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Assessment of Quality of Life of Caregivers of Persons living with Cancers: a tertiary health centre-based cross-sectional study

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Abstract

Background: Caregivers of persons living with cancers experience a level of subjective satisfaction from their role of care giving, but many also report a significant burden on their physical and psychological well-being as well as their social and personal relationships. The present study was thus aimed at assessing the quality of life of caregivers of persons living with cancers, and identifying the possible factors affecting their quality of life.

Methods: a cross-sectional study was conducted among 100 consecutive, consenting persons who were caregivers of cancer patients attending the Pain and Palliative Care Clinic and the Oncology Outpatient department in a tertiary care hospital in Hyderabad, India, over a period of 2 months. The WHOQoL-BREF tool was used to assess the quality of life of the respondents under 4 domains: physical, psychological, social, and environmental. The domain scores were compared using Mann-Whitney U test.

Results: Majority of the respondents were males (67%), resided in urban localities (74%), were literate (82%), and were either children (52%) or spouses (39%) of the cancer patients. Assessment of Quality of life through domain scores showed that mean score was highest for social domain (14.19 + 1.75) and lowest for psychological domain (12.19 + 1.85). There were statistically significant differences between domain scores when compared based on gender, residence, education, marital status, relationship with the cancer patients, and modality of treatment.

Conclusions: Psychological health and well-being of the caregivers of cancer patients are very poor. It is thus imperative to support the caregivers of the cancer patients and provide them with regular counseling sessions.

Keywords: Caregivers, Quality of Life, Cancer.

Introduction

Worldwide the number of people living with cancer has been on the raising edge.[1] Cancer has been one of the leading causes of death since 2000. [2] Cancer and its treatment affect not only the patients but also their family members and caregivers. Caregivers are the main advocates of people who endure from cancer. [3] A Caregiver is defined as a relative, friend or neighbor, who provides practical day-to-day unpaid support for a person unable to complete all of the tasks of daily living on their own. During the course of illness when cancer patients are not admitted to the hospital, family caregivers assume significant role to support the patient. [4] This role, in turn, has a substantial influence on the “Quality of Life” of the caregiver.

The quality of life of any person automatically demonstrates their physical as well as psychological health, their personal believes, their social relationships and their relationship to their environment. [5] When giving care to persons with life threatening illness such as cancer, caregivers are confronted with physical and emotional challenges. [6][7] Care of the cancer patients has both positive and negative impacts on caregivers. Many caregivers experience a high level of satisfaction from their caring roles, conversely many report a significant burden to their physical and psychological well-being, their economic circumstances, and their social and personal relationships. [4]

As the cancer advances, the caregivers will be in need of taking more responsibilities, comprising a long period of home care and more recurrent hospital visits which in turn results in increased caregivers burden and in due course endanger their quality of life. [8][9][10] The present study thus aims at assessing the Quality of Life (QoL) of caregivers of cancer patients.

Objectives

Primary Objective: To assess the Quality of Life of caregivers of Cancer patients attending Out-Patient departments of Pain and Palliative Care Clinic and Oncology, at a tertiary care hospital.

Secondary objective: To identify the factors affecting the quality of life of caregivers of cancer patients.

Materials and methods

Study design: Cross-sectional study

Study setting: a tertiary care hospital in Hyderabad, Telangana, India.

Selection of participants: Caregivers of cancer patients attending the Pain and Palliative Care Clinic and the Oncology Outpatient department.

Time frame: 2 months (December 2021 – January 2022)

Sample size and Sampling: A review of the registers at the Pain and Palliative Care Clinic and the Oncology Outpatient department showed that about 50 to 60 patients attended here every month. Based on this, a convenient sample size of

100 was chosen for this 2-month study. Consecutive caregivers (one per patient) who met the selection criteria, were included in the study.

Inclusion criteria:

- Adult (aged > 18 years) caregivers of either gender
- Caregivers of patients with chronic cancers i.e., duration of illness more than 2 months
- Caregivers who are willing to participate and give consent

Exclusion criteria: Caregivers having cancer in the present, or, who had cancer in the past were excluded from the study.

Study tools: A semi-structured questionnaire based on the WHOQoL-BREF instrument was utilized for data collection.

