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The Quality Of Life of Caregiver's of Cancer survivors

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Abstract:

Family caregivers play a major role in managing all aspects of the patient's care. Family caregivers who care for cancer survivors may have to cope with a range of physical, social, and economic problems during the care process. The decrease in the quality of life of caregiver's directly influences on cancer survivors health. The majority (75%) of caregivers had moderate quality of life, remaining 25 % had mild quality of life and none of them had good quality of life. The Percentage of QOL score with 95% CI was 59.0% (57.3%-60.6%) indicates that the majority of caregiver's had moderate quality of life. The caregiver's who have more income, early stage and recently diagnosed cancer survivors leading the moderate QOL.

Key wards: *Quality of life, Caregiver's, Cancer survivors, and malignancy*

1.Introduction:

Oncology is one of the dynamic field experiencing fastest development in the previous few years. New management methods brought about greater chances of survival for cancer survivors and on the other hand, cancer is still a disease with severe impact on the survivors as well as his/her family and close friends.(1) The growing number of persons living with chronic diseases like cancer ,and other terminal illness makes a greater dependence on outpatient care, has increased demands away from professional caregivers toward family caregivers.(2) The responsibility of caring for the cancer patient at home is challenge for the patient's spouse, children, relatives or friends.(3)

Home care has gradually gained more importance and cost effective. It is a great burden on the shoulders of caregivers, but they are having a vital role in care of patients. Caregivers have to undertake the responsibility of the home management, organize care and arrange health care services according to the changing needs of survivors only makes to get accurate and complete care. But they have to cope with a range of physical, social, and economic problems during the care giving process. (4) Morimoto and Schrener (2003) suggested that caregiver's physical health was dependent on the patient's performance status as well as the education level of the caregivers and caregiver's burden is related to increased psychological and physical problems. The family/marital life, career, health state, and social life of caregivers of cancer patients are also proportionately affected during this care provision process. (5) As patients move through the trajectory of cancer, and as disease progresses, the required needs of patients and caregivers increase exponentially.(6) Care giving process exercise a great influence on caregiver

Quality of Life, not only during the time that they are providing care but throughout the trajectory of the illness.(7)

According to GLOBOCAN (2013), an estimated 14.1 million new cancer cases and 8.2 million deaths due to cancer - related occurred in 2012, compared with 12.7 million and 7.6 million, respectively, in 2008.The most common cancer worldwide were lung (1.8 million, 13.0% of the total), breast (1.7 million, 11.9%), and Colo-rectal (1.4 million, 9.7%). The most common causes of cancer death were cancers of the lung (1.6 million, 19.4% of the total), liver (0.8 million, 9.1%), and stomach (0.7 million, 8.8%). The report also found that globally, the overall cancer incidence in age-standardized rate is almost 25% higher in men than in women, with rates of 205 per 100,000 for men and 165 per 100,000 for women. Projections based on the GLOBOCAN (2012) predicts an increase to 19.3 million new cancer cases per year by 2025, due to growth and ageing of the global population.(8)

1.1 Need For The Study:

. The current modalities of management brought about better chances of survival for cancer patients and cancer became a chronic disease like Hypertension, Diabetes etc., Cancer can worsen the caregiver's health, impair social life, increase stress, and cause depression. The number of Cancer survivors and people with cancer symptoms under control is increasing and therefore the research in their quality of life increases more and more importance as well. An important role for nurses is to provide support to promote health and QOL of the patients and as well as the family caregivers. In order to achieve this goal the research is focus on caregiver's situation in terms of QOL and emotional distress and factors influencing these variables.

1.2 Statement of problem: A study to evaluate the Quality of life of caregiver's of Cancer survivors.

2. Objectives

1. To assess the Quality of Life of caregivers of cancer survivors.
2. To associate quality of life of caregiver's with selected demographic variables and malignancy related variables of cancer survivors.

3. Materials and methods

The necessary Permission was obtained to conduct this study. A convenient sampling technique was employed to select the sixty samples from Oncology outpatient clinic, TamilNadu Government Multi Super Specialty Hospital, Chennai-02.Informed consent was obtained from the participants. The structured interview method was used to collect data from the participants of 10-15 minutes without having any possible interaction with other participants. QOL of caregivers was assessed by using QOLLTI-F (Quality of Life in Life Threatening Illness – Family Carer Version) was developed by Dr. Robin Cohen of the division of Palliative Care, Departments of Oncology and Medicine, McGill University. The test-retest reliability for the QOLLTI-F total score was 0.77- 0.80.Among the 16 questions six questions are transposed. The scores are interpreted as Mild <50 %, Moderate 51-75% and Good quality of life 76-100%..

