

“Quality of life of family caregivers of patients with advanced cancer

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Abstract: Cancer is a major public health problem of the world. Diagnosis of cancer has a significant impact not only on patient, but also on their family caregivers. Therefore cancer has a substantial impact on both patients and families. Objectives of the study were to assess the Quality of Life (QOL) among caregivers and to find the association between mean score of quality of life of family caregivers with selected variables. A cross sectional study was done among 399 family caregivers those who are providing care to the hospitalized patients with advanced cancer. A non probability purposive sampling was used to select family caregivers by using structured and validated questionnaire on quality of life. Data were collected by interview technique from caregivers. Result shows that majority of family caregivers were in the age group of 20-40yrs (53.6%), most of the family members had to stop working, and most of them lost their savings. Majority of the family caregivers expressed that ‘financial burden’ had negative influence on the quality of life. The mean Quality Of Life was 63.36 and SD was 15.73. The present study suggests that to improve QOL of caregivers, measures should be taken to decrease the economic burden that cancer places on patient’s family. It also revealed that increasing the self- confidence of family care givers in managing cancer pain is vital to the quality of life of both the patient and caregiver.

Key words: Quality of life, Family caregivers, Advanced cancer

I. Introduction:

Cancer is a major public health problem of the world. According to the World Cancer Report, Cancer rates could further increase by 50% to 15 million new cases in the year 2020, the most comprehensive global examination of the disease to date. In the year 2000, malignant tumours were responsible for 12 per cent of the nearly 56 million deaths worldwide from all causes. In many countries, more than a quarter of deaths are attributable to cancer¹. Cancer affects many people directly or indirectly. Cancer can worsen the caregiver’s health, impair social life, increase stress, and cause depression. Diagnosis of cancer has a significant impact not only on patient, but also on their family caregivers. Therefore cancer has a substantial impact on both patients and their families. Caregiver burden is relative to patient demands, and health is considered the overall outcome of the care giving process. The inability of a caregiver to meet a patient’s need for practical assistance may compromise the patient’s physical well-being and ability to comply with treatment^{2,3,4}.

Recurrent breast cancer compromised the quality of life of patients and their family members. Family members’ quality of life also was affected, but 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 patients’ scores themselves. Family members reported less support, less satisfaction with health professionals⁵.

The purpose of the study was to assess the quality of life of care givers of cancer patients with life limiting illness. Family caregivers have become increasingly responsible for providing home care for cancer patients.

OBJECTIVES

Objectives of the study were to:

- Assess the Quality of Life among caregivers by using quality of life questionnaire.
- Find the association between mean score of quality of life of family caregivers with selected variables such as age, education, income, type of cancer of client, employment status, area of living, duration of illness and treatment.

Hypothesis: Hypothesis was tested at 0.05 level of significance

- H₁: There will be significant association between quality of life and selected variables of family caregivers such as age, education, family income, duration of illness, duration of treatment, type of cancer.

II. Material & Methods

Research approach: Survey

Research design: Explorative survey

Variables:

Outcome Variables caregivers:

QOL of family caregivers of advanced cancer patients

Extraneous Variables:

Age of caregiver, gender, education, employment status, income, type of family, marital status, religion, type of cancer diagnosed, treatment settings, duration of illness, status of disease (stage), treatment modality, relationship with cancer patients.

Research settings: Selected hospitals of Karnataka state.

Population: Family caregivers those who are closely related (spouse, parents, children or siblings) to cancer patients (diagnosed as having breast, cervical, head and neck, lung, GIT or colorectal cancer stage 3 or above) aged above 18years and mostly involved in patient care (at least 2-3 hours per day).

Sample: Family caregivers those who are closely related to cancer patients (spouse, parents, children or siblings) aged above 18years and mostly involved in patient care (at least 2-3 hours per day) of selected hospitals.

