UDC 616.89

DOI: 10.15587/2519-4798.2022.265395

LIFE AND CAREGIVER BURDEN IN CAREGIVERS OF CANCER PATIENTS

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Caregivers of cancer patients were prone to deterioration of their QOL due to the caregiving burden. A high caregiving burden and low QOL were common among CG. In India, only a few studies were done on the caregivers of cancer patients. Hence this study was undertaken.

The aim: To study psychopathology, quality of life and burden in caregivers of cancer patients

Materials and methods: The study was done on 100 caregivers of cancer patients attending after fulfilling the inclusion criteria. A semi-structured Proforma was administrated to collect the socio-demographic details. Following by Mini International Neuropsychiatric Interview (MINI), WHO-QOL and Burden assessment scale was administered to the caregivers. Data were analysed using SPSS. Descriptive statistics, Pearson and Spearman Correlations and ANOVA were used.

Results: 31 % of caregivers suffer from generalised anxiety disorders (15 %) and depression (16 %). The environmental domain of QOL (mean-18.2, SD-15.4) was the most affected. 83 % of caregivers experienced a moderate burden, and 17 % had a severe burden. These variables are significantly associated with caregiver relation with patient and socio-economic status (<0.05). A significant correlation was found between Psychiatric morbidity, QOL and Burden in caregivers.

Conclusion: psychiatric morbidity, quality of life and burden in CGs influence one another. The least attention was paid to caregivers' mental health, many of them left unidentified and untreated. These results highlight the need to educate them about mental health and counsel and treat them for their psychiatric problems

Keywords: caregiver, psychiatric morbidity, quality of life, burden, unidentified, untreated, mental health and counsel, socio-economic status

How to cite:

Sanjeevani, G., Ramakanth, P., Chaitanya, A. (2022). A cross-sectional study of psychopathology, quality of life and caregiver burden in caregivers of cancer patients. ScienceRise: Medical Science, 5 (50), 57–64. doi: http://doi.org/10.15587/2519-4798.2022.265395

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1. Introduction

According to the National Cancer Registry in India, the cause of cancer is multifactorial, the burden of cancer is multidimensional, and treatment is multidisciplinary. It affects both the patients and their family members multi-dimensionally [1]. Advances in cancer treatment enable care to be implemented in the home setting and the engagement of family members to assume significant roles as caregivers [2]. CG needs time, cognitive capacity and physical strength to navigate the complex process of cancer care, such as hospital policies, economic difficulties and communication and accessibility to cancer care services. Consequently, family caregivers place the needs and well-being of their ill relatives ahead of their own needs, and caregivers can neglect their health [3]. CG can experience burden and stress while caring for the patient. Caregiver burden is influenced by patient characteristics like diagnosis, stage of disease, treatment and amount of caregiving-related tasks [4]. Cancer can negatively affect the Quality Of Life (QOL) of the patients and their family caregivers. CGs of cancer patients were prone to deterioration of their QOL due to the caregiving burden. A high caregiving burden and low QOL were common among CG [2]. Diagnosis of

cancer in the family impairs family function, which was significantly associated with depression and anxiety in both patients and caregivers. Increased demand for care and support from CG during treatment of terminal stage of illness, palliative care increases the vulnerability to psychological problems like anxiety, depression, and post-traumatic stress disorder in CG compared to cancer patients [5–7].

The aim of the research was to study psychopathology, quality of life and burden in caregivers of cancer patients.

2. Materials And Methods

- **Study Design:** A Cross-sectional study. The study was done in January–February 2020 at MNJ Institute of Oncology and Regional Cancer Centre, a Tertiary Health Care Centre.)

Study setting:

- The study sample was collected from caregivers of inpatients at MNJ Cancer Hospital from different cancer treatment departments.
- MNJ Institute of Oncology and Regional Cancer
 Centre is a Tertiary Health Care Centre. It is a 450 bedded hospital situated in Hyderabad city of Telangana state.

Sampling: Sample collection was done utilizing convenient sampling.