Data collection: After briefly explaining the purpose of the study and taking oral informed consent, the participants were interviewed face-to-face for 15-20 minutes each. Basic demographic details of the caregiver, details of the type of cancer, duration of illness and modality of treatment received were collected and quality of life was assessed under four domains viz. physical, psychological, social and environmental, with the help of the questionnaire.

Outcome measures: The participants were questioned on various aspects pertaining to their physical health, psychological health, social relationships and their relationship with the environment, and their responses were captured on a Likert scale and graded accordingly.

Statistical analysis: For each participant, the graded responses under each domain i.e., physical, psychological, social and environmental domain, were summed domain-wise and mean domain scores were obtained. The arithmetic mean of each domain was multiplied by 4. The mean scores of all the participants put together were then compared between the four domains with respect to different characteristics viz., gender, residence, education, occupation, income, marital status, relationship with patient, type of cancer, duration of illness, and modality of treatment. Descriptive and inferential statistics were performed with the help of Microsoft Excel 2010 and IBM SPSS version 20.0.

Ethical guidelines: Ethical approval was obtained from the Institutional Ethical Committee of ESIC Medical College, Hyderabad. Participants were clearly explained about the purpose and objectives of study and were interviewed only after acquiring oral informed consent. Participant anonymity was maintained by removing names from the results and confidentiality of their information was ensured.

Results

The participants were aged between 20 to 70 years, with a mean age of 40.65 + 12.98 years. Two-thirds (67%) of the participants were males. Majority of the participants resided in urban localities (73%). About 29% of the caregivers were educated upto intermediate or post-high school diploma, and another 21% were graduates/post-graduates (16%) or professionals (5%). However, 18% of the caregivers were illiterate (Figure 1). Majority of the participants were employed in skilled work (33%), followed by semi-skilled work (17%), while 16% were unemployed. Combining the education, occupation and income aspects, the socioeconomic status of the participants was classified based on the modified Kuppuswamy socioeconomic scale. More than half of the respondents belonged to Lower Middle socioeconomic class (58%), followed by Upper Lower (22%) and Upper Middle (11%). However, these findings of income and socio-economic status of the participants may be influenced by the fact that all the participants are caregivers of ESI-insured cancer patient.

