Original Article

Correlation between Quality of Life and Burden in Caregivers of Advanced Stage Cancer Patients on Best Supportive Care

Manavalan Manivannan[1], Gunaseelan Karunanithi[2], Subitha Lakshminarayanan[3]

Departments of [1]Radiation Oncology, [2]Radiation Oncology (Regional Cancer Center), [3]Preventive and Social Medicine, Jawaharlal Institute of Postgraduate Medical Education and Research, Puducherry, India.

ABSTRACT

Objectives: Patients with advanced cancer with incurable diseases are generally cared for by their families in India. There is a lack of data on the perceived caregiver burden, quality of life (QOL) of patients and caregivers in India, especially among cancer patients not on any oncologic management.

Material and Methods: We conducted a cross-sectional study among 220 patients of advanced cancer on best supportive care and their respective 220 family caregivers. Our primary objective was to identify a correlation between caregiver burden and QOL. After taking informed consent from both patients and caregivers, we assessed the QOL of the patient using the European Organization for the Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire Core 15 Palliative Care (QLQ C15PAL) questionnaire from the patient, assessing the Caregiver Burden using Zarit Burden Interview, assessing the QOL of the caregiver using the WHO QOL BREF Questionnaire, in a single session during their routine follow-up in the Palliative Care Clinic of our institution.

Results: We noticed a statistically significant negative (Spearman) correlation between the Caregiver Burden as assessed by Zarit Burden Interview (ZBI) and the psychological ($r = -0.302$, $P < 0.01$), social ($r = -0.498$, $P < 0.01$) and environmental ($r = -0.396$, $P < 0.01$) domains of the WHO QOL BREF Questionnaire. Caregiving Burden as assessed ZBI total score was noted to have a statistically significant negative correlation with physical functioning ($r = -0.37$, $P < 0.01$), emotional functioning ($r = -0.435$, $P < 0.01$) and global QOL scores ($r = -0.499$, $P < 0.01$) assessed from the patient using the EORTC QLQ C15 PAL questionnaire. It also had a statistically significant small positive correlation with EORTC QLQ C15 PAL symptom scores, such as dyspnoea, insomnia, constipation, nausea, fatigue and pain. The median caregiver burden score was 39, showing higher burden as compared to previous studies. Caregivers who were spouses of the patient, illiterate, homemakers, with low-income families reported higher burden.

Conclusion: A high perceived caregiving burden is associated with impaired QOL in family caregivers of advanced cancer patients on best supportive care. Multiple patient related factors and demographic factors tend to affect burden of the caregiver.

Keywords: Caregiving burden, Advanced cancer, Best supportive care, Quality of life

INTRODUCTION

Cancer ranks as one of the leading causes of death globally.[1] Given the late presentation to centres for treatment, locoregionally advanced or metastatic nature of the disease,[2] a sizable proportion of the patients become unfit for curative therapies. They are often started on palliative therapies which can be chemotherapy, radiation therapy and rarely surgery to prolong life with a good performance status for as long as possible. At some point in time, the patient may no longer be a candidate for further therapy. These patients are referred to as on Best Supportive Care in this study. Moreover, given inadequate access to hospice facilities, most of the patients are cared for at homes by families, which can impact the family at large, primarily their family caregivers. There is paucity of data regarding Quality of Life (QOL) and caregiver burden among family caregivers of cancer patients in this subgroup. We hypothesised that the burden felt by the caregiver might adversely impact their QOL. Hence, we did this study to see the correlation between the QOL of the patient's caregiver and the burden of caregivers for advanced-stage cancer patients who are on Best Supportive Care in our hospital.

We also assessed the patient's QOL and tried to evaluate its relationship with the burden felt by the caregiver.

Objectives

Primary objective

The primary objective of this study was to study the correlation between QOL and burden in caregivers of advanced-stage cancer patients on Best Supportive Care.

Secondary objectives

The secondary objectives are as follows:
- To study the correlation between Patient's QOL and caregiver's burden among advanced-stage cancer patients on Best Supportive Care and their caregivers
- To identify clinicodemographic factors affecting Burden in Caregivers of advanced-stage cancer patients on Best Supportive Care.

MATERIAL AND METHODS

This is a prospective and cross-sectional study done in the Palliative Care Unit of a tertiary care centre in India. This study was started after the Institutional Ethics Board approval. The patients were with advanced cancer no longer suitable for any oncologic therapy, as decided by their treating oncologist. These patients are referred to be on Best Supportive Care and are on OPD follow-up in the Palliative Care Unit of our centre. 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. We included all consecutive advanced stage cancer patients on Best Supportive Care on OPD follow-up and their respective caregivers. We excluded patients <18 years of age, those on any form of oncologic treatment and those unable to complete the questionnaires. After the patient has finished the follow-up with the Palliative Care Clinic and after informed consent from both Patient and Caregiver, the principal investigator collected demographic and clinical details, then assessed the patient's QOL from the patient using the EORTC QLQ C15 PAL questionnaire, local language version and the Caregiver Burden and Caregiver QOL from the Caregiver using the Zarit Burden Interview and the WHO QOL BREF questionnaire, respectively, local language version, in a single setting.

