



Quality of Life of Primary Caregivers Attending a Rural Cancer Centre in Western Maharashtra: A Cross-Sectional Study

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Abstract

Introduction Caregiver plays a vital role in taking good care of a cancer patient. But often, the caregiver's quality of life (QOL) is overlooked.

Objectives This study aimed to understand the Caregiver QOL Index–Cancer (CQOL-C) score of the primary caregivers and to find the significant predictors affecting CQOL-C.

Materials and Methods A cross-sectional study was conducted among the caregivers attending a rural cancer center in western Maharashtra. The primary caregiver is an immediate relative who assists the patient in most routine activities and is not a professional caregiver. A pretested and predesigned questionnaire using the CQOL-C scale was used to interview the caregivers from December 2019 to June 2020. We analyzed the data using Statistical Package of Social Sciences (SPSS) software. Univariate analysis was done using Student's *t*-test and a multivariate model was generated using linear regression analysis of the data.

Results A total of 114 caregivers were interviewed. The mean total CQOL-C score was 44.15 ± 17.24 (confidence interval [CI]: 41–47.3). About 71% of the caregivers reported moderate-to-severe hampering of their QOL. The mean CQOL-C scores in caregivers of patients with and without recurrent cancer were 58.24 (CI: 51.66–64.81) and 40.58 (CI: 37.35–43.80), respectively ($p < 0.001$). The mean CQOL-C scores in caregivers of patients with and without metastatic cancer were 56.68 (CI: 51.13–62.22) and 39.80 (CI: 36.45–43.14), respectively ($p < 0.001$). The mean CQOL-C score in caregivers of patients with hematological malignancies was 60.03 (CI: 58.88–61.17) which was significantly higher compared with other sites ($p = 0.0257$).

Conclusion The majority of the caregivers in our study have moderate-to-severe detrimental QOL. Recurrence of cancer and metastatic cancer at presentation are the two significant factors affecting CQOL-C. There is an unmet need to cater to the primary caregiver's concerns while we focus on treating cancer patients.

Keywords

- primary caregiver
- cancer
- quality of life
- rural India

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Introduction

Cancer is one of the most feared and dreaded chronic diseases across the world.¹ The patient spends more time at home as compared with the cancer center during this prolonged treatment duration, often spanning from months to years.²⁻⁴ In rural India, majority of the people still live in joint families. Diagnosis of cancer in a family member enforces the family to put efforts collectively to help the patient.⁵ The socio-economic conditions in rural India do not permit hiring a professional caregiver, and hence, it becomes mandatory to take the role of “primary caregiver” by spouse, sibling, or children.⁶

The primary caregiver is involved in monitoring the changes in the patient's condition, making decisions, providing hands-on care, making adjustments, accessing resources, negotiating with health care system, emotional support, and often arranging funds for the treatment.⁷ Balancing the cancer patient's care with his or her own personal routine is a challenging task, physically and emotionally, to the primary caregiver.^{8,9} Caregiving from historical times has been regarded as a meaningful experience but the sequelae of the caregivers is often overlooked.⁸ At Kolhapur Cancer Centre which is a rural cancer center in western India, we have reported approximately 3,000 new cancer patients in a year with two out of three patients presenting with either stage III or stage IV.¹⁰ The Caregiver Quality of Life Index–Cancer (CQOL-C) scale is a measure of effect of the illness of the cancer patient on the caregiver's physical, emotional, social, family, and other areas of functioning. The total score ranges from 0 to 140. The higher the score, the worse is the CQOL-C.¹¹ There is paucity of data over the CQOL-C in rural India. Hence, we conducted this study to understand the score of the primary caregivers and to find the significant predictors affecting it, attending Kolhapur Cancer Centre, India.

Materials and Methods

This cross-sectional study was conducted among the primary caregivers of cancer patients attending our center. Primary caregiver was an immediate relative who is assisting the patient in most routine activities and is not a professional caregiver. The duration of the study was from December 2019 to June 2020. The 114 caregivers were selected by convenience sampling. All the primary caregivers were above 18 years of age. The minimum duration between the date of cancer diagnosis and the interview of caregiver was 3 months.

A pretested and predesigned questionnaire adapted from current literature was used to interview the caregivers.¹¹ The questionnaire had two parts. The first part included the age, gender, site of cancer, Eastern Cooperative Oncology Group (ECOG) status of the patient, relationship with the caregiver, age of caregiver, gender of caregiver, presence of metastases, and whether it was new or recurrent cancer case. The second part consisted of the CQOL-C scale.¹¹ It had 35 QOL specific items each graded from 0 to 4 on Likert's scale of which “0” was “Not at all,” “1” was “A little bit,” “2” was “Somewhat,” “3” was “Quite a bit,” and “4” was “Very

much.” Question numbers 10, 12, 16, 22, 27, 28, and 34 were reverse graded and analyzed. Question number 4 in the scale was omitted from the analysis due to missing data. A total score was obtained by adding all the 34 items and final score was considered for analysis.

The scale was translated to Marathi language by two independent translators and a final approved version was used to collect the data. Data were collected by interviewing the caregivers in person. A pilot study was conducted among 10 caregivers to finalize the questionnaire. This pilot also revealed the standard deviation of total CQOL-C score to be 16.23. Using this, with 95% confidence interval (CI) and 3.5% error, we found the minimum sample size to be 86.¹² For our convenience, we included all 114 interviewed caregivers in the present study.

Statistical Analysis

The data were collected and compiled in Microsoft Excel. The data were analyzed using statistical package of social sciences (SPSS) version 20.00. The data were coded and analyzed using the guidelines published by the Measurement Instrument Database for Social Sciences (MIDSS).¹³ The qualitative variables were expressed in terms of percentages. Quantitative variables were expressed in terms of mean and their 95% CIs. The total score of CQOL-C was categorized based on the quartiles of our dataset into less than 30, 30 to 60, and more than 60 and then expressed in terms of percentages. To test the difference between 2 means, Student's *t*-test was used and more than 2 means, analysis of variance (ANOVA) was used. Univariate analysis was done for all the factors and those factors which had *p*-value of <0.10 included in multiple linear regression analysis. Normality of the data were tested using probability plots. Linearity of the factors was tested using scatter diagrams. The independence was tested using Dubin–Watson test. After all these assumptions were met, stepwise method of multiple linear regression analysis was used to find the significant predictors which affect the CQOL-C. The best model fit was determined and *R*² statistics was reported for the model. All of them were two-tailed analyses and the significance was set at 0.05.

Ethics

Kolhapur Cancer Center institutional ethics committee (ECR-/523/INST/MH/2014/RR-17, dated December 16, 2019) approval for the study was obtained. Written informed consent was taken from all the participants with precautions to maintain the confidentiality. The procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation and with Helsinki Declaration of 1964, as revised in 2013.

Results

We included a total of 114 primary caregivers in the present study. The mean age of the caregivers was 40.75 ± 11.45 years

with male preponderance (male:female = 1.32:1). Majority of the primary caregivers were related as children (50.86%) of the cancer patients. The proportion of recurrent cancer and metastatic cancer at the time of interview were 20.18 and 25.44%, respectively. More than half of the patients had an ECOG performance score of 3 or 4 (► **Table 1**).

Head and neck (47.37%) was the most common site of cancer in the present study (► **Fig. 1**).

The mean total CQOL-C score was 44.15 ± 17.24 (CI: 41–47.3) with 71.05% of the caregivers having moderate-to-severe hampering of their QOL (► **Table 2**). The mean CQOL-C scores in caregivers of patients with and without recurrent cancer were 58.24 (CI: 51.66–64.81) and 40.58 (CI: 37.35–43.80), respectively ($p < 0.001$). The mean CQOL-C scores in caregivers of patients with and without metastatic cancer were 56.68 (CI: 51.13–62.22) and 39.80 (CI: 36.45–43.14), respectively ($p < 0.001$). The mean CQOL-C scores in caregivers of patients with hematological malignancies was 60.03 (CI: 58.88–61.17) which was significantly higher compared with other sites ($p = 0.0257$; ► **Table 3**). Stepwise linear regression analysis showed the presence of recurrence and metastases in patients were significant predictors affecting the primary caregivers' CQOL-C score (► **Table 4**).

Table 1 Demographic particulars of the participants

Demographic particulars	Frequency	Percentage
Age of the caregiver (y)		
<30	19	16.67
31 to 40	34	29.82
41 to 50	30	26.32
51 to 60	22	19.30
>60	9	7.89
Gender of caregiver		
Female	49	42.98
Male	65	57.02
Relation with patient		
Children	58	50.88
Spouse	43	37.72
Sibling	9	7.89
Parents	4	3.51
Recurrence		
Yes	23	20.18
No	91	79.82
Metastasis		
Yes	29	25.44
No	85	74.56
ECOG		
0–2	55	48.24
3–4	59	51.75

Abbreviation: ECOG, the Eastern Cooperative Oncology Group.

Table 2 Distribution of the total CQOL-C score

CQOL-C score	Frequency	Percentage
0–30 (mild)	33	28.95
30–60 (moderate)	67	58.77
60–136 (severe)	14	12.28
Total	114	100.00
Mean	44.15	
SD	17.24	

Abbreviations: CQOL-C, caregiver quality of life index—cancer; SD, standard deviation.

Table 3 Univariate analysis of the different parameters affecting CQOL-C

Parameters	CQOL-C	
	Mean	Confidence interval
Age (y)		
<40	43.34	39.08–47.59
>40	45.18	40.40–49.95
<i>p</i> -Value	0.5723	
Gender		
Female	45.96	42.02–49.91
Male	41.74	36.60–46.87
<i>p</i> -Value	0.2054	
Relation with patient		
Children	45.22	40.38–50.05
Spouse	42.61	37.69–47.52
Sibling	42.00	33.25–50.74
Parents	50.00	39.81–60.18
<i>p</i> -Value	0.7659	
Recurrence		
Yes	58.24	51.66–64.81
No	40.58	37.35–43.80
<i>p</i> -Value	<0.001	
Metastasis		
Yes	56.68	51.13–62.22
No	39.80	36.45–43.14
<i>p</i> -Value	<0.001	
Site of cancer		
Breast	40.28	32.44–48.11
Colorectal	40.10	33.44–46.75
Gynecology	55.00	42.57–67.42
Hematological	60.03	58.88–61.17
Head, face, and neck	42.26	37.79–46.73
Others	51.83	38.57–65.07
<i>p</i> -Value	0.0257	

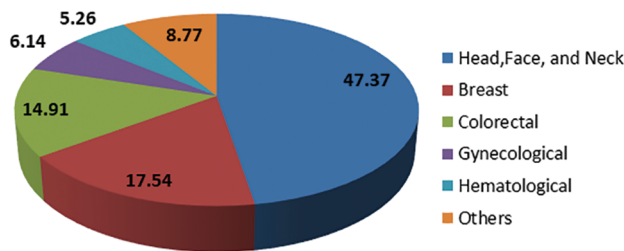
Abbreviation: CQOL-C, caregiver quality of life index—cancer.

Table 4 Stepwise multiple linear regression analysis of the different parameters affecting CQOL-C

Parameters	Unstandardized beta (95% CI)	Standard error	Standardized beta	t-Value	p-Value
Constant	38.88 (35.55–42.22)	1.68		23.11	0.000
Metastasis (present/absent)	11.88 (4.34–19.38)	3.79	0.301	3.12	0.002
Recurrence (present/absent)	11.09 (2.93–19.26)	4.12	0.259	2.69	0.008

Abbreviations: CI, confidence interval; CQOL-C, caregiver quality of life index—cancer.

Note: Adjusted R^2 = 0.224; Durbin-Watson = 2.21.

**Fig. 1** Distribution based on the site of the malignancy.

Discussion

Treating a cancer patient is the most common service offered in a cancer center with little attention to the caregiver's needs. The QOL of caregivers of cancer patients is often a neglected part in routine practice. Improving the caregiver's QOL has a positive impact on the cancer patient's care.^{14,15} To highlight the importance of the QOL among the caregivers, we conducted a cross-sectional study to analyze CQOL-C in the patients attending a rural cancer hospital in western India.

There are numerous scales to quantify the caregiver's QOL like "the Caregiver Reaction Assessment," "Brief Assessment Scale for Caregivers," "Quality of Life in Life-Threatening Illness—Family Carer Version," "the Functional Assessment of Cancer Therapy Scale—General Format," "Measurement of Objective Burden and of Subjective Burden," "the Caregiver Strain Index," "Bakas' Caregiver Outcome Scale," and "the Caregiver Quality of Life Index—Cancer Scale."⁷ We chose the CQOL-C scale because it is a comprehensive assessment tool of physical, negative emotions, social, spiritual, and financial dimension of the primary caregiver of a cancer patient. The psychometric properties of the CQOL-C, such as internal consistency, test-retest reliability, content validity, and convergent validity, are well defined.⁷

The studies conducted in South East Asia and Middle Eastern countries which do share somewhat similar social norms and have reported higher CQOL-C score than the present study.^{16–23} Other studies conducted in the West revealed much higher CQOL-C as compared with the South East Asian and Middle Eastern studies.^{24–27} This reflects the role of societal norms and coping attitudes of caregivers of our region in providing the appropriate care along with handling their QOL.

The various factors affecting cancer caregivers QOL were gender, marital status, educational status, income status, insurance status, and relation of caregiver with patient

reported in various studies.^{16–18} In the present study, the CQOL-C was significantly hampered in patients who had recurrence and metastasis. Other factors, like age of the caregiver, gender, site of cancer, and relationship of the caregiver with the patient, did not differ in their CQOLC scores. The primary caregiver experiences the natural course of the cancer patient from diagnosis, treatment initiation, treatment complications, treatment failure in terms of recurrence, decision to discontinue treatment and opting out for alternative treatment modalities, terminal illness, and death.⁷ Caregivers with recurrent cancer cases have poor QOL which might be due the shattering of the hope which was generated in the previous treatment modalities. The pain and suffering of metastatic cancer patients adversely affects the negative emotions of the primary caregiver.²⁸ Higher symptom burden of the cancer patients, more economic strain, role changes during different modalities of treatment, loss of personal wages due to repeated visits to hospital, and family function disruption are some important cues which explain detrimental effects of CQOL-C among patients with metastatic disease at the time of interview.^{29–32}

Limitations and Strengths

Our study had some limitations. It was a single-center study with smaller sample size. The follow-up of caregiver's QOL in the different phases of treatment modality was not addressed. There was no scope to intervene and assist the primary caregivers with significantly worst QOL. The future studies could be built on this knowledge to intervene in coping attitude of the primary caregiver. Nonetheless, this is one of the studies which has been conducted on caregiver's QOL in India and thus will add to the existing literature on the topic.

Conclusion

Majority of the caregivers in our study have moderate-to-severe detrimental QOL. Recurrence of cancer and metastatic cancer at presentation are the two significant factors affecting CQOL-C found in this study. There is unmet need to cater the primary caregivers' concerns while we focus on treating cancer patients.

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Conflict of Interest

None declared.

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