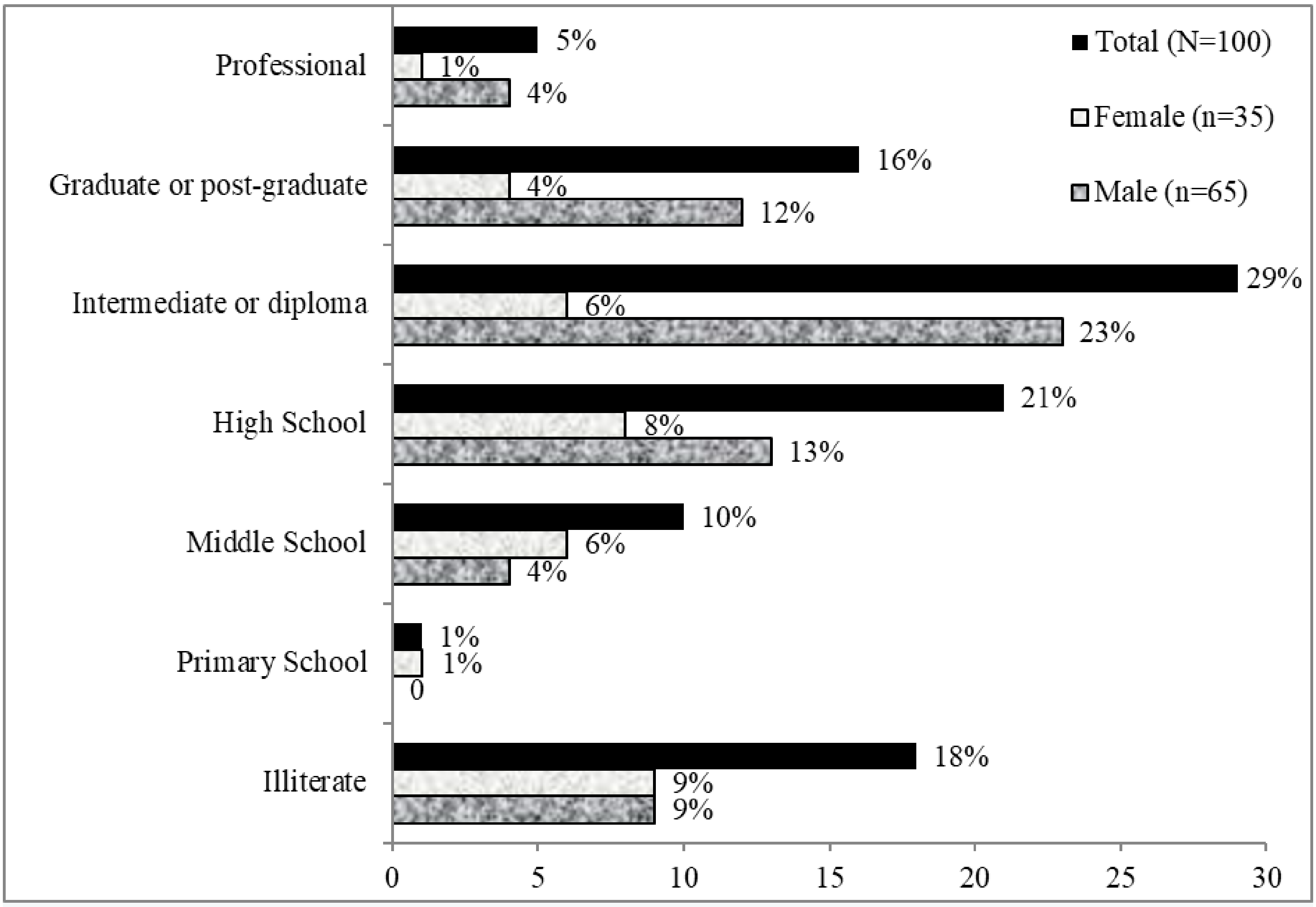

Figure 1. Distribution of study participants of either gender, and total study participants, based on their education.

Majority of the study participants were married and only 18% were unmarried. More than half of the participants were children of the cancer patients (37% sons, 15% daughters) and about 39% were spouses of the patients (Table 1).

Table 1. Distribution of the study participants based on their relationship with the cancer patients

Relationship with the patient	Frequency (n=100)
Child	52%
Son	37%
Daughter	15%
Parent	3%
Mother	3%
Spouse	39%
Husband	30%
Wife	9%
Sibling	1%
Daughter-in-law	4%
Friend	1%

Breast cancer was the most common type of cancer among the cancer patients (31%) followed by cancers of the Cervix (11%) and Lung (8%), while miscellaneous cancers (*Penile, Urinary Bladder, Adrenal, Sarcoma, Multiple Myeloma, Meningioma, Medulloblastoma, Paratesticular rhabdomyosarcoma, and Neuroendocrine tumors*) comprised of 9% of the cancer patients accompanied by the corresponding subjects of interest (Figure 2).

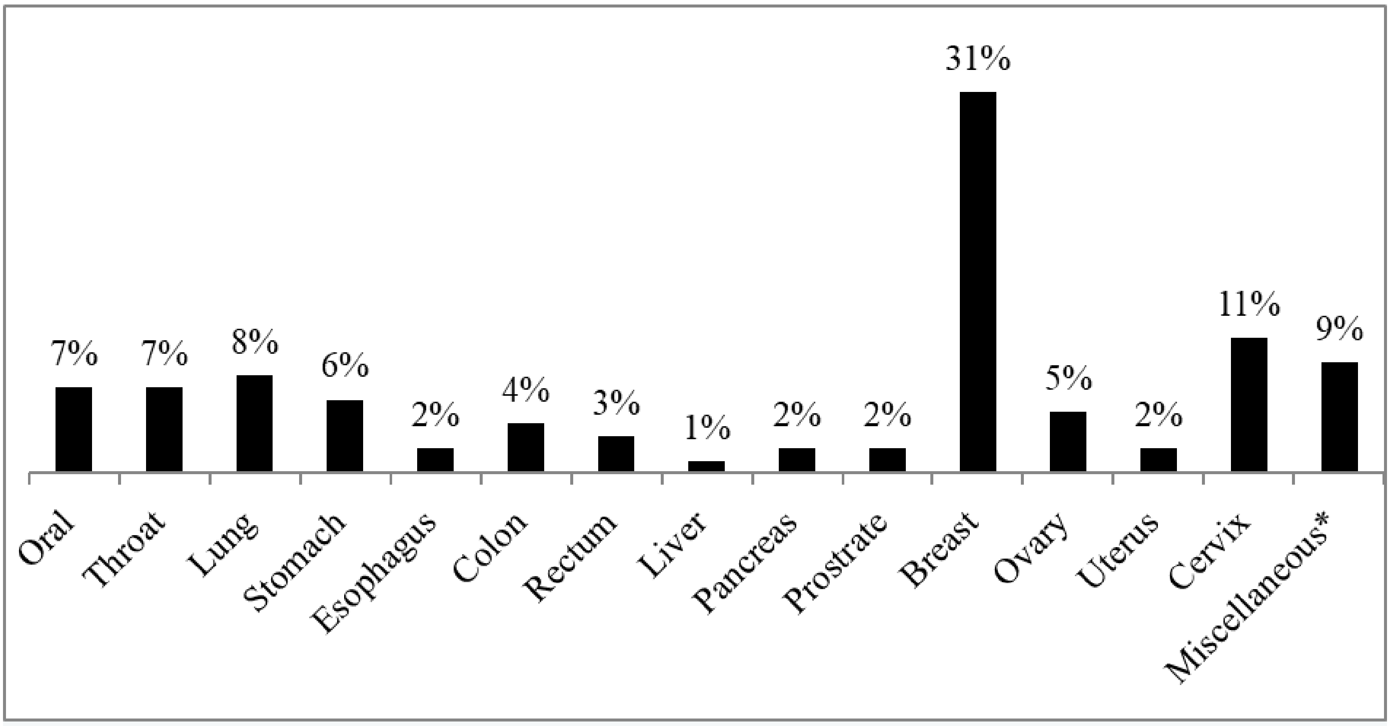

Figure 2. Distribution of caregivers based on type of cancer (anatomical site) in the patient.

**Miscellaneous includes 1 case each of: Penile, Urinary Bladder, Adrenal, Sarcoma, Multiple Myeloma, Meningioma, Medulloblastoma, Paratesticular rhabdomyosarcoma, and Neuroendocrine tumors*

About two-thirds (65%) of the cancer patients were recently diagnosed i.e., had < 1 year duration of illness, whereas only

7% had been living with cancers for more than 5 years (Figure 3). More than one-fifth of the cancer patients were receiving ‘Only Chemotherapy’ (22%) and another 21% were receiving ‘Chemotherapy & Radiation’ (Figure 4). About 14% were on no treatment, suggesting that they may be under the process of initial stages of identification of the cancer and deciding on the ideal and suitable treatment modality (Figure 4).

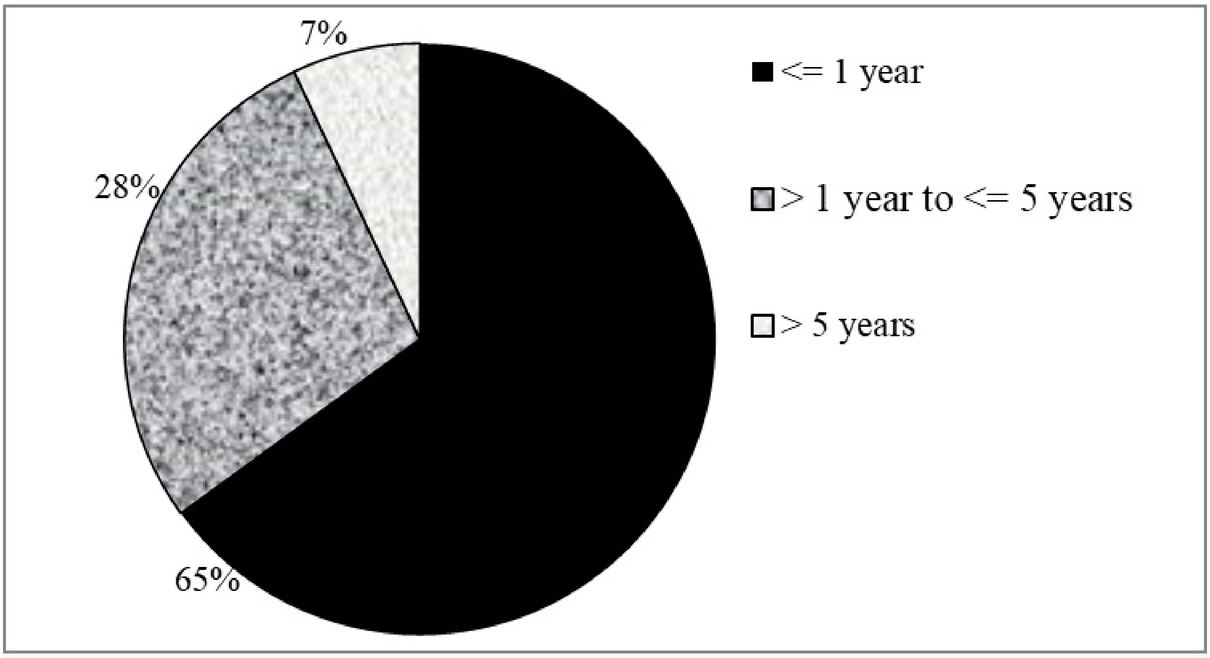

Figure 3. Distribution of caregivers based on the duration of their illness in the cancer patients.

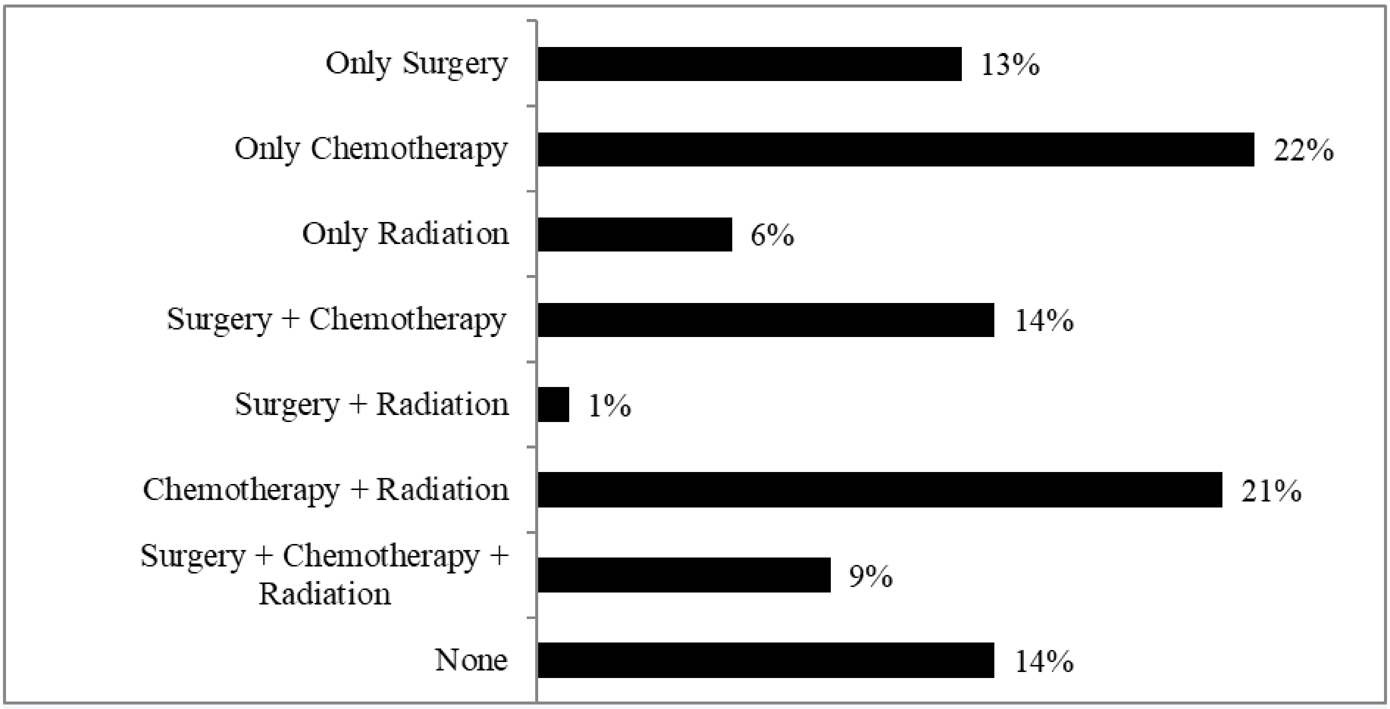

Figure 4. Distribution of caregivers based on the modality of treatment received by the corresponding cancer patients.

On comparing the computed domain scores overall, the Social domain had the highest mean score (14.19 + 1.75), while the mean scores of the remaining three domains only differed slightly (Table 2). Physical domain had the highest minimum (8.57) and maximum scores (17.14). Psychological domain had the lowest mean, lowest minimum and lowest maximum score.

Table 2. Minimum, maximum and mean scores of each domain, with standard deviation.

Domain	Minimum Score	Maximum Score	Mean Score + SD
Physical	8.57	17.14	12.62 + 2.07
Psychological	5.33	16.00	12.19 + 1.85
Social	8.00	16.00	14.19 + 1.75
Environmental	8.00	16.50	12.86 + 1.93

The mean scores of physical, psychological and environmental domains were higher among males as compared to females, except that of the social domain (Table 3). The gender-based difference in mean scores of physical and psychological domains was found to be significant (p=0.026 and 0.014, respectively). Participants from urban resident had higher mean scores in all the four domains. While semi-urban participants had higher mean scores in the physical and psychological domain, rural participants had higher mean scores in the social and environmental domains, and the difference was significant for psychological domain (p=0.033). Caregivers who were graduates or post-graduates had the highest mean scores in the physical and social domains, and, those with professional education had highest mean scores in the psychological and environmental domains (Table 4). Illiterates had the lowest mean score of psychological domain. These differences in mean domain scores across different levels of literacy were statistically significant (p=0.001, 0.002, 0.033, and 0.007 for physical, psychological, social and environmental domains, respectively) (Table 4). The caregivers who were in clerical or farming work or were shop workers had higher mean scores in physical and psychological domain. The highest mean score of social domain was seen for semi-professionals while professionals had the highest mean score for environmental domain. Among the income groups, caregivers with the highest total monthly family income i.e., greater than or equal to Rs.52734 per month, had the highest mean scores of physical, psychological as well as environmental domains. The mean score of social domain was highest for the caregivers with Rs.19759 – 26354 monthly family incomes. The caregivers belonging to “Upper” socioeconomic class (according to the Modified Kuppuswamy Socioeconomic Status Classification) had the lowest mean scores in the physical and psychological domains while those of the “Lower” socioeconomic class had the lowest mean scores in social and environmental domains (Table 5). The differences in mean psychological, social and environmental domain scores across different socioeconomic classes was statistically significant (p=0.014, 0.008, and 0.001, respectively) (Table 5).

Table 3. Mean domain scores with standard deviation by (a) gender and (b) place of residence.

Variable	Physical	Psychological	Social	Environmental
(a) Gender				
Male	12.95 +2.05	12.53 + 1.70	14.15 + 1.80	13.06 +1.78
Female	11.95 + 1.96	11.52 + 1.97	14.26+1.68	12.45 +2.71
p - value	**0.026**	**0.014**	0.772	0.232
(b) Residence				
Urban	12.85 + 1.98	12.41 + 1.60	14.30 + 1.64	12.95 +1.98
Semi-urban	12.30 + 2.36	12.00 + 2.70	13.80 + 2.11	12.56 + 1.86
Rural	11.43 + 1.85	10.93 + 1.41	14 + 2.01	12.75 + 1.74
p - value	0.079	**0.033**	0.679	0.703

Table 4. Mean domain scores with standard deviation by education and occupation.