Study population: Caregivers of patients admitted to MNJ cancer hospital with lung, breast, cervical, ovarian, acute lymphoblastic leukaemia, and osteosarcomas who were taken.

Sample size: 100 caregivers of cancer patients. **Study period**: 2 months (Jan2021–Feb 2021)

Bioethics: Ethics clearance was given by the Institute Ethics Committee of Osmania Medical College, Telangana, India, number-18106001005D and the date of the protocol-02/04/2018. Informed consent was taken from the participants of the study. Individuals had the right to withdraw their consent from participation after inclusion in the study. The identity of the individual was kept confidential. The scales included in the study were used after taking permission from the author.

Recruitment Criteria for participants Inclusion criteria:

1. A caregiver who is taking care of the patient for a minimum of 6 months

Age of caregiver: 18-60 years

2. Caregivers do not have major medical and surgical illnesses.

Exclusion Criteria

1. The caregiver is not willing to give consent.

Tools used

- **1. A semi-structured intake Proforma** containing Socio-demographic details of CGs like age, gender, religion, domicile, education, occupation, type of family, socio-economic status, relationship with the patient, and medical and psychiatric history of the subjects.
- 2. MINI International Neuropsychiatric Interview (MINI): It was developed by Dr David Sheehan et al. it is a brief structured diagnostic interview scale used for diagnosing 16 major psychiatric disorders as per DSM-5 and ICD-10 criteria. The interview is conducted with precise questions about psychological problems, requiring a Yes or No answer. The general format of MINI is divided into modules identified by letters (A-P), each corresponding to a diagnostic category [8].
- **3. WHO QOL BREF:** It was developed by Alison Harper on behalf of the WHOQOL group. The WHO QOL BREF is a 26-item concise version of the WHO QOL-100 assessment used for assessing the Quality of Life. It consists of 4 domains- physical, psychological, social relationship and environmental. Each of these domains is rated on a 5-point Likert Scale. Mean scores are taken from each domain which is multiplied by 4. These raw scores are converted to transformed scores on a 0-100 scale [9].
- **4. Burden assessment scale (BAS):** It was developed by Thara et al. at the schizophrenia research foundation (SCARF). This is a semi-quantitative, 40-item scale measuring 9 different areas of objective and subjective caregiver burden. Each item is rated on a 3-point scale. The responses are 'not at all, 'to some extent, and 'very much. Some of the items are reverse coded. The authors have not suggested cut-off scores for low and high burdens since it will depend on the sample. We have taken cut-off scores like 0–40 as mild, 41–80 as moderate and 81–120 as severe burden [10].

5. Modified kuppuswamy scale: This scale was used to assess the socio-economic status of the study population. It classifies the study population into lower, middle and upper socio-economic status based on education, occupation and income [11].

Methodology: Caregivers were screened for inclusion criteria. CGs willing to participate in the study were taken. Study details were explained, and written informed consent was undertaken. A semi-structured Proforma was administered to collect the socio-demographic details. After this, the MINI, WHO-QOL BREF scale and burden assessment scale was administered to them.

Statistical analysis: Statistical analysis was performed using SPSS version 25 software. Descriptive statistics of each item were determined for analysing the psychiatric morbidity, QOL, and Burden and their relation with a socio-demographic profile of CGs. ANOVA, Spearman rho and Pearson correlation tests were used. A significant p-value less than or equal to 0.05 was taken.

3. Results

The participants in this study are 100 caregivers of cancer patients who were admitted to different departments of tertiary cancer care hospitals in Hyderabad. The socio-demographic details of caregivers are discussed in table-1. Occupations of the CGs are as follows 33 %-housewives, 24 %- labourers, 16 %-skilled workers, and 12 %-farmers.

The total duration of caregiving was found to be higher in CGs of patients receiving radiotherapy and palliative care with means of 30.8 and 20.8 months (SD-51.4 and 20.2). The mean time spent per day for caregiving was found to be more in paediatric cancer patients receiving chemotherapy and palliative care with means of 18.9 and 14.7 hours per day (SD-6.89 and 7.4), respectively. The number of times patients were admitted to the hospital was high in patients receiving palliative care, combined chemotherapy and radiotherapy and chemotherapy alone, with the means of 5.8, 5.5 and 4.5 times (SD-5.96, 6.98 and 4.41).

