,*P<0.05)

Mean scores on the subscale of Financial concern for Lung cancer caregivers was (mn=11.63) slightly higher as compared to Breast cancer caregiver (mn= 10.700). The mean score for the Lung cancer caregivers is higher than the Breast cancer caregivers though the difference between the two groups was not significant (t=1.89, df=58, P>.05)

On the subscale of Other the mean is 19.06 for Lung cancer caregivers and 17.73 for breast cancer caregivers. The caregivers of Lung cancer patients experience more of distress like greater mental strain, focus of day to day activities affected, their social life being limited etc. than compared to breast cancer caregivers. The mean score of caregivers of Lung cancer patients is higher than that of caregivers of breast cancer patients, although the difference between the two groups was not significant (t=1.078, df=58, p>.05)

TABLE 2 shows t test for significance of difference between the caregivers of Breast cancer and Lung cancer patients on Self-Efficacy

	Group	n	M	SD	SEM	t	Sig. (2-tailed)
Symptom	lung cancer caregivers	30	185.6667	36.64210	6.68990	-.998	.322
	breast cancer caregivers	30	200.3333	71.65450	13.08226		
Function	lung cancer caregivers	30	131.3333	65.42874	11.94560	-2.409(*)	.019
	breast cancer caregivers	30	171.6667	64.27759	11.73543		
Pain	lung cancer caregivers	30	171.0000	56.46787	10.30958	-.024	.981
	breast cancer caregivers	30	171.3333	51.57742	9.41670		
Total Self Efficacy	lung cancer caregivers	30	487.3333	103.92084	18.97326	-2.063(*)	.044
	breast cancer caregivers	30	550.0000	129.93367	23.72253		

Note: df = 58
** t value is significant at the 0.01 level (2-tailed).
* t value is significant at the 0.05 level (2-tailed).

The total mean score of Quality of life of caregivers of Lung cancer patients is very low compared to the Breast cancer caregivers. The caregivers of Breast cancer patients had better Quality of life than the caregivers of Lung cancer patients where the difference between the two groups is significant (t=2.815, df=58, **P<.01)

On the subscale of Symptom the Lung cancer caregivers have a lower mean value as compared to Breast cancer caregivers although there is no significant difference between the two groups of caregivers (t=0.998, df=18, P>.05). With regard to function subscale there is a significant difference between the Breast cancer and Lung cancer caregivers with Breast cancer caregivers showing greater Self-Efficacy (t=2.409, df=28, P<0.05). On the subscale of Pain, there was not much difference between the two groups of caregivers, though there is marginal difference between the two groups (t=0.024, df=58, P>.05). Overall the Lung cancer caregivers have low Self-Efficacy compared to Breast cancer caregivers with a significant difference between the two groups (t=2.063, df=58, *P<0.05).

TABLE 3: shows the correlation between S-E and QOL for the caregivers of Lung cancer patients.

Lung cancer	QOL						
		Burden	Disruption	Positive Adaptation	Financial Concern	Other	Total
Symptom	Pearson r	-.319	-.428(*)	-.230	-.027	-.262	-.357
	Sig. (2-tailed)	.086	.018	.221	.887	.162	.053
Function	Pearson r	-.247	-.538(**)	-.242	-.333	-.277	-.505 (**)
	Sig. (2-tailed)	.188	.002	.197	.072	.139	.004
Pain	Pearson r	-.283	-.085	-.058	.037	-.308	-.216
	Sig. (2-tailed)	.129	.657	.763	.845	.098	.251
Total	Pearson r	-.425(*)	-.543(**)	-.284	-.200	-.445(*)	-.573 (**)
	Sig. (2-tailed)	.019	.002	.129	.290	.014	.001

Note: df = 28
** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Pearson correlation was used to find the correlation between QOL and Self-Efficacy among the caregivers of Lung cancer and Breast cancer caregivers. A negative significant correlation is seen between Symptoms and Disruption subscale in QOL (r= -.230, df= 28, *P<.05). As the Self-Efficacy with regard to symptom management decreases the Disruption of the caregiver increases. Inverse negative relationship is seen between Function and Disruption on QOL. There is a significant inverse relationship between the two subscales (r= -.538, df=28, **P <.01). As the function management decreases the overall QOL score also has increased (r= -.505, df=28, **P<0.01) meaning that QOL is poor. Overall as the Self-Efficacy decreases there is an increase in Burden (r= -.425, df=28, *p<0.05), Disruption (r= -.543, df=28, **P<0.01) and Others (r= -.445, df=28, *p<0.05). As the Self-Efficacy decreases the QOL of the caregivers also decreases (r= -.573, df=28, **P=<0.01)

Table 4 shows the correlation between S-E and QOL for caregivers of BC patients

		Burden	Disruption	Positive Adaptation	Financial Concern	Other	Total QOL
Symptom	Pearson r	-.278	-.313	-.202	-.633(**)	-.230	-.401(*)
	Sig. (2-tailed)	.136	.093	.284	.000	.221	.028
Function	Pearson r	-.190	-.266	-.374(*)	-.415(*)	-.152	-.309
	Sig. (2-tailed)	.314	.155	.042	.023	.423	.097
Pain	Pearson r	.346	.124	.140	.096	.122	.227
	Sig. (2-tailed)	.061	.514	.461	.615	.519	.227
Total Self Efficacy	Pearson r	-.060	-.253	-.245	-.511(**)	-.145	-.257
	Sig. (2-tailed)	.752	.177	.191	.004	.444	.171

Note: df = 28
** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

The above table shows significant correlation on certain dimensions of QOL and Self-Efficacy. As there is low Self-Efficacy in symptom management there is an increase in financial concern (r= -.633, df=18, **P<0.01) and also on total of QOL (r= -.401, df=18, P<0.05). In the subscale of function of breast cancer a negative correlation between function and positive adaptation (r= -.374, df=28, *P<0.05) and financial concern (r= -.415, df=28, *P<0.05) is seen.