Before the start of the study, local language versions were obtained from the respective organisations for use in the study. Scoring was done per the scoring manuals of the respective questionnaires. Of note, the WHO QOL BREF domain scores were transformed in the 4–20 range. Higher score in the ZBI total score and symptom scales of EORTC C-15 PAL represents higher burden and higher symptoms. Higher scores in the WHO QOL BREF domains, EORTC C-15 PAL functional scores and global QOL score represent better QOL/functioning.

Sample size calculation

Assuming the minimum correlation coefficient among ZBI and subdomain of WHOQOL BREF to be −0.198 (per a previous study),[3] power 80% and alpha error 5%, the minimum sample size was calculated to be 198 using the MedCalc version18.2.1. Considering a 10% non-response rate, 220 patients and 220 caregivers, a total of 440 individuals were recruited for this study.

RESULTS

In this cross-sectional study, 220 patients and their respective 220 family caregivers were enrolled in this study. Data from 440 subjects were used for statistical analysis.

Mean age of the patients was 53.8 years (SD – 14.3). Age of the patients ranged widely from 18 to 90 years of age. One hundred and eight (49.1%) were males. Majority were married ($n = 170$, 73.5%), Hindu, illiterate or educated up to primary school. The most common primary cancer diagnosis in our study was gastrointestinal malignancies ($n = 89$, 40.4%). The subsite of gastrointestinal malignancies included in the study in order of decreasing frequency was carcinoma of the stomach, oesophagus, gallbladder, colon and pancreas. Most patients in our study were with metastatic disease, with Eastern Cooperative Oncology Group performance status 3. Among the patients with metastatic disease or distal recurrence, lung metastasis (73.3%) was the most common, followed by liver/peritoneal metastasis (51.8%). Majority of the patients ($n = 96$) were on active oncologic interventions for < 6 months in our study. Some patients ($n = 39$) were never on any active oncologic therapy previously. In our study, 42.3% ($n = 93$) had previous surgery, 64.1% ($n = 141$) had previous chemotherapy and 48.6% ($n = 107$) had previous radiotherapy. Patient characteristics are summarised in [Table 1].

The mean age of the family caregivers was 45.5 years (SD-14). Age of the family caregivers ranged widely from 18 to 78 years. A larger proportion of caregivers were female ($n = 119$, 54.1%), homemakers, residing in rural areas ($n = 128$, 58.2%) and spouses of the patient. Caregivers were generally better educated compared to the patients' group. The characteristics of family caregivers are summarised in [Table 2].

The median score for ZBI in the study population ($n = 220$ Caregivers) was 39 (IQR – 10). The median scores for the caregiver QOL ($n = 220$ Caregivers) as assessed by the domains of the WHO QOL BREF questionnaire were for the physical, psychological, social and environmental domains 16 (IQR-2), 13 (IQR-3), 13 (IQR-3) and 12 (IQR-3), respectively. The patient QOL as measured by the EORTC C15 PAL questionnaire ($n = 220$ patients) showed median scores of 55.6 (IQR-22.2), 33.3 (IQR-33.3) and 16.7 (IQR-16.7), respectively, for physical functioning, emotional functioning and global QOL scores.

Correlation between Caregiver Burden and Caregiver and Patient QOL was done using the Spearman test. The

Table 1: Clinicodemographic factors of patients (*n*=220 patients).

Clinicodemographic factors	*n* (%)
Educational qualifications	
Illiterate	39 (17.7)
Primary education	82 (37.3)
Secondary education	47 (21.3)
Higher secondary education	39 (17.7)
Graduate and above	13 (5.9)
Cancer diagnosis	
Breast	16 (7.2)
Head and neck	21 (9.5)
Gastrointestinal tumours	89 (40.4)
Genitourinary tumours	43 (19.5)
Melanomas	10 (4.5)
Sarcomas	19 (8.6)
Miscellaneous	16 (7.3)
Disease status at enrolment	
Upfront metastatic	107 (48.6)
Locally advanced	66 (30)
Local recurrence	19 (8.6)
Distal recurrence	28 (12.7)
ECOG performance status	
2	30 (13.6)
3	148 (67.3)
4	42 (19.1)
Time duration on active oncologic management	
No treatment taken	39 (17.7)
<6 months	96 (43.6)
6–12 months	51 (23.2)
>12 months	34 (15.4)

Table 2: Clinicodemographic factors of caregivers (*n*=220 caregivers).