No significant relation was found between variables like age, literacy, domicile, type of family, socioeconomic status, relation with patient and substance use with psychiatric morbidity of CG (Table 1).

Table 1

Socio-demographic details of caregivers Socio-demographic details of caregivers Mean±SD 37.08±10.46 Literacy – Illiterate 23.45±8.46 21.57±11.85 **Primary** 22.47±10.56 Secondary Intermediate 26.14±10.14 Graduate 22.43±6.89 No.of hospital admissions of patient 3.6 ± 4.39 No.of hours spent in caregiving per day 12.86 ± 8.14 The total duration of caregiving in months 15.9 ± 20.35

Out of 100 CGs, 31 % were found to have psychiatric morbidity. Among them, 15 % were diagnosed with Generalised Anxiety Disorder (GAD) and 16 % with Major Depressive Disorder (MDD).

The relation between CGs psychiatric morbidity and demographic correlates was analysed using

spearman's rho correlation test. A statistically significant negative correlation was found between psychiatric morbidity (GAD and MDD) and the gender of CGs with r_s =0.32 p=0.001. Among female CGs, 15 % were found to have GAD, and 14 % had MDD, whereas, among male CGs, only 1 % had GAD and MDD (Table 2).

Table 2 Relation between psychiatric morbidity and demographic correlates of CGs

	N	%
Gender –Male	28	28
Female	72	72
Domicile-Rural	48	48
Semi-urban	5	5
Urban	47	47
Type of family-Nuclear	97	97
Joint	<u>3</u>	<u>3</u>
Socio-economic status-lower	5	5
Lower middle	30	30
Upper lower	58	58
Upper middle	7	7
CG relation with patient-Parents	39	39
Spouse	35	35
Children	29	29
Other family members	5	5
Head of the family-Husband	30	30
Fathers	40	40
children	20	20
Wife	5	5
Mother	5 3 2	5 3 2
Sibling	2	2
Type of treatment given to the patient		
Chemotherapy	39	39
Radiotherapy	8	8
Chemotherapy+Radiotherapy	16	16
Palliative care	11	11
Surgical care	26	26

Quality Of Life in CGs of cancer patients

QOL in CGs was assessed in four domains according to the WHO-QOL BREF scale. Mean scores of these domains are Physical(D1)-23.25, SD-9.02, Psychological(D2)-26.5, SD-13.39, Social relationship(D3)-62.9, SD-22.85, Environmental(D4)-18.22, SD-15.40. The highest mean score was seen in the social domain, which indicates good QOL in this domain, and the least mean score was scored in the environmental domain, indicating poor QOL in this domain (Table 3).

Table 3 Relation between MINI and socio-demographic variables of caregivers

of caregivers					
Relation between Socio-	MINI				
demographic variables and MINI	r	p-value			
Age	-0.23	0.8			
Gender	-0.32	0.001*			
Relation with patient	-0.16	0.09			
Socio-economic status	0.03	0.7			
Literacy	0.17	0.07			
Domicile	-0.16	0.1			
Type of family	0.02	0.7			
Number of hours spent in caregiving	0.07	0.4			
The total duration of caregiving	-0.13	0.1			
Type of treatment given to the patient	-0.07	0.9			

Note: P-value is significant at <0.01 level (2-tailed); and at the 0.05 level (2-tailed)

Burden in caregivers

The burden on caregivers was assessed using Burden Assessment Schedule (BAS). No cut-off scores were mentioned for this scale. Mean and Median scores of BAS were 68.19 and 67 (SD-13.05). Based on the median, we have set cut-off scores. In our study, 83 % of CGs experienced moderate and 17 % experienced severe burdens (Table 4).

Table 4 Quality of life domains of caregivers

 WHO-QOL DOMAINS
 MEAN±SD

 Physical domain (D1)
 23.25±9.026

 Psychological domain (D2)
 26.5±13.38

 Social relationships (D3)
 62.09±22.83

 Environment (D4)
 18.22±15.40

Association between the quality of life and demographic correlates of CGs

One-way analysis of variance(ANOVA) was performed to see the effect of socio-demographic correlates on the QOL of CGs. Statistically significant association was found between the psychological domain of QOL of CGs with gender (F=4.18, P=0.04), relation with the patient (F=2.28, P=0.02) and type of treatment given to the patient F=2.6, P=0.02). Statistically significant association was seen between the social relationship domain of QOL with relation to the patient (F=2.6, P=0.009) and the type of treatment given to the patient (F=2.7, P=0.002). In addition, a significant association was found between the environmental domain of QOL and the socio-economic status of the CG (F=4.56 P=0.02) type of treatment given to the patient (F=4.5, P=0.001). A significant negative correlation was seen between the environmental domain and the number of hours spent in caregiving (R=0.22, P=0.02) (Table 5)

No significant association was found between the QOL of CG with other variables.

Association between burden and demographic correlates of CGs

One-way analysis of variance was used to find the association between burden and demographic correlates of CGs. A significant association was found between burden and relationship with the patient (F=3.7, p<0.001), socio-economic status of the caregivers (F=4.92, p<0.01) and type of treatment given to the patient (F=2.4, p<0.04). In addition, a significant positive correlation was seen between burden and total duration of caregiving (R=0.31, p<0.002) (Table 5).

No significant association was found between caregiver burden and other variables.

Burden in caregivers

 Burden in caregivers

 Burden in caregivers
 N
 %

 Mild burden (0-40)
 0

 Moderate burden (41-80)
 83
 83 %

 Severe burden (81-120)
 17
 17 %

Correlation between MINI, QOL and Burden in caregivers

Spearman's rho correlation tests were used to assess the relationship between psychiatric morbidity and

Table 5

QOL in CGs. Statistically significant negative correlation was seen between psychiatric morbidity(MINI) and psychological domain(r_s =0.45, p-0.00), environmental domain (r_s =0.02, p<0.05) of QOL (Table 6).

Pearson correlation test was used to assess the relation between QOL and Burden in CGs. Statistically significant negative relation was seen between physical (r=-0.339, p<0.001), psychological(r=-0.335, p<0.001) and social relationship domains (r=-0.39, p<0.00) of QOL with burden in CGs. A statistically significant positive correlation was seen between burden (r_s =0.39, p<0.00) and psychiatric morbidity in CGs (Table 7).

Table 6

Association between socio-demographic variables and QOL, Burden on caregivers

	Quality of life domains				
ANOVA Tests	D1	D2	D3	D4	Burden
Gender	F=0.49	F=4.18	F=0.30	F=0.02	F=0.85
	p=0.8	p=0.04*	p=0.5	p=0.8	p=0.3
Relation with patient	F=0.81	F=2.28	F=2.6	F=0.8	F=3.7
	p=0.6	p=0.02*	p=0.009*	p=0.5	p=0.001*
Socio-economic status	F=3.66	F=0.78	F=1.61	F=4.56	F=4.92
	p=0.08	p=0.5	p=0.1	p=0.02*	p=0.01*
Literacy	F=0.2	F=1.11	F=0.3	F=0.8	F=0.60
Literacy	p=0.8	p=0.3	p=0.8	p=0.5	p=0.65
Domicile	F=1.08	F=0.48	F=1.8	F=1.2	F=0.58
	p=0.3	p=0.6	p=0.1	p=0.3	p=0.56
Type of family	F=0.68	F=0.54	F=2.03	F=0.29	F=0.3
Type of family	p=0.4	p=0.4	p=0.1	p=0.5	p=0.5
Type of treatment given to the patient	F=1.95	F=2.6	F=2.7	F=4.5	F=2.4
	p=0.09	p=0.02*	p=0.02*	p=0.001*	p=0.04*
Pearson correlation tests					
Age	r=0.24	r=0.36	r=0.16	r=0.08	r=0.12
	p=0.8	p=0.7	p=0.09	p=0.3	p=0.2
	r=-0.001	r=-0.13	r=-0.003	r=0.08	r=0.31
The total duration of caregiving	p=0.9	p=0.13	p=0.7	p=0.3	p=0.002*
	•	•	•	1	
Number of hours spent in caregiving	r=-0.74	r=-0.15	r=-0.03	r=-0.22	r=0.44
	p=0.4	p=0.1	p=0.7	p=0.02*	p=0.6

Note: *Significant at p<0.05

Table 7

Correlation between MINI, OOL and Burden in caregive	
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QOL Domains	MINI (Spearman's)	Burden (Pearson's)
Physical domain-D1	$r_{s} = -0.27$	r=-0.339
	p=0.006	p=0.001*
Psychological domain-D2	$r_s = -0.45$	r=-0.335
	p=0.00*	p=0.001*
Social relationship domain-D3	$r_s = -0.17$	r=-0.39
	p=0.08	p=0.00*
Environmental domain-D4	$r_s = -0.02$	r=-0.09
	p=0.005*	p=0.3
Burden	$r_{s}=0.39$	_
	p=0.00*	_

Note: * - Correlation is significant at the 0.05 level

4. Discussion

Cancer patients, from the time of illness diagnosis, need a caregiver who offers physical, emotional and financial support. In this study, CGs belonged to the age group of 18–60 years with mean–37.08 years. Moreover, most CGs were females (72 %) and married (97 %). Similar to our study, in other studies done by Centre Manjeet et al. and Unnikrishnan et al., the majority of the caregivers were middle aged with mean scores of age 35.4 and 40.4 years, but in contrast majority of the caregivers were males in their studies. This might be due to the studies mentioned above being done on CGs of patients suffering from a particular type of cancer. In contrast, in the current study, a sample was collected from CGs of cancer patients [1, 12].

In our study, female CGs might feel that women are obliged to look after ill family members, which is considered their important duty as a wife and mother because males in the family were breadwinners. This might be one of the reasons for female caregivers' predominance in our study. In a study by Govinda et al., female caregivers perceived their role in caregiving as more of an obligation than male caregivers [13].

CGs were equally distributed in our study's rural (48 %) and urban (47 %) areas. However, CGs from rural areas had difficulty approaching healthcare facilities for cancer treatment and had an increased physical burden.

Most of the CGs were illiterates (60 %), but the remaining CGs (40 %) had minimum education to understand the diagnosis and treatment of cancer.

In our study, the head of the family in most CGs families were males (87 %), and only 13 % of females (wife and mother) were the head of the family. Among them, 33 % had to play the dual role of head of the family and caregiver. They experienced subjectively more burden because of the dual role compared to other CGs. CGs relation with patients were spouse(35 %), parents(39 %) and children(29 %) and among them 72 % were female CGs. The majority of the CGs belonging to nuclear families (97 %) experienced inadequate physical and emotional support from other family members.

In the current study, CGs were taking care of the patient for a minimum duration of 8 months to a maximum duration of 13 years and the mean duration of caregiving was found to be 12.86 hours/day, which is higher than 24.4hr/week reported by the national alliance for caregiving. Similar to our study, in other studies done by Anneke Ullrich et al., Borges et al., Nik Ruzyanic et al. and Unnikrishnan et al., the mean time spent by CGs was 4hours-20hours per day, and the mean duration of caregiving was 13.3 months [1, 6, 7, 14, 15].

In the present study, a longer duration of caregiving with multiple hospital admissions was seen among patients receiving combined chemotherapy, radiotherapy and palliative care. In palliative care, patients already in an advanced stage of disease needed assistance with eating, bathing, toileting, taking medication and monitoring their symptoms. In par with the current study, Borges et al. reported that the number of hours spent per day for providing direct caregiving was greater among CGs. Their patients had advanced-stage cancer than early-stage cancer patients [15].

Psychiatric morbidity in CG

In our study, at a significant level, CGs of cancer patients were found to be suffering from psychiatric morbidities like generalised anxiety (15 %) and major depressive disorder(16 %). CGs did not consider this psychiatric morbidity a problem and continued their daily routines without seeking help from mental health professionals. Similar results were seen in a previous study done on Indian CGs by Centre Manjeet et al.. They found that 66 % of the CGs had psychiatric morbidity like 32 % were suffering from anxiety and 34 % from depression. Another study by Gema Costa-Requena also found psychiatric morbidities like anxiety among 76.1 % and depression among 77.4 % of CGs of palliative care patients [16]. In both the above studies, a higher percentage of psychiatry morbidity was seen, possibly due to differences in sample size and assessment methods.

Relation of psychiatric morbidity with sociodemographic variables of CGs

Our study found a significant negative correlation between psychiatric morbidity and the gender of CGs. It was seen that both females and males were suffering from anxiety and depression, but morbidity was found to be higher in females than males. Similar to our results Joshua Kanaabi Muliira, Irene Betty Kizza et al., in their studies, have found significantly higher prevalence rates of distress in female CGs because of the caregiving process [17]. However, in contradiction to this study, The current study has not considered coping mechanisms amongst the caregivers who could have played a role.

In our study, 13 % of the female CGs who was head of the family had increased workload because of their multiple responsibilities and were more prone to have psychiatric morbidity due to increased physical, emotional and financial demands. Even though we did not find a significant relationship between psychiatric morbidity in CGs with relation with the patient, many of our CGs were wives and mothers of patients who were suffering from anxiety and depression. A study done by Centre Manjeet S et al. also found that female CGs who had a dual role of maintaining the home and also caring for the patient, such females are more prone to depression in the general population, and CGs' relationship to the patient is an important factor to the emotional distress they suffer. The level of emotional distress varies with the degree of emotional attachment and the relation of the caregiver to the recipient [12].

Quality of life in caregivers of cancer patients

In the present study, CGs had over all poor quality of life. Among the four domains, the QOL was poor in the environmental domain, which might be because most of them are from nuclear families with rural backgrounds and belong to low socio-economic status. They might have inadequate physical, emotional and financial support. A study by Marcia Grant et al. also found that QOL was significantly decreased over time in CGs during caregiving. But in their study, psychological well-being had the least score, followed by social, spiritual and physical well-being [4].

Association of QOL with socio-demographic variables of CGs:

A significant association was seen between the psychological domain of QOL with gender, relation with patient and type of treatment. Females CGs, like wives and mothers, were found to be suffering from anxiety and depression at a significant level which needs attention. This might be due to their attachment to patients, unable to see the suffering of loved ones and negative feelings towards the prognosis of cancer in terminal stages. Similar findings were seen in studies done by Avinash Tippani et al. and N.Hacialioglu et al., where the QOL of CGs was significantly associated with relation with the patient; they found that spousal CGs had low QOL in the psychological domain. Furthermore, QOL in a spouse was found to be low compared to another family CGs [18, 19]. In contrast to our study findings, Ullrich et al. found that CGs' gender and patient-caregiver relation had no impact on the quality of life outcomes of CGs. These results suggest that female CGs were at more risk for developing psychiatric problems during the caregiving process.

CGs of palliative care and paediatric cancer patients receiving chemotherapy and radiotherapy were found to have poor QOL, more stressed because of increased demand for caregiving, and increased risk of developing psychiatric problems. Weitzner et al. found that caregivers of patients in palliative care had significantly low QOL scores and lower scores on physical and mental health [1].

CGs in the present study had good QOL in the social relationship domain, which might be due to their good personal relations with family members and adequate social support from friends and relatives. So

their QOL did not affect much in this domain. N. Hacialioglu et al. found that QOL was good in CGs getting support from other family members than CGs without support [19]. Even though our study had poor QOL in CGs, the social relationship domain was not much affected.

CGs with low socio-economic status had poor QOL in the environmental domain. CGs of upper socio-economic status QOL were not much affected. Especially in CGs of advanced cancer patients receiving palliative care needed long hours of caregiving, which had a greater impact on their incomes and further deteriorated their economic status. Molassiotis, A. et al. found that low-income levels affected the caregiving process adversely and that CGs with high-income levels had a significant and positive effect on life satisfaction [5].

The burden on caregivers of cancer patients

In this study, we found that many CGs felt burdened by caregiving. The burden assessment schedule has shown predominantly moderate levels of burden (83 %) and severe levels (17 %) of burden amongst the CGs. CGs might feel burdened because of a lack of adequate physical and financial support and increased caregiving demand depending on the stage of cancer. Similar findings were found in a study by Unnikrishnan et al., who found that almost half of the caregivers had psychosocial burden with moderate to severe levels of burden [1].

Association between CG burden and sociodemographic variables of caregivers:

Concerning the significant association of CG burden to relation with patient, mothers of paediatric age group patients and wives of patients with other types of cancer perceived more burden than other CGs. This might be because they are first-degree relatives taking care of the patient from the beginning, and some of them had the dual role of caregiving and family responsibility. But the other family members did not seem to be burdened like these CGs. Kim H et al., in their study, also found CGs having a spousal relationship and whom were co-residents experienced significantly higher caregiver burden than CGs who were non-spousal and non-resident [20]. In contrast to the present study, Memnun Seven et al. found less caregiver burden in first-degree relatives of the patients compared to others because it is thought that the bond between first-degree relatives can lead to the perception of caregiving as less of a burden. Even though they had a severe burden subjectively, they did not express it objectively because of their love for their patients and willingness to take care of them [21].

CGs of low socio-economic status showed moderate and severe burden levels in the present study. They have felt burdened financially because of their unemployment, low incomes, no support from others and increased work burden. Ourania Govinda et al. have found caregiver burden was more in unemployed CGs than in employed CGs because of additional economic burden [13]. In contrast to the present study Centre, Manjeet S et al. found CGs did not feel the burden of finances for treatment as their relatives suffering from cancer got treatment free of cost from the hospital [12].

This study found a significant positive correlation between CG burden and the total caregiving duration. This significantly implies that the CG burden was increased in patients with chronic illness and advanced stage of cancer than newly diagnosed cancer patients. Because of the longer duration of illness, CGs had spent most of their time with patients for caregiving. A study by Ahmad Zubaidi Z. S. et al. found that caregivers of advanced cancer patients had an increased subjective caregiving burden. Because of this subjective burden, CGs strongly tended to experience distress [22].

A significant correlation was seen between CG burden with the type of treatment. Irrespective of treatment modalities, CGs had a moderate to severe burden. But CGs of palliative care and surgical interventions with long duration of caregiving and repeated hospital admission were found to be more burdened because of increased physical, emotional and financial needs. Grunfeld et al., in their study, found that CGs of palliative care patients had significant psychological morbidity, which resulted in increased caregiver burden by the time the patient reached a terminal state [23].

Correlation between psychiatric morbidity and quality of life in CGs:

Our study found a significant negative correlation between the psychological domain (D2) and environmental domain (D4) of QOL with psychiatric morbidity in CGs. 31 % of CGs were suffering from anxiety and depression, and they have shown poor QOL in:

D2 and D4 domains. However, none strived for medical help. Qiuping Li et al. and Mohammad Ali et al., in their studies, have found that psychological issues like depression and anxiety in patients and caregivers have a negative impact on the QOL of both patient and caregiver. The psychological health of CG had an impact on QOL, and they have seen a significant negative correlation between depression and QOL of CG [24, 25].

Correlation between burden and quality of life in CGs:

In our study, CGs with increased burden had poor QOL. This might be due to low socio-economic status, increased caregiving stress and burden, lack of support from other family members and suffering from disorders like anxiety and depression. Marcia Grant et al. and Borges et al., in their studies, found that high caregiver burden and low QOL were common in caregivers, and QOL was decreased in all domains. However, it was worse in the psychological domain because of subjective stress [4, 15].

Correlation between burden and psychiatric morbidity in CGs:

have found a significant positive correlation between burden and psychiatric morbidity in CGs. The severe burden was seen in CGs who had depression and anxiety features because of emotional distress and low self-esteem. In support of the present study, a study done by Karabekiroğlu A et al. found that depression was highly prevalent among caregivers, and cognitive strategies and social support are needed to determine the risk of depression in caregivers of cancer patients [26]. Caroline Palacio et al. found that CGs who felt burdened while

caring for the patient reported significantly higher anxiety levels [27].

Limitations

- 1. In this study, staging and type of cancer might have implications on QOL, burden and psychiatric morbidity, which were not addressed.
- 2. Coping mechanisms used by the CGs were not studied.

Future directions: Longitudinal and comparative studies involving all types of cancers should be done. In addition, interventions for psychiatric disorders are suggested to strengthen the mental health of CGs, which affects their caregiving.

5. Conclusion

CGs in our study had significant psychiatric morbidities like anxiety-16 % and depression-14 % with notable moderate levels-83 % of burden affecting the QOL of caregivers. The results were consistent with the majority of existing literature. CGs with psychiatric morbidity in our study had never consulted a mental health professional.

Thus highlighting the need to educate them about mental health and counsel and treat them for their psychiatric problems. When they visit the hospital along with the patient concerned physician and Psychologist should also address the caregiver's needs. Caregiver burden was the influential factor that negatively affected CGs' QOL.

Implications

- 1. The majority of the CGs do not have proper knowledge regarding the caregiving process. Therefore, there is a need to assist, support and motivate caregivers in their new and demanding role. The treating physicians should address CGs needs and doubts.
- 2. Health care professionals should also provide caregivers with social and psychological support to avoid its negative effects on their health and patient care.

Conflict of interest

The authors declare that they have no conflict of interest in relation to this research, whether financial, personal, authorship or otherwise, that could affect the research and its results presented in this article.

Financing

The study was performed without financial support.

Acknowledgements

The authors would like to thank Dr Uma Shankar, Professor and Superintendent Institute of Mental Health, Hyderabad, for granting permission to conduct the study and Dr LVR Usha, MD Psychiatry, Professor of psychiatry and Dr Jayalalitha, HOD and Professor of Radiology, MNJ cancer hospital for their support and guidance.

References

- 1. Unnikrishnan, B., Rathi, P., Saxena, P. U. P., Aggarwal, A., Shekhar, S., Bansal, S. et. al. (2019). Psychosocial Burden Among Informal Caregivers of Adult Cancer Patients Attending a Tertiary Care Cancer Center in Coastal South India. SAGE Open, 9 (3), 215824401987628. doi: https://doi.org/10.1177/2158244019876287
- 2. Rha, S. Y., Park, Y., Song, S. K., Lee, C. E., Lee, J. (2015). Caregiving burden and the quality of life of family caregivers of cancer patients: the relationship and correlates. European Journal of Oncology Nursing, 19 (4), 376–382. doi: https://doi.org/10.1016/j.ejon.2015.01.004
- 3. Saimaldaher, Z. H., Wazqar, D. Y. (2019). Relationships between caregiving stress, mental health and physical health in family caregivers of adult patients with cancer: implications for nursing practice. Scandinavian Journal of Caring Sciences, 34 (4), 889–898. doi: https://doi.org/10.1111/scs.12795
- 4. Grant, M., Sun, V., Fujinami, R., Sidhu, R., Otis-Green, S., Juarez, G., Klein, L., Ferrell, B. (2013). Family Caregiver Burden, Skills Preparedness, and Quality of Life in Non-Small Cell Lung Cancer. Oncology Nursing Forum, 40 (4), 337–346. https://doi.org/10.1188/13.onf.337-346
- 5. Molassiotis, A., Wang, M. (2022). Understanding and Supporting Informal Cancer Caregivers. Current Treatment Options in Oncology, 23 (4), 494–513. doi: https://doi.org/10.1007/s11864-022-00955-3
- 6. Nik Jaafar, N. R., Selamat Din, S. H., