



“FAMILY CAREGIVERS (FCs) QUALITY OF LIFE (QOL) OUTCOMES DURING THE DEDICATED INPATIENT PALLIATIVE CARE (IPC) OF THEIR ADVANCED CANCER PATIENTS” – STUDY FROM A TERTIARY CARE CENTRE IN ANDHRA PRADESH, SOUTH INDIA.

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ABSTRACT **Objectives:** Family Caregivers (FCs) of cancer patients often suffer from impaired quality of life (QOL) due to stress arising from the responsibility of care giving. Thus, in this study we assessed family caregivers (FCs) quality of life and its association with demographic variables during inpatient palliative care (IPC) of their advanced cancer patients.

Material and Methods: 211 FCs of advanced cancer patients were assessed using either English or Telugu versions of the Caregiver Quality of Life Cancer (CQOLC) index scales to evaluate their QOL. We used descriptive and correlation analyses to obtain statistical results..

Results: The summative mean CQOLC score was 54.42±/ 19.7. Statistically significant higher scores were observed for FCs who reside in rural regions (p=0.27) and those who belong to Below poverty line (BPL) families (p=0.035) suggesting poor quality of life among these groups. High CQOLC score was noticed for socially backward (OBC's, SC and ST castes) communities, but statistically not significant (p=0.210).

Conclusion: FCs from rural regions and lower income groups experience poor QOL. Regular assessment, resource support and specialist care are needed for improving FCs quality of life.

KEYWORDS : Family Caregivers (Fcs), Cancer, Palliative care, Quality of Life (QOL)

INTRODUCTION:

Cancer is a chronic disease with its treatment lasting almost for lifetime. Family caregivers (FCs) are relatives, friends or neighbors who provide assistance related to an underlying physical or mental disability but who are unpaid for those services [1]. FCs are a pivotal source for quality of life, well-being and quality of care in terminally ill patients.

In India, approximately 50–70% of patients present with advanced stages of cancer during their first consultation with physicians [2]. In these advanced patients, palliative care plays a vital role in their management along with curative therapy. The cancer disease per se has had impact on the family of the patient due to poor prognosis and lifelong treatment [3]. The FCs are emotionally unprepared for this care. This makes them vulnerable to physical, psychological, social, financial as well as spiritual burden, which affects the respective dimensions of their health resulting in poor quality of life (QOL) [4].

FCs cannot take sufficient time for themselves, are unable to attend social gatherings, and in some extreme cases, not even able to sleep properly [5]. Advanced stage of cancer renders the patient even more dependent on caregivers resulting in higher caregiver burden and it may indirectly affects patient's health as well [6].

Unfortunately, most of the published studies on the associations between caregivers' QOL and demography have been conducted in Western societies and settings [7]. There is paucity of these studies in developing countries such as India. Of this limited literature, mostly urban areas were studied [8]. Thus, there is paucity of literature in rural settings especially in our backward regions like Rayalaseema, of Andhra Pradesh state. This lack of literature represents a gap in service provision for this group of caregivers.

Hence primary aim of this study was to assess the quality of life (QOL) in Family Caregivers (FCs) of advanced cancer patients treated in a dedicated Inpatient palliative care (IPC) unit of a tertiary care centre in Kurnool, Andhra Pradesh, India.

MATERIAL AND METHODS:

Study setting:

Study was conducted in Government general hospital (GGH), Kurnool, Andhra Pradesh, India, a tertiary care teaching hospital, which is a 1000-bedded multidisciplinary specialty center. Our Department of Radiotherapy and Oncology is providing radiotherapy, chemotherapy and palliative care services. We established dedicated Inpatient Palliative care (IPC) center in 2019 for providing rational, quality pain relief and palliative care to the needy, as an integral part of Cancer care.

Study design:

It was a hospital-based cross-sectional study, conducted within the time period of nine (9) months from March-November 2020. We recruited 211 FCs of admitted advanced cancer patients, consecutively within 72 h after the patient's admission. Eligible caregivers were required to be related to patients, older than 18 years, and unpaid for their services. FCs who were primarily assisting patients at home were given preference. Informed consent was obtained from all the FCs included in the study. Paid caregivers and with insufficient cognitive function were excluded. Data was collected through FC questionnaire which was either handed over to the FCs or were interviewed by trained interviewers in case of difficulty.

Permission to complete this study was granted by the Institutional Ethics Committee, Kurnool medical college, Government general hospital (GGH), Kurnool.

Measurements of outcomes:

In order to assess FCs quality of life (QOL), FCs were given a questionnaire consisting of the following validated scale-

The Caregiver Quality of Life Index- Cancer (CQOLC) scale assesses the carer of a cancer patient's quality of life. The CQOLC has the best psychometric properties among all disease-specific QOL measures for cancer caregivers and has been validated in India and is used extensively worldwide. It assesses QOL using a 35-item self-report measure. Each of the 35 items is rated on a five-point Likert-type scale, from 0 (not at all) to 4 (very much), and the items cover four domains: burden, disruptiveness, positive adaptation and financial concerns. The total score will be obtained by summing up the scores of all the items (maximum score of 140), with a higher score denoting poor QOL.

The CQOLC questionnaire was translated and back translated in local vernacular language (Telugu) for translational validity.

STATISTICAL ANALYSIS:

Data analysis was done using SPSS v.26. Descriptive analyses were calculated to evaluate baseline demographics. We used Spearman's rho and Pearson's r to assess bivariate associations between demographic variables and mean CQOLC index scores. Standard deviations were calculated with each mean score. Statistical significance was confirmed for p < 0.05.

RESULTS:

The demographics of included FCs were described in Table 1.

Table 1. Baseline Caregiver Demographics and Mean CQOLC Index Scores.

Demographic variables	Frequencies of Fcs (n=211)	CQOLC index scores (MeansSD)	Significance P value
1.Age groups			
60 years or older of age	85 (40.3%)	56.65±18.22	.235
Below 60 years of age	126 (59.7%)	53.63±17.89	
2.Gender			
Male	110 (52.1%)	54.90±17.89	.976
Female	100 (47.9%)	54.34±17.71	
3.Relation to the patient			
Spouse	81 (38.4%)	54.38±18.83	.768
Non spouse	130 (61.6%)	55.14±17.59	
4.Marital status			
Unmarried	19 (9%)	56.05±11.69	.761
Married	192 (91%)	54.73±18.57	
5.Religion			
Hindu	138 (64.9%)	54.30±18.05	.609
Minority	73 (35.1%)	55.88±18.10	
6.Caste			
General	83 (39.3%)	50.04±18.32	.210
Non-general (OBC's, SC and ST castes)	127 (60.2%)	58.17±17.13	
7.Education			
Illiterate	99 (46.9%)	54.55±19.44	.819
Literate	112 (53.1%)	55.18±16.78	
8.Employment			
Unemployed	47 (22.3%)	54.30±16.42	.813
Employed	164 (77.7%)	55.01±18.52	
9.Income			
Below poverty line (BPL)	147 (69.7%)	56.57±19.78	.035*
Above poverty line (APL)	64 (30.3%)	50.89±12.47	
10.Residency			
Rural	166 (78.7%)	56.17±18.58	.027*
Urban	45 (21.3%)	50.29±15.76	
11.Diagnosis of the relative			
Ca Head & Neck	87 (41.2%)	54.45±19.17	.310
Ca Breast	29 (13.7%)	49.79±11.53	
Gynaecological cancers	25 (11.8%)	60.60±18.52	
Ca Lung	13 (6.2%)	52.23±12.69	
GI malignancies	37 (17.5%)	52.43±17.09	
Other sites	20 (9.5%)	61.84±22.36	

-OBC's-other backward castes, SC-Scheduled castes and ST-Scheduled tribe

*A clinically meaningful difference was observed

The summative mean CQOLC score was 54.42±19.7. Statistically significant higher scores were observed for FCs who reside in rural regions (p=0.27) and those who belong to Below poverty line (BPL) families (p=0.035) suggesting poor quality of life among these groups. High CQOLC score noticed for Non-general (OBC's, SC and ST castes) communities, but statistically not significant (p=0.210). No significant association observed among other socio-demographic characteristics.

The mean score for each individual subdomain is conveyed in Table 2.

Table 2. Mean Scores and Standard Deviations for each subdomain of the CQOLC Index.

CQOLC Subdomains	Means & SD scores
1.CQOLC -Burden (10 items)	17.31±5.51
2.CQOLC-Disruptiveness (7 items)	9.45±4.45
3.CQOLC -Positive adaptation (7 items)	9.34±4.52
4. CQOLC -Financial concerns (3 items)	7.86±1.34
5. CQOLC-Undefined items(8 items)	11.32±3.97
Summative CQOLC score	54.75±18.02

DISCUSSION:

The findings from this single-institutional, cross-sectional study convey the QOL deterioration that is evident among rural residents and lower-income below poverty line families in the FCs of advanced cancer patients. Rural and Lower-income group FCs may face greater burden because of limited accessibility to services and support at home. Trends toward worse CQOLC index scores were observed among FCs belonging to backward communities (OBC's-other backward castes, SC-Scheduled castes and ST-Scheduled tribes) and above 60 years of age.

A study by Lim HA et al in Singapore, observed that FCs who were male, had parental relationships with their care recipient, or cared for advanced-stage cancer patients were found to have impaired QOL [9]. Whereas in our study, we found no such association regarding gender, relationship status with the patient in their QOL outcomes. This also highlights the need for region-specific interventions to address the impaired QOL in FCs.

A basic understanding of the impaired QOL experienced by rural, lower-income and backward community FCs could lead to socio economic interventions that may improve overall QOL.

The limitations of this study were, as it is a cross-sectional study, a temporal association cannot be established between factors determining impaired QOL among patients. An analytical study design like case-control or cohort study should be conducted to find out the determinants of QOL among caregivers of cancer patients, preferably in multi centric settings.

CONCLUSION:

In conclusion, FCs of terminally ill cancer patients seems to suffer from impaired QOL in dedicated Inpatient palliative care (IPC) settings. FCs from rural regions and lower income groups experience poor QOL. These findings indicate the importance of regular assessment of quality of life of FCs. Resource support and specialist care can be provided for improving FCs quality of life.

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