Original Article

An Observational Study to Identify Socio-demographic Factors on Primary Caregivers' Quality of Life of Cancer Patients Attending a Tertiary Cancer Hospital

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We aimed to identify Socio-demographic factors affecting a primary caregiver's Quality of Life (QoL) during the period of cancer treatment. Along with assessing its association with ECOG for determining the QoL of caregivers of cancer patients attending a Tertiary Cancer Hospital, in West Bengal. This was a single Tertiary Hospital-based observational, descriptive study performed from February, 2023 to 12th June, 2023. 175 adult primary caregivers were assigned, aged 18 years of age to >65 years and those involved with their actual care not less than 12 hours per day. All participants went through the assessment of QoL by using validated tools. Eastern Cooperative Oncology Group (ECOG) was analysed on an interview basis. Descriptive statistics, the Chi-square test, and 't' test were used to meet the objectives. The statistical significance was set at <0.05. The majority of the caregivers were of the age group 31-40 years (35%) and female caregivers (61%) were more than male individuals (39%). About 60.57% of the caregivers reported severe hampering of their QoL. A significant relation was found between the caregivers with poor CQOL-C and ECOG performance scores (p=<0.000). The current study demonstrates that the caregiver's socio-demographic background more likely had created an impact on their QoL while comparing with their respective counterparts to have a lower level QoL.

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Cancer is a life-threatening illness that is stressful not only to the patients but also to the caregivers in terms of how it might be experienced. During this lengthy treatment period, which frequently lasts for months or years, the patient and their primary caregivers spends more time at the cancer centre than at home. There are significant changes in the daily routines of both parties and they need to work very hard to adapt to the demands of this life-threatening disease. The family feels obligated to work together to support the patient after learning that a family member has cancer[1].

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Editor's Comment :
- To identify Socio-demographic factors affecting a primary caregiver's Quality of Life (QoL) during the period of cancer treatment.
- To assess its association with ECOG for determining the QoL of caregivers of cancer patients attending a Tertiary Cancer Hospital in West Bengal.
- Caregiver's Socio-demographic background more likely had created an impact on their QoL while comparing with their respective counterparts to have a lower level QoL.

As is clear, daily practice reflecting the rise in cancer cases in India over the past ten years, the emotional anguish that it causes the family members, and the difficulty in coping with the diagnosis of their loved ones. The patient's primary caregiver is responsible for making decisions, monitoring changes in the patient's condition, giving hands-on care, adjusting care as needed, gaining access to resources, negotiating with the healthcare system, providing emotional support and frequently securing funding for the treatment. The primary carer has a difficult responsibility to complete both physically and emotionally: juggling the care of the cancer patient with his or her own daily routine[2]. Since ancient times, providing care has been valued as a worthwhile experience but the effects on the carers themselves are frequently disregarded. According to the Quality

of Life in Life-Threatening Illness-Family Carer Version (QOLLTI-F) assessment, half of the carers in a recent study on the Quality of Life of carers had a bad quality of life. The statistical results showed that characteristics like gender, religion, location, financial burden, lung cancer stage and kind, disability, and patient depression had a substantial impact on the carers' Quality of Life (QoL).

The Quality of Life of the patient's primary carer, a group that is frequently disregarded, is a very important concern that has been addressed by the widespread usage of this questionnaire and its translation into many languages. The Turkish translation of the English CQOLC yielded results that were comparable to those of our study, suggesting that there were some concerns that were shared by families of cancer patients. It was also administered alongside the World Health Organisation Quality of Life Short Version (WHOQOL-BREF) to breast and gynaecological cancer patients and validated to the German version[3]. It demonstrated good reliability for burden, disruptiveness and financial concerns but low reliability for positive adaptation. Utilising the same CQOLC scale, similar studies were carried out in Korea and the United Arab Emirates, with comparable results on demographic comparisons[3,4].

The primary carer is in a particularly vulnerable position as a result of the cancer treatment and the heavy emotional and financial burdens that the family must face. This could ultimately result in a mental breakdown that will have an impact on the patients as well. The CQOLC was first created in the USA and was well suited to their population's various cultural makeup. Now, we aimed to identify the significant Socio-demographic factors affecting a primary caregiver's Quality of Life of cancer patients during the period of cancer treatment.

MATERIALS AND METHODS

Research Design : This study was a descriptive, observational study. This design was chosen because it helps describe or gather information about variables of a specific population, making it the most suited design for the nature of the study. Through this study we were able to understand specific demographic variable that affect a patients'primary caregivers' Quality of Life.

Setting of the Study : Data were collected from medical oncology department from Medica Superspeciality Hospital, Kolkata, West Bengal, India.

Population : The target sample of the study was all the primary caregivers of patients with cancer who were undergoing standard care treatment (surgery,

radiation, chemotherapy) and palliative care treatment. We defined the family caregiver as the person most involved in the patient's care without receiving financial reimbursement for the care that they provided. To be eligible for the study, potential samples had to —

(1) Being identified by the patient as the primary caregiver most involved with their actual care.

(2) 18 years of age to >65 years of age.

(3) Able to understand Bengali and give consent for the participation in the study.

Exclusion criteria –

(1) Having a history of psychiatric disorder.

(2) Those on any form of oncologic treatment.

(3) Caregiver not staying with the patient for not less than 12 hours per day.

(4) Those unable to complete the questionnaires.

Trained clinical research assistant and doctors approached to care givers for recruitment and informed consent form during day OPD timings. The study was approved by the Institutional Scientific and Ethical Review Board following terms and condition of Indian Council of Medical Research (ICMR). A total of 175 caregivers of diagnosed cancer patients were selected as per sample of convenience and consecutive sampling technique during a 4-month periods (from February, 2023 to 12 June, 2023). Clinical Psychologist used a valid tool to collect data about Quality of Life from the above mentioned number of samples.

Procedure :

Participants were explained about the study and written informed consent was obtained. Participants were interviewed by experienced psychologist using structured questionnaire. The questionnaire was validated in local language, Bengali. It took about 15-20 mints to take interview from a single participant, which was done during the time the patients and their caregivers were waiting for doctor consultation or after the completion of the visit to doctor. All the information was documented on the Caregiver Quality of Life Index as per the tool of which are specifically focused QoL respectively. Doctors also recorded patients' performance (as per caregivers' version) during the treatment through Eastern Cooperative Oncology Group (ECOG) Performance Status (Fig 1).

Measurement :

Demographic Questionnaire : Demographic data questionnaire was used to obtain data about information related to age, gender, marital status, family income, level of education, occupation, relation with patient, patient's present treatment, present status of the disease (recurrent, metastatic, non-metastatic).

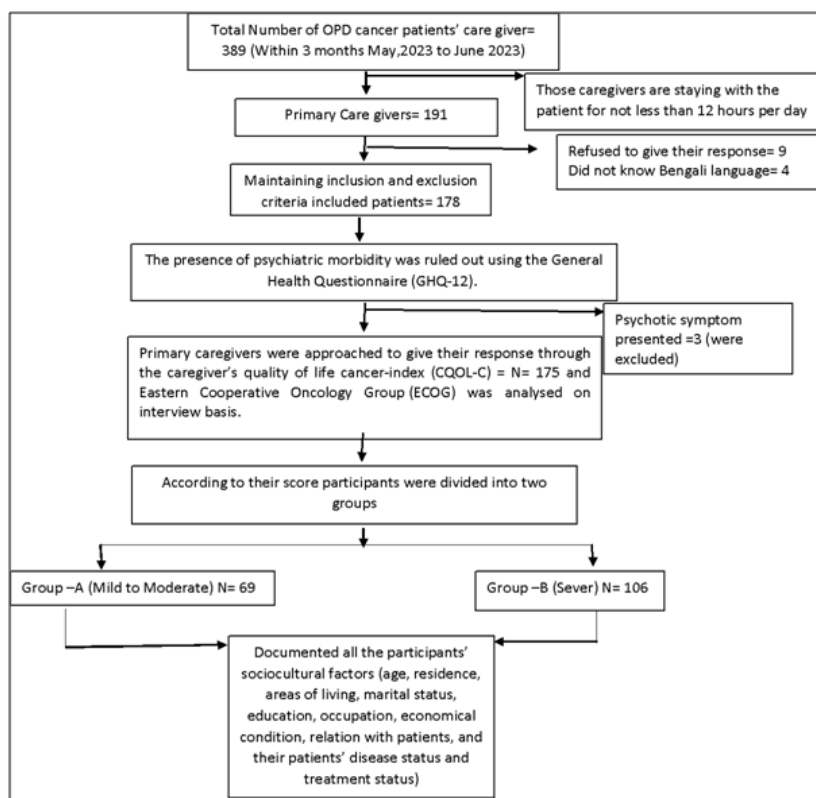**Caregiver Quality of Life Index :** The CQOL-C