Inclusion criteria for care givers:

Care givers those who are

- closely related to cancer patients (Family member- person who provide the most assistance like spouse, children, parents and siblings).
- Involved in the care of cancer patients (at least 2-3 hour per day)
- aged ≥ 18 years and including both genders
- know the language Kannada or English
- are willing to participate.

Exclusion criteria:

Those caregivers who have

- Psychiatric and mentally retarded problems

Sample size: 399

Data collection tools:

1. Demographic proforma of family care giver

2. Quality Of Life (QOL) questionnaire for family care givers

QOL of caregivers will be assessed by using QOLLTI-F (Quality of Life in Life-Threatening Illness – Family Carer Version) was developed by Dr. Robin Cohen⁶ 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 for the seven domain scores. Domains are carer’s own state, environment, carer’s outlook, quality of care, relationship, patient condition and financial. The tool was translated into Kannada language and reliability found $r=.74$

Pilot study: Pilot study was done among 20 Family care givers those who provide care to the cancer survivors from the selected hospital.

A cross sectional study was done among 399 family caregivers those who are providing care to the hospitalized patients with advanced cancer. A non probability purposive sampling was used to select 399 family caregivers. Data were collected by interview technique from family caregivers by using structured and validated questionnaire on quality of life.

The data for the study collected from various hospitals after obtaining permission from the respective hospitals, ethical committee clearance and consent from the family caregivers.

III. Result

A total 399 samples data were collected and analysis done by using SPSS 16 version based on the objectives and hypotheses of the study.

Section 1: Demographic proforma of family caregivers of cancer patients:

Table 1: Frequency & Percentage of family care givers based on demographic characteristics.
n=399

SI. NO		f	%
1	Age in years:		
	20-30	109	27.3
	31-40	105	26.3
	41-50	99	24.3
	Above 50	86	21.6
2	Gender:		
	Male	159	39.8
	Female	240	60.2
3	Religion:		
	Hindu	346	86.7
	Christian	20	5.0
	Muslim	33	8.3
4	Marital status:		
	Married	337	84.5
	Unmarried	59	14.8
	Widow	3	.8
5	Income of the family per month in rupees:		
	≤ 2500	15	3.8
	2501-5000	152	38.1
	5001- 10000	119	29.8
	10001-15000	62	15.5
	>15000	51	12.8

Table 1 – Continued.....

SI. NO		f	%
6	Educational status:		
	Illiterate	78	19.5
	Primary	107	26.8
	High School	89	22.3
	Pre University	45	11.3
	Graduate	69	17.3
	Post Graduate	11	2.8
7	Employment status:		
	Professional	55	13.8
	Skilled	32	8.0
	Unskilled	107	26.8
	Retired	13	3.3
	House wife	181	45.4
8	Place of residence:		
	Urban	175	43.9
	Rural	224	56.1

Data shows that majority of family caregivers were in the age group of 20-40yrs (53.6%), 26.8% had their education till primary school, 45.4% of them were housewives. Majority (38.1%) of the samples had their monthly income between Rs. 2501-5000. (Table 1).

Table 2: Frequency & Percentage of cancer patients based on type of treatment and duration of illness and stage of cancer
n=399

1	Type of treatment taken:		
	Chemotherapy (CT)	48	12
	Radiotherapy (RT)	57	14.3
	Surgery	06	1.5
	RT+Surgery	35	8.8
	CT+Surgery	72	18
	RT+CT	101	25.3
2	Duration of illness in years:		
	< 1	288	72.1

	1-5	98	24.6
	6-10	11	2.8
	>10	2	.5
	Duration of treatment in months (after diagnosis):		
3	Less than 6	281	70.4
	6 to less than 12	85	21.3
	12 to less than 24	16	4.0
	More than > 24	17	4.3
4	Stage of cancer		
	Third	228	57.1
	Fourth	171	42.9

Majority of the cancer patients (45.4%) were had undergone combination of treatment i.e chemotherapy+ radiotherapy and surgery, 72.1% of them were suffering from the illness for less than 1year, 70.4% were under treatment since 6 months and 57.1% were in third stage of cancer (Table 2). Majority of the cancer patients suffered with head & neck cancer (35.6%), 45.9% of them cared by their spouses (Fig 1 &2).

Section 2: Quality of Life of family caregivers of cancer patients:

Table 3: mean & SD of total score of QOL among caregivers: n=399

	Total score of the QOL tool	Mean	SD	Minimum	Maximum
Total score of QOL among caregivers	160	63.36	15.73	28	140

Table 3 shows that the mean of FCG ‘s QOL was 63.36 and SD 15.73.

Table 4. Mean & SD of Quality of Life score (area wise) of family caregivers of cancer patients: n=399

Sl.No	Sub areas	Mean	SD
1	Environment	9.28	3.069
2	Patient State	2.56	1.65
3	Carer’s own state	14.022	6.50
4	Carer’s outlook	13.93	5.32
5	Quality of care	17.41	1.49
6	Relationships	4.73	3.40
7	Financial worries	1.60	1.39

Majority (70%) of the samples reported that their self control and their status distressed, 60% of samples reported no time to concentrate on their own work, 80% of samples experienced psychologically weakened, 72% samples reported that their relationship with other people affected and 80% samples indicated their financial situation has been stressful due to disease condition of the family member.

Association between mean of QOL and study variables:

One way ANOVA test used to test the association between family caregivers QOL mean score and study variables such as age, gender, education, income, type & duration of illness. Result shows that there is association between means Family caregivers score and income of the family (F=3.062, p=.017), type of cancer (F=2.781, p=.027), duration of illness (F=4.745, p=.003). Thus research hypothesis was accepted for income, type of cancer and duration of illness.

IV. Discussion

Cancer is a chronic disease that causes patients and caregivers to lose control over their lives, has an adverse effect on their social activities, work, family/marital life and decrease their health status and quality of life.

The mean score of present study among caregivers QOL was 63.36, similar findings was found in the study done by Nihan Turkoglu, Dilek Kılıc(2012)⁶ mean QOL of family caregivers was 36.65. In present study majority of the family caregivers expressed that ‘financial burden’ had negative influence on the quality of life, similar study reported that variables such as bad health conditions, lack of family support, and financial difficulties increased the burden of caregivers and decreased their quality of life scores (Dumont et al., 2006)^{4,7}. Current evidence suggests that family caregivers can be negatively impacted by a loved one’s cancer diagnosis. Caregiver-specific support interventions are needed to eliminate the burden of caregiving in lung cancer⁸

Other studies addressed these problems under categories titled disturbance, burden and quality of life they concluded that the issues they experience were parallel to those experienced by the patient (Foxall and Gaston-

Johansson, 1996; Nijboer et al., 1998; Weitzner et al., 1999a; Carter and Chang, 2000; Andrews, 2001; Babaoğlu and Öz, 2003; Borneman et al., 2003; Grunfeld et al., 2004; Carter, 2005; Gaugler et al., 2005; Grov et al., 2005; Dumont et al., 2006; Bostancı et al., 2007; Chang et al., 2007; Chen et al., 2007; Mystakidou et al., 2007)^{9,10,11}.

VI Conclusion

The present study suggests that to improve QOL of caregivers, measures should be taken to decrease the economic burden that cancer places on patient’s family. It also revealed that increasing the self- confidence in managing the cancer patients care in need is a vital to the quality of life of both the patient and caregiver. Therefore health care providers should pay more attention to maintain their health status and improve their QOL.