3.1. CRITERIA FOR THE SELECTION OF SAMPLES:

Inclusion criteria:

Caregivers those who are,

- 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 have,

- Psychiatric and mentally retarded .
- not willing to participate.
- Not known the language of Tamil or English
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4. Results and discussion:

The collected data were analyzed by using descriptive & inferential statistics and discussed as follows:

Table 1: Frequency & Percentage Distribution Of Family Caregiver's

S.No	Demographic variables of caregiver's		No. of caregivers	%
1.	Age	20 -30 yrs	9	15.0%
		31 -40 yrs	17	28.3%
		41 -50 yrs	24	40.0%
		51 -60 yrs	6	10.0%
		> 60 yrs	4	6.7%
2.	Gender	Female	40	66.7%
		Male	20	33.3%
3.	Religion	Hindu	36	60.0%
		Christian	16	26.7%
		Muslim	8	13.3%
4.	Education	No formal education	13	21.7%
		School level	35	58.3%
		UG	11	18.3%
		PG	1	1.7%
5.	Family type	Nuclear family	33	55.0%
		Joint family	27	45.0%
6.	caregivers	Spouse	28	47.5%
		Parents	15	25.4%
		Children	11	18.6%
		Siblings	5	8.5%
7.	Occupation	Employed	42	70.0%
		Unemployed	18	30.0%
8.	Family income	Rs.1000 - 2500	15	25.0%
		Rs.2501 - 5000	31	51.7%

		> Rs. 5000	14	23.3%
9.	Residence	Rural	24	40.0%
		Urban	36	60.0%
10.	Marital Status	Married	42	70.0%
		Unmarried	13	21.7%
		Divorced	4	6.7%
		Widowed	1	1.7%

Among 60 samples, the majority (40%) were in the age group of 41-50yrs and only 7% in age group of above 60 yrs. Regarding gender, the maximum level of 67 % were female and remaining 33% male. The majority (60%) of caregivers were belongs to Hindu and 58% had school level education. Nearly half of the caregivers (55%) were belongs to nuclear family and 47% of type of caregivers were mostly spouse. The majority (70%) of the caregivers were employed and married. Considering about residential area, the majority (60%) were from urban and 40% were from rural areas.

Table 2 Shows Distribution Of Malignancy Related Variables of Cancer Survivors

S. No	Malignancy related variables		No. of caregivers	Percentage
1.	The organ involved with malignancy	Oral	8	13.3%
		Lungs	19	31.7%
		Stomach	15	25.0%
		Ovarian	5	8.3%
		Rectum	7	11.7%
		Others	6	10.0%
2.	Stage of malignancy	II stage	32	53.3%
		III stage	22	36.7%
		IV stage	6	10.0%
3.	Functional status of the client	Ambulatory	27	45.0%
		Ambulation with assistance	30	50.0%
		Bedridden	3	5.0%
4.	Treatment in progress	Chemotherapy	18	30.0%
		Radio therapy	20	33.3%
		Surgery	5	8.3%
		RT+ surgery	11	18.3%
		CT+ surgery	4	6.7%
		CT+RT	2	3.3%
5.	Duration of illness in years	1 -5 yrs	38	63.3%
		6 -10 yrs	20	33.4%
		> 10 yrs	2	3.3%

Table 2 shows the malignancy related variables, among 60 samples the 32% had lung cancer, and 10% had other type of cancer includes prostate and skin cancer. Regarding the stage of malignancy half of (53%) survivors were in II stage of illness. The 50% of cancer survivors needs ambulation for assistance, 45% had no problem in ambulation and remaining 5 % were bed ridden. Considering with treatment in progress, 30-33% had chemo and radiation therapy. The majority (63 %) cancer survivors were diagnosed their illness in 1-5 yrs and only 3% were >10 yrs.

Table 3 Shows Mean & SD Of QOL Score Of Caregivers Of Cancer Survivors

sno	Domains	No. of questions	Maximum score	Mean	SD	% of mean score
1	Environment	2	20	11.25	1.78	56.3%
2	Patient state	1	10	5.92	1.43	59.2%
3	Carer's own state	5	50	28.73	4.44	57.5%
4	Carer's outlook	3	30	20.03	3.57	66.8%
5	Quality of care	2	20	13.12	4.01	65.6%
6	Relationships	2	20	9.68	3.22	48.4%
7	Financial worries	1	10	5.67	1.57	56.7%
	Total	16	160	94.40	10.15	59.0%

Table 3 depicts that, the mean and standard deviation of quality of life score of caregiver's of cancer survivors. The majority (66 %) of caregivers were not considered about their personal life, self control and quality of care. The 59% of caregivers had distressful conditions, 57% don't have time to care for themselves, 56% were not satisfied even in residential area & worried in financial aspects and 48 % were not satisfied interaction with neighbors and other peoples. Govina and Vlachou (2014) stated that continuous care of cancer patients compromised the quality of life of family members and it primarily related to their mental health. Family members' mental health was significantly worse than the normal population, and their emotional well-being scores were slightly worse than even patient's scores(9)

Table 4 shows level of quality of life of caregivers of cancer survivors.