Overall an inverse relationship is noticed (r= -.511, df=28, **P<0.01) between Self-Efficacy and financial concern among the caregivers of both Lung cancer and Breast cancer groups.

Discussion:

The present study was set to study the relationship between quality of life and self-efficacy of the caregivers of lung and breast cancer patients in palliative care. The findings reveal that burden of caring is greater among the Lung cancer caregivers. Lung cancer poses significant challenges for patients and their caregivers including aggressive medical treatments and an uncertain prognosis. In addition to pain, patients often must cope with fatigue, shortness of breath and other troubling symptoms. The complications of Lung cancer patients during Palliative care are several like accumulation of fluids around the heart, fluid between the lung and chest which can cause shortness of breath, further spread of cancer and side effects of chemotherapy and radiation therapy. Apart from the above the common problems are coughing up blood, persistent cough, shortness of breath and unexplained weight loss. [5] As the chances of recovery is poor in case of Lung cancer patients the burden experienced by the caregivers are greater compared to other cancers.

The death rate for Lung cancer can sometimes be high as all deaths put together in instances of colon, prostrate and Breast cancer together which will illustrate the magnitude of the problem. It becomes a greater burden for the family members to take care of the patient at home, especially for the caregiver. In case of the Breast cancer patients though they are in Palliative care the management of symptoms is easier. Giving complete physical care to the breast cancer patient may not be that burdensome as that of Lung cancer patient.

As the patients health starts slipping to a limited stage the Disruption of the caregiver also increases. The routine work of the caregiver also gets disrupted to a greater extent which may result in greater burden and becomes difficult to manage their health. The financial concern for both the types of cancer is more or less same but slightly greater in case of Lung cancer patient since the patient's health condition becomes critical which needs hospital care. The patient needs to be admitted often to intensive care ward, thus increasing the financial burden of the caregiver. Regarding, others on QOL scale though caring for both the groups of patients, like management of pain being overwhelming, feeling sad, increased mental strain, inadequate information from doctors about the patient's condition, there is not much difference between the two groups of caregivers.

Although symptom management like making the patient feel better, helping the patient to control his/her fatigue is difficult in Lung cancer patients than the Breast cancer patients, the caregivers of both the group have poor Self-Efficacy in symptom management though the difference between the two groups is not significant. The caregivers of Breast cancer patients show greater confidence when it comes to function management like managing the patient's physical symptoms regulate the patient's activity and continue with most of their daily activities, than the caregivers of Lung cancer patients. With respect to pain management, the caregiver's confidence in reducing the pain of the patient or reducing pain without medication was low with both groups of caregivers. Overall the caregivers of Lung cancer patients had poor Self-Efficacy compared to caregivers of Breast cancer patients. [6] For the Lung cancer caregivers the Self-Efficacy varies negatively with QOL. As the confidence of the caregiver decrease with regard to symptom management and function of the patient, the disruption of the caregiver also increases

It is seen that as the patient condition deteriorates to limited stages with more severe pain, reduced activity and poorer management of self, the burden and disruption of the caregiver's increases [7] leading to much poorer QOL. In case of Breast cancer caregivers as the patient's condition worsens and symptom management becomes difficult managing the patient at home becomes difficult and hospital care becomes necessary. The patient has to be readmitted very often and this leads to greater anxiety, stress and financial burden for caregivers [8]. Care givers concern over family income was associated with the symptom of distress [9]. Communicating with the doctors, managing finances, not getting adequate information about the patient's health condition leads to poorer adaptation to life. The deteriorating condition of the patient does not give them any hopes or they lose hope in spirituality and have a negative outlook towards life.

The findings of the study indicate that as the Self-Efficacy of the caregivers to manage patients of both the groups' decreases due to the increased hidden cost of caring, decreased pain and symptom management and greater burden of caring, the poorer will be the quality of life of the caregiver.

These findings raise the possibility that adequate provision of information regarding critical care management may increase the caregiver's self-efficacy and help in avoiding poor quality of life.

The findings of the study seem to have some practical implications for future research. Admissions to critical care may be very frightening for both the patient and the caregiver. Provisions of training the caregivers during emergencies from the treating doctors and nurses can help the caregiver's to have confidence in themselves to manage the patients pain, symptom and function, as the caregivers find it difficult to shift the patient immediately from the rural area to the treating hospital. Interventions such as relaxation technique and meditation may prove useful for caregivers as it may help to reduce anxiety and manage the patient effectively to some extent. Adequate provision of information regarding critical care management and information about the patient's deteriorating condition is an important means of making the caregivers to adapt to the poor health condition of the patient and maintain their own quality of life.

In spite of the findings of the study there are also some limitations. It might be noted that the spousal caregivers or the gender differences of the caregivers were not considered for the study. The age of the caregivers was not emphasized. A comparative study of rural and urban caregivers may also provide further insights into the quality of life and self-efficacy of caregivers.

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