Clinicodemographic factors	*n* (%)
Relation of caregiver with patient	
Spouse	113 (51.3)
Son/Daughter	61 (27.7)
Others	46 (20.9)
Educational qualifications	
Illiterate	19 (8.6)
Primary education	54 (24.5)
Secondary education	53 (24)
Higher secondary education	54 (24.5)
Graduate and Above	40 (18.2)
Occupation	
Homemaker	103 (46.8)
Agricultural labourer	45 (20.5)
Salaried employee	48 (21.8)
Miscellaneous	24 (10.9)
Family income per month	
≤2000	56 (25.4)
2001–10000	77 (35)
10001–20000	42 (19.1)
>20000	45 (20.5)

Spearman Rho values for the correlation of ZBI total scores with the WHO QOL BREF Domain scores are mentioned in the [Table 3].

Our study tried to find clinicosocial parameters associated with statistically significant changes in the caregiver burden. The ZBI total score was found to significantly vary with the age and gender of the patient being cared for, different cancer diagnoses, ECOG performance statuses. Caregiver occupation, caregiver educational qualifications, relation of caregiver with the patient and family income were also factors with statistically significant differences in ZBI Total Scores, as shown in [Table 4].

DISCUSSION

Results of this study from 440 study participants, that is, 220 patients and their respective 220 family caregivers, showed a statistically significant negative (Spearman) moderate correlation between the caregiver burden as assessed by ZBI total score and the social domain of the WHO QOL BREF, and low correlation between ZBI total score and the psychological and environmental domains of WHO QOL BREF Questionnaire. A similar result has been reported by Rha *et al.*,[3] in their study among caregivers of patients on oncologic therapy in South Korea, had achieved a statistically significant correlation between caregiver burden (ZBI scores) and caregiver QOL (WHO QOL BREF Domains). However, our study did not report a statistically significant correlation of burden with the physical domain of WHO QOL BREF, possibly due to our different caregiver

Table 3: Correlation between Caregiver Burden and QOL.

Caregiver QOL (*n*=220 Caregivers)	Caregiver Burden (*n*=220 Caregivers)		*P*-value
	Rho (ρ)	95% Confidence interval	
Physical domain	−0.122	−0.254, 0.014	0.071
Psychological domain	−0.302	−0.421, −0.173	<0.001
Social domain	−0.498	−0.594, −0.389	<0.001
Environmental domain	−0.376	−0.487, −0.253	<0.001
Patient QOL (*n*=220 Patients)			
Physical functioning	−0.37	−0.482, −0.246	<0.001
Emotional functioning	−0.435	−0.539, −0.318	<0.001
Global QOL score	−0.499	−0.595, −0.389	<0.001
Dyspnoea	0.154	0.018, 0.284	0.022
Insomnia	0.212	0.078, 0.339	0.002
Appetite Loss	0.087	−0.050, 0.220	0.2
Constipation	0.151	0.015, 0.281	0.025
Nausea	0.14	0.004, 0.271	0.038
Fatigue	0.303	0.174, 0.421	<0.001
Pain	0.336	0.209, 0.451	<0.001

Statistically Significant *P*<0.05. Analysis done with spearman correlation, QOF: Quality of life

Table 4: Comparison of clinicodemographic factors with caregiver burden (*n*=220 patients and 220 caregivers).

Clinicodemographic factor	*n*	ZBI Total Score		*P*-value
		Median	IQR	
Patient-related factors				
Age				
<55 years	105	41	9	<0.001
≥55 years	115	37	10	
Gender				
Male	108	40	10	0.009
Female	112	37	10	
Cancer diagnosis				
Breast	16	38	7.5	0.028
Head and neck	21	40	12	
Gastrointestinal tumours	89	40	9	
Genitourinary tumours	43	39	9	
Melanomas	10	31.5	14	
Sarcomas	19	41	13	
Miscellaneous	16	40	9.5	
ECOG performance status				
2	30	29	16	<0.001
3	148	38	8	
4	42	42	5	
Caregiver Related Factors				
Age				
<45 years	105	37	10	0.141
≥45 years	115	40	9	
Gender				
Male	101	38	8	0.736
Female	119	40	10	
Relation of caregiver with patient				
Spouse	113	40	9	0.043
Son/daughter	61	37	7	
Others	46	36	12	
Educational qualifications of caregiver				
Illiterate	19	41	4	0.022
Primary education	54	40.5	7	
Secondary education	53	37	9	
Higher secondary education	54	38.5	9	
Graduate and above	40	35	14	
Occupation				
Homemaker	103	40	10	0.011
Agricultural labourer	45	40	9	
Salaried employee	48	35	10	
Miscellaneous	24	35	6	
Family Income (INR per month)				
≤2000	56	42	3	<0.001
2001–10000	77	39	10	
10001–20000	42	33.5	10	
>20000	45	35	13	