	No. of patients	%
Mild	15	25.0%
Moderate	45	75.0%
Good	0	0.0%
Total	60	100.0%

Table 4 reveals that, the quality of life of caregivers of cancer survivors. The majority (75%) had moderate quality of life, remaining 25 % had mild quality of life and none of them had good quality of life.

Table 5 shows incidence of QOL score of caregiver's of cancer survivors

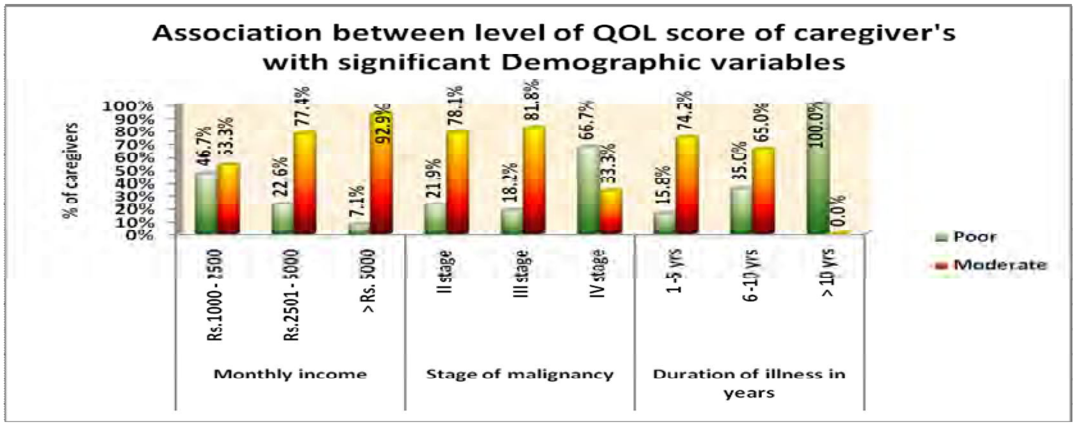
Total score of the QOL tool	Caregivers Mean QOL score	SD	Mean QOL score with 95% CI	Percentage of QOL score with 95% CI
160	94.4	10.2	94.4 (91.8-97.0)	59.0% (57.3%-60.6%)

Table 5 depicts that, the mean quality of life score with 95% CI of 94.4 (91.8-97.0). In that Percentage of QOL score with 95% CI was 59.0% (57.3%-60.6%). It indicates that the majority of caregiver's were had moderate quality of life.

Table 7 shows significant variables for quality of life of caregiver's of cancer survivors.

S.No	Significant Variables		Total score				Total	Chi square test	Odds ratio
			Mild		Moderate				
			n	%	n	%			
1.	Family income	Rs.1000 - 2500	7	46.7%	8	53.3%	15	χ2=4.09 P=0.04* significant	3.5(0 .0– 1.5)
		Rs.2501 – 5000	9	20.0%	36	80.0%	45		
2.	Stage of malignancy	II stage	12	22.2%	42	77.8%	54	χ2=5.45 P=0.02* significant	7.0(0.0-64.0)
		IV stage	4	66.7%	2	33.3%	6		
3.	Duration of illness in years	1 -5 yrs	6	25.6%	32	74.4%	38	χ2=4.68 P=0.03* significant	3.7(0 - 15.0)
		>5 yrs	9	28.6%	13	71.4%	22		

Table 7 shows, significant variables for quality of life of caregivers of cancer survivors. The family income, stage of malignancy and duration of illness has significant variables and it's statistically proved with odds ratio. It depicts that, the caregiver's who have more income, early stage and recently diagnosed cancer survivors leading the moderate QOL.



5. Recommendations

- The research findings helps to identify variables leading to improved or increased QOL and well-being among caregivers
- This study helps to identify the needs of caregivers will enable healthcare providers to develop interventions to enhance the QOL and well-being of caregivers of cancer survivors.
- Family caregivers need specific attention regarding psychological distress and their concerns about diagnose and coping ability.
- Family caregivers also need to have appropriate counseling methods.
- This study can be done on larger samples.
- The study findings helps to Plan for family centered care in order to improve psychological well being of the caregivers.

6. Conclusion:

Caregiver's burden exists at every point along the illness trajectory, including diagnosis, survivorship, death, and bereavement. Because, physical well-being is so closely associated with the medical condition of the patient and the associated symptom burden. This is not a static domain but rather, one that should be assessed and reassessed over time. We nurses are uniquely positioned to play a vital role in recognizing caregiver's strain and intervening to break the cycle of unremitting physical and psychosocial burden. This study emphasis, need for better nurse - caregivers communication and education, particularly in the areas supportive management. Additional research should focus on factors that affect caregivers QOL, their educational needs, and interventions to assist nurses in better delivering new information or reinforcing old information helps to improve the caregiver's quality of life.

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