Fig 1 — Study Design

is a self-administered rating scale designed to assess QoL issues in family caregivers of patients with cancer. It had 35 QoL-specific items, each of which was graded from 0 to 4 on the Likert scale, where "0" denoted "Not at all," "1" denoted "A little bit," "2" denoted "Somewhat," "3" denoted "Quite a bit," and "4" denoted "Very much." The maximum total score for the instrument is 140. All 35 things were added together for a final score, which was taken into consideration for analysis [2]. Three separate translators (2 with medical background and one with a master's degree in Bengali) translated the scale into Bengali and the final, approved version was utilised to gather the data. The caregivers were personally interviewed for the data collection. Test-rest reliability was 0.95 and internal consistency was 0.90. The instrument has good divergent validity. The instrument is also responsive to changes in the health state of the patient, as measured by the ECOG-PSR (r=0.45).

Eastern Cooperative Oncology Group (ECOG) Performance Status :

Eastern Cooperative Oncology Group (ECOG) Performance Status Scale is one such measurement. It describes a patient's level of functioning in terms of their ability to care for themself, daily activity, and physical ability (walking, working, etc).

Statistical Analysis :

Statistics were analysed using version 22.0 of SPSS software. Descriptive statistics were calculated as the Mean ± Standard Deviation of age and frequency of demographic factors was tabulated according to age, gender, marital status, family income, level of education, occupation, relation with patient, patient's present treatment, present status of the disease (recurrent, metastatic, non-metastatic), treatment history, CQOL-Cresponse in Mean±SD form and ECOG score. To define Socio-demographic impact on Caregivers' Quality of Life, we had dived two groups according to level of CQOL-C (following scale's norm)- Group-A (those whose score lies under mild and moderate) and Group-B (those whose score were lied under severlevel).We had used "t" test to compare the Mean±SD between mentioned two groups to determine the impact of Socio-demographic factors. We had used "t" test to compare the Mean±SD between mentioned two groups according to their patients' ECOG response.

RESULTS

Demographic Information :

Table 1 depicts the baseline demographic and clinical characteristics of their patients of the study participants. In the present study percentage of female caregiver was more than male individuals (61% *versus* 39%). In part of age group, caregivers with age within 31-40 years were higher (35%) than other age groups, living with spouse (88%), 67% of participants were coming from urban areas and 48.5% of participants belongs under middle class family. Majority (33.5%) of the primary caregivers were related to their children (son or daughter).

In case of patients' Clinico-pathological and treatment history, most of the patients were diagnosed with solid tumour (79%) and 41% patients were under chemotherapy. 73.1% of patients were under treatment within <6 months.

In area of CQOLC response, 60.57% of caregivers having sever hampering their QoL.