Acknowledgement

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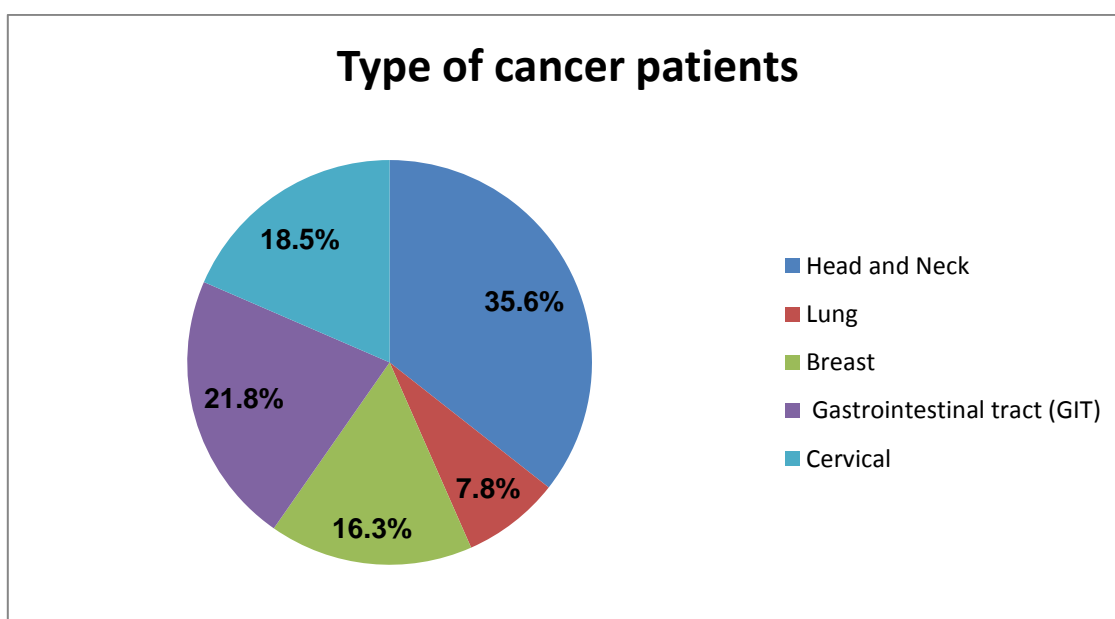


Fig.1: Percentage of type of cancer patients surveyed in the study

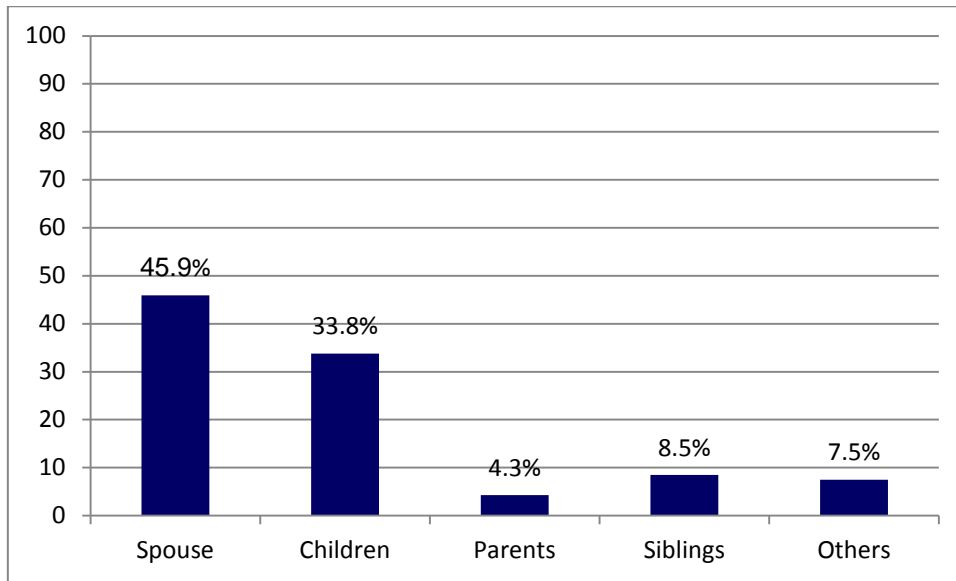


Fig 2: Percentage of relationship of caregivers with the cancer patients