Statistically significant *P*<0.05. Analysis was using Kruskal–Wallis (>2 groups)/Mann–Whitney U-test (=2 groups)

study population, which is caregivers of patients who are not on any active oncologic therapy. A similar significant

negative correlation was discussed in another study,[4] but they used different questionnaires to assess caregiver burden. Our study suggests that worse patient QOL or higher patient symptoms will negatively impact the caregiver by increasing the severity of the burden perceived by the caregiver. This is similar to the conclusions drawn by Lee *et al.*,[5] and Tang *et al.*,[6] although with different questionnaires. Other studies have used cutoffs in ZBI total scores to classify caregivers as those with low burden, high burden and severe burden, like Lukhmana *et al.*[7] from Delhi. They had reported the majority of their patients with no burden or mild-to-moderate burden, with their ZBI total scores being less than 40 for >90% of their study population. The median score here, however, was 39. Another study[8] done on caregivers of patients on chemotherapy in India has also shown around 70% of the caregivers reporting mild-to-moderate burden and around 21% reporting moderate-to-severe burden with ZBI. In this study, however, we noticed 37.2% of caregivers reported moderate-to-severe burden and 58.6% reported mild-to-moderate burden. This can be because they had chosen caregivers of patients on treatment, while, in this study, we chose caregivers and patients who are not on any active oncologic therapy and in advanced disease stages.

We also tried to assess clincosocial parameters with caregiver burden. Due to the scarcity of data, comparisons were drawn from studies on patients on treatment instead of our population, which are patients not on any oncologic therapy. Caregiver burden scores were on average significantly higher for caregivers of younger patients (<55 years) as compared to older patients. This finding was also noted by Choi *et al.*,[9] but they suggested that though family caregivers of younger patients felt a higher burden, they were more likely to adapt positively.

The statistically significant differences in the ZBI caregiver burden scores based on cancer diagnosis were noted on subgroup analysis due to melanoma patients versus other groups. This could be because these patients had low volume metastatic disease with better ECOG performance status than others. Caregiver burden scores were on average lower with better ECOG Performance status of the patient, similar to previous studies in cancer patients.[3,10,11]

Spouses reported on average a statistically significant higher caregiving burden than other relations in our study. Other studies have also shown similar results with co-resident caregivers in the general population.[12] Illiterate caregivers were noted to have, on average, a higher burden compared to well-educated caregivers, as noted in a previous study.[13] On average, it was noted that salaried employees had lower caregiver burden, similar to a study done previously.[3] Caregiver burden scores were significantly different between different income groups. The general trend was towards lower caregiving burden scores for higher-income groups, similar to a previous study.[3]

Limitations

Since it was a single institutional study, it is prone to institutional bias in selecting patients and the conduct of the study. Our study population may not be representative of the entire population of advanced cancer patients in India. Furthermore, given that this study was conducted in a tertiary care centre's Palliative Care Clinic, there may be many patients who could not come to the hospital to avail palliative care services.

Our patient population is heterogeneous. While most of the patients included in the study can be considered to have a life expectancy of <6 months, we noticed a small subset of patients, especially in the melanoma subgroup, with good performance patients, low volume advanced incurable disease were included due to the unaffordability of immunotherapy medications. They may have influenced the results of the study. Worldwide, a large proportion of patients receive chemotherapy at or near their end of life.[14,15] Due to COVID-19 pandemic, many guidelines have also largely decided not to offer palliative chemotherapies or radiation therapies if significant survival or symptom benefit is not expected and the benefits are lower than the risks associated with treatment during the pandemic.[16] Given that the study recruited patients during this period, the population can be expected to be different from previously reported studies.

This study's cross-sectional design only allows identifying associations between the different socioeconomic variables. To confirm the associations identified in the present study, further research should be performed. We have also not assessed factors such as patient or caregiver depression and anxiety and the positive aspects of caregiving. These can also impact the QOL and burden of patients and caregivers in the study.

CONCLUSION

This study shows that a higher caregiving burden is associated with a decrease in the caregiver's QOL. This study also shows that a decline in patient QOL or increase in the symptom scores of patient can be associated with a higher perceived caregiving burden.

Many socioeconomic and clinical factors were associated with the caregiving burden scores or patient QOL and symptom scores, or caregiver QOL scores, and these factors require further analysis and studies to target these factors with interventions or with longitudinal follow-up to aim to decrease perceived caregiver burden and improve the QOL of the patient and caregiver.

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Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

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Conflicts of interest

There are no conflicts of interest.

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