Table 2 depicts the baseline demographic and

Table 1 — Prevalence of Demographic details among all Participants	
Socio-demographic Factors	**N=175**
Gender :	
Male	39%
Female	61%
Age :	
<30 years	9%
31 to 40 years	35%
41 to 50 years	23%
51 to 60 years	14.5%
>60 years	18.5%
Relationship Status :	
Living with spouse	88%
Living without spouse	12%
Community areas :	
Urban	67%
Rural	33%
Education :	
Primary	10%
Secondary	44.2%
Graduate	45.8%
Socio-economic status (Kuppus- wamy scale) :	
Lower middle class	29.1%
Middle class	48.5%
Upper middle class	22.4%
Relation with patients :	
Children	33.5%
Spouse	28.4%
Sibling	27.1%
Parent	11%
Diagnosis :	
Solid tumour	79%
Haematological Malignancy	21%
Treatment : Standard care treatment	
Surgery	36%
Chemotherapy	41%
Radiation	5%
Chemotherapy and Radiation	10%
Palliative care	8%
Duration *of* treatment :	
<6 months	73.1%
>6 months	26.9%
CQOLC - score :	
Mild (0-30)	12% (N=12)
Moderate (30-60)	27.43% (N=48)
Sever (60-136)	60.57 (N=106)

clinical characteristics of the study participants. The majority of them belonged to lower middle-class Socio-economic status (according to Kuppus- wamy scale). Both the study groups were comparable at baseline except gender (p= <0.00) age (p= <0.00), Socio-economic status (p= <0.00), areas of living (rural and urban) (p= <0.00), relation with spouse (p= <0.00) and their patients' treatment at that time (p= <0.00).

Table 3 was presented the statistical variation between two groups according to the domain of the scale. The score of disruptiveness (p= <0.00), financial condition (p= <0.00) and positive adaptation (p= <0.00) was made statistical significant difference between two groups.

Table 2 — Prevalence of Demographic details among Participants according to CQOLC's Response			
Socio-demographic Factors	Group-A (N=69)	Group-B (N=106)	P-value
Gender :			
Male	67%	49%	0.002*
Female	33%	51%	
Age :			
<30 years	21%	11.3%	0.000*
31 to 40 years	25%	9.1%	
41 to 50 years	18%	10%	
51 to 60 years	18.2%	31.1%	
>60 years	17.8%	38.5%	
Relationship Status :			
Living with spouse	69%	66.4%	1.21
Living without spouse	31%	33.6%	
Residential areas :			
Rural	43.2%	34.5%	0.002*
Urban	56.8%	65.5%	
Education :			
Primary	33.6%	34%	0.075
Secondary	34.2%	29.2%	
Graduate	32.2%	36.8%	
Socio-economic status :			
Lower middle class	21.3%	51%	0.000*
Middle class	18.5%	30.4%	
Upper middle class	60.2%	18.6%	
Relation with patients :			
Children	31.5%	11.5%	0.000*
Spouse	28.4%	39.2%	
Sibling	29.1%	13.4%	
Parent	11%	35.9%	
Diagnosis :			
Solid tumour	13.9%	71.2%	0.003*
Haematological Malignancy	86.1%	28.8%	
Treatment : Standard care treatment			
Surgery	36.9%	12.3%	0.000*
Chemotherapy	9.4%	45.1%	
Radiation	25.7%	10.1%	
Chemotherapy and Radiation	16.7%	9.7%	
Palliative care	11.3%	22.8%	
Duration *of* treatment :			
<6 months	33.1%	49.5%	1.3
>6 months	66.9%	50.5%	

Table 3 — Mean Scores and Standard Deviations for each Subdomain of the CQOLC Index among all Participants			
Subdomain	Group A	Group B	p-Value
Burden	21.08±11.7	22.13±13.1	1.12
Disruptiveness	39.34±12.65	55.2±16.3	0.000*
Positive adaptation	55.09±18.7	31.06±2.1	0.003*
Financial Concerns	65.12±22.1	89.21±19.7	0.000*
Undefined Subdomain	12.09±12.5	13.11±1.9	1.14

Table 4 was elaborated in statistical form, variation in patients' performance (according to ECOG) and their caregivers' response about QoL.