Education	Physical	Psychological	Social	Environmental
Illiterate	12.22 + 2.20	10.78 + 2.38	13.26 + 1.80	12.50 + 2.40
Primary School	11.43	12.67	10.67	13.50
Middle School	13.09 + 1.56	11.67 + 1.38	14.27 + 1.55	12.70 + 1.55
High School	11.70 + 1.70	11.84 + 1.49	13.90 + 2.09	12.05 + 1.74
Intermediate or diploma	12.10 + 1.95	12.57 + 1.51	14.44 + 1.51	12.66 + 1.61
Graduate or post-graduate	14.54 + 1.82	13.42 + 1.48	15.08 + 1.26	14.06 + 1.66
Professional	14.06 + 0.87	13.60 + 1.01	14.93 + 1.12	15.10 + 1.39
p-value	**0.001**	**0.002**	**0.033**	**0.007**

Table 5. Mean domain scores with standard deviation by Socioeconomic class of caregivers.

Socioeconomic status	Physical	Psychological	Social	Environmental
Lower	12.16 + 2.46	11.62 + 1.76	12.19 + 1.43	11.71 + 2.21
Upper Lower	12.67 + 2.11	11.76 + 1.78	14.30 + 1.94	13.05 + 1.83
Lower Middle	12.38 + 1.96	12.14 + 1.84	14.23 + 1.65	12.52 + 1.79
Upper Middle	14.18 + 1.79	13.88 + 1.29	15.15 + 1.37	15.00 + 1.38
Upper	11.71 + 2.83	11.33 + 1.89	13.33 + 0.00	13.00 + 0.71
p-value	0.106	**0.014**	**0.008**	**0.001**

Unmarried caregivers had higher mean scores in all the four domains (13.94 + 2.38, 13.41 + 1.63, 14.37 + 1.34 and 13.72 + 1.95 in physical, psychological, social and environmental domains, respectively) when compared to married caregivers and this difference is mean scores was statistically significant for physical (p=0.008), psychological (0.001) and environmental (p=0.040) domains. Male relatives (sons and husbands) had better mean scores in the physical, psychological and environmental domains as compared to female counterparts (Table 6). Overall, mothers had the lowest mean domain scores in all the four domains compared to other relatives (Table 6). The difference in mean scores based on relationship of the caregiver with the cancer patient was significant in the psychological (p=0.011) and social domains (p=0.011).

Table 6. Mean domain scores with standard deviation by the relationship of the caregiver with the patient

Relationship with patient	Physical	Psychological	Social	Environmental
Child				
Son	13.36 +2.16	12.88 +1.66	14.59 +1.44	13.26 +1.98
Daughter	12.34 +1.91	12.40 +1.55	14.76 +1.55	13.20 +1.92
Parents				
Mother	10.48 +2.31	10.00+0.67	12.89 +2.78	11.00 +1.32
Spouse				
Husband	12.29+1.79	11.87 +1.66	13.51 +2.00	12.62+1.65
Wife	11.68 +1.79	11.33 + 1.37	13.78 +1.63	11.61 +2.56
Sibling	12.00	14.00	16.00	14.00
Daughter-in-law	12.57+2.72	9.83 + 3.19	14.33+1.28	13.25 + 0.65
Friend	14.86	15.33	16.00	14.50
p-value	0.247	**0.011**	**0.011**	0.052

The mean score of the physical domain was lowest for caregivers of patients with lung (11.43 + 1.43) and liver (11.43) cancers, followed by prostate cancer (11.71 + 4.44). Mean scores of the Psychological and Social domains were lowest in the caregivers of patients with liver cancers (10.00 and 12.00, respectively) followed by those with cancers of the uterus (10.67 + 1.89 and 12.00 + 3.71, respectively). The mean score of the environmental domain was lowest for the caregivers of patients with throat cancers (11.43 + 1.88). Comparison of mean domain scores between caregivers of cancer patients with different durations of illness showed that shorter duration of illness (< 1 year) was associated with poorer mean scores in psychological (12.47 + 2.00), physical (11.99 + 1.96) and environmental (12.78 + 2.11) domains. However, the mean domain score of the social domain was lowest in those with duration of illness between 1 to 5 years (13.90 + 1.47). A higher duration of illness among the cancer patients was thus found to be associated with better mean scores, suggesting an overall better quality of life, and this may be due to understanding the disease, adjusting with the care-giving practices, or improvement in the patient's health condition, etc. over the course of time. The mean scores of the physical, psychological and environmental domains were the lowest for the caregivers of patients receiving "Only surgery" (11.43 + 1.32, 11.18 + 1.25, and 11.65 +1.60, respectively) whereas mean social domain score was lowest for the caregivers of patients on "Surgery + Radiation" (13.33). This finding suggests poorer quality of life associated with surgical treatment of cancers. The mean scores of only the physical domain differed significantly across different modalities of treatments (p=0.006).

Discussion

The caregivers of the cancer patients attending the Pain and Palliative Care Clinic and the Oncology Outpatient departments are primarily males, from urban populations, literate and employed, married persons. A simiar study done by Thirumoorthy et al in 2016 [10] also found that males were predominant (63.7%) among the caregivers of cancer patients, 8 in 10 caregivers were married and literate. However, contrary to the present study, their study showed a higher proportion of caregivers from a rural domicile. Majority the caregivers in the present study were children (52%) or spouses (39%) of the cancer patients. A similar study conducted by Malathi GN in 2014 [11] reported that 46% of the family caregivers of patients with advanced cancer were spouses while 34% were children.

Breast, cervix and lung were the most common types of cancers affecting nearly half of the cancer patients attending the Pain and Palliative Care Clinic and the Oncology Outpatient departments at ESIC Medical College & Hospital, Sanath nagar. This finding is in line with the national findings reported by Mathur et al [12] in 2020, which showed that breast, lung, mouth, cervix and uterus were the five leading sites of cancer in the country. The ICMR-NCDIR also stated similar findings in their report on Profile of Cancer and Related Factors – Telangana, 2021 [13], wherein breast and cervix were the leading sites of cancers among women, and lung was the second most common site of cancer among men.

Nearly two-thirds of the respondents were caregivers of cancer patients with duration of illness <= 1 year. "Only chemotherapy" and "chemotherapy + radiation" were the most common modalities of treatment. Nearly one in seven cancer patients were on no treatment, yet. Malathi GN [11] also reported that more than 72% cancer patients had a duration of illness < 1 year. However, their study found that "radiotherapy + chemotherapy" was the most common type of treatment taken (25.3%), and only 12% were on “only chemotherapy”.

Overall, psychological domain was the most affected, followed by physical domain, while social domain had the highest mean score. The differences in mean scores of all the four domains, across different levels of education, were statistically significant. Gender, marital status, socioeconomic status, relationship with the patient and modality of treatment also caused statistically significant differences in the mean domain scores. Khan S. et al [9] reported similar findings in their study 2015, wherein the quality of life of caregivers of cancer patients with a control group, and found that caregivers had better social relationships while the control group had better psychological health. Thirumoorthy et al [10] reported that female gender, unemployment and low level of education had negative effects on the quality of life of the caregivers. Malathi GN [11] also reported similar findings, stating that 80% of their study sample experienced psychological weakening, and their study also showed statistically significant association between the mean scores of family caregivers and the total family income, type of cancer and duration of illness.

Conclusions

Psychological health and well-being of the caregivers of cancer patients is very poor. Female caregivers, caregivers with lower levels of literacy and married caregivers had low quality of life. The caregivers of patients with duration of illness not more than 1 year had the lowest quality of life. The caregivers of patients undergoing surgery alone as a modality of treatment, and of those who had not started treatment yet had poor quality of life.

The study thus recommends the following interventions:

- Focus on psychological health and well-being caregivers of the cancer patients is of prime importance.
- Patient and family counselling sessions can improve the overall health outcomes of the patient as well as the health of the caregivers.
- Health education, especially awareness of the warning signs of various familial / hereditary cancers, especially Breast cancer, should be provided to the family members.
- Universalisation of home-based care for cancer patients can reduce the burden on the caregivers.
- A large, multi-centric, community-based study is recommended to assess the quality of life of the caregivers at the home of the patients.

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