DISCUSSION

The findings from the present single institution, observational and descriptive study shows us that the number of female caregivers was higher than male

Table 4 — *Distribution of CQOLC Scores according to the Performance Status of their Patients*			
ECOG-Performance Status	Group A	Group B	(Mean±SD) p-Value
Fully active, able to carry on all pre-disease performance without restriction	55.6%	5.2%	(51.23±12.4) *versus* (88.21±21.9) = 0.000*
Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, eg, light house work, office work	14.2%	15.7%	(50.23±11.6) *versus* (76.34±20.1) = 0.000*
Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours	9.3%	21%	(48.12±17.4) *versus* (74.09±19.2) = 0.000*
Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours	11%	27%	(49.3±19.1) *versus* (79.12±20.12) = 0.000*
Completely disabled; cannot carry on any selfcare; totally confined to bed or chair	9.9%	31.1%	(42.09±13.2) *versus* (71.23±18.7) = 0.000*

individuals (61% *versus* 39%). QoL deterioration is evident among female primary caregivers compare with male (83.12±20.98 *versus* 51.16±12.07) of cancer patients in India. The overall goal of this study was to identify the significant clinico-demographic factors affecting a primary caregiver's Quality of Life of cancer patients during the period of oncological care.

Most of the primary caregivers fall in the age range of 40.43±12.33 years. According to the statistical analysis, age difference of the caregivers significantly correlated with their QoL scores (Table 2). It has been observed that young caregivers can handle the process of caregiving better and more smoothly than older caregivers. Moreover, young caregivers, often neglect their education; putting their education on hold or dropping out entirely which can impact their future career. That's why trends toward worse CQOL-C index scores were observed among caregivers under 30 years of age. In our study, the majority of caregivers were females than males. The women are commonly the ones that take care of the routine of the house. Simultaneously, the current study confirms symptoms of physical condition in older caregivers (>65 years) seems to be a risk factors for their reduced QoL[5]. This gender differences had created positive impact of the CQOL-C scores (Table 2)[6]. This is consistent with our tradition and culture where male provide financial support to the family as mostly they are the sole bread concerns. The loss in the caregiver's income and reduction in savings is regularly excluded in estimates quantifying the cost of cancer care. Specifically, lower income caregivers' who are responsible for other dependence are at high risk for losing a significant portion of their financial reserves because cancer treatment is relatively costly and this economic factors can affect caregiver's Quality of Life. It has been also observed that caregivers with low levels of education affected their QoL. In part of education, caregivers with primary level education or a lack of education find difficulty in understanding the symptoms of the disease and tends to have miscommunication with the doctors. The caregivers who are daughter or son, who are married were seen to have problems in their marital lives as their entire focus goes to the care of the patient and thus they tend to ignore their spouses and babies. The duration of caregiving also affects the QoL of the caregivers because during the long period of caregiving, the caregivers' experience stress and burden resulting from the rigorous activity of caregiving which can have a negative impact on their physical, psychological and social lives, thereby decreasing their QoL[7]. Since, West Bengal is culturally and economically diverse, it is very important to take into account the Socio-demographic aspects of the caregivers as it can impact the psychological distress of an individual.

The difficult experience of dealing with cancer is unique to each patient. When we compare the QoL scores according to the type of cancer, it has been observed that in patients with Head and Neck cancer, their primary caregivers' QoL is mostly affected than other types because late side-effects of the surgery, eg. it is difficult for the patients to communicate post-surgery and the facial changes in the patients also lead to distress in patients and their caregivers. Activities deteriorates which in turn becomes difficult for the caregivers to manage. In part of treatment perspective, those patients were under pain and palliative care, their caregivers' Quality of Life was more affected when comparing other treatment. It is difficult for them to accept the fact that cancer is no more curable or day to day their patients' physical deterioration after giving their best level of dedication to give a better Quality of Life or economical condition[8]. During the period of chemotherapy, patients who are highly symptomatic either due to cancer or due to side effects of chemotherapy need more constant and increased duration of caregiving time that prone to psychological, physical, financial and social reactions and leads to worse QoL to a caregiver[9].

Caregivers of patients with ECOG 2-3 experienced a worse QoL than better ECOG patients, which is understandable as patients with worse ECOG are more dependent on caregivers for their Activities of Daily Living (ADL). The knowledge of the caregiver's Quality of Life and burden during the treatment of cancer patients at any stage or ECOG are very important support for caregivers by the multidisciplinary team (social worker, nursing and psychology) could contribute to a better Quality of Life for patients and caregivers[10].

Limitations :

Our study was a single centred study with smaller sample size. The follow up of caregivers' QoL in case of good QoL as well as moderate towards sever QoL in the different phase of treatment modality was addressed but the study did not follow up caregiver population who had good QoL and mild, moderate psychological distress. Those populations need to be reassessed for early identification of QoL.

CONCLUSION

Majority of the caregivers in our study have presented worse score of QoL. QoL is affected by the Socio-demographic aspect that is a caregivers' marital status, economical condition, education as well as a patient's health performance. We are going to propose screening for differences in perception of patient QoL as a way of identifying distressed caregivers as well as provider-facilitated communication between patients and caregivers as possible interventions that should be examined in future research.

Relevance for Clinical Practice :

Cancer can impact the psychological well-being of both patients and their primary caregivers. Caregivers provide both practical and emotional support and often play an important role in the coordination of the best care for breast cancer patients. However, but, so far, there have been but few studies discussing the relationship between Socio-demographic factors and caregivers' Quality of Life. Present papers have documented the considerable impact that caregiving has on caregiver Quality of Life (QoL).

Conflicts of interest : There are no conflicts of interest.

REFERENCES

1　Kulkarni SS — Quality of Life of Primary Caregivers Attending a Rural Cancer Centre in Western Maharashtra: A Cross-Sectional Study. *Indian J Med Paediatr Oncol* 2021; **42**: 268-72.

2　Weitzner MA, Jacobsen PB, Wagner ., Friedland J, Cox C — The Caregiver Quality of Life Index-Cancer (CQOLC) scale: Development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Qual Life Res* 1999; **8**: 55-63.

3　Ehmann AT, Mahler C, Klafke N — Validation of a German version of the Caregiver Quality of Life Index-Cancer (CQOLC) in a sample of significant others of breast and gynaecologic cancer patients. *Psicol Reflex e Crit* 2020; **33.**

4　Rhee YS — Korean version of the Caregiver Quality of Life Index - Cancer (CQOLC-K). *Qual Life Res* 2005; **14**: 899-904.

5　Jafari H, Ebrahimi A, Aghaei A, Khatony A — The relationship between care burden and quality of life in caregivers of hemodialysis patients. *BMC Nephrol* 2018; **19**: 1-8.

6　Manivannan M, Karunanithi G, Lakshminarayanan S — Correlation between Quality of Life and Burden in Caregivers of Advanced Stage Cancer Patients on Best Supportive Care. *Indian J Palliat Care* 2022; **29**: 89-93.

7　Vashistha V, Poulose R, Choudhari C, Mohan A — 283-Article Text -for regular issues-1713-1-10-20190716, 2019. **4**: 87-93.

8　Krug K, Miksch A, Peters-Klimm F, Engeser P, Szecsenyi J — Correlation between patient quality of life in palliative care and burden of their family caregivers: A prospective observational cohort study. *BMC Palliat Care* 2016; **15**: 1-8.

9　Kilic ST, Oz F — Family caregivers' involvement in caring with cancer and their quality of life. *Asian Pacific J Cancer Prev* 2019; **20**: 1735-41.

10　Singh K — Factors Impacting Quality of Life of Caregivers of Cancer Patients in the Sub-Himalayan Region: A Cross-Sectional Study. *Cureus* 2023; **15**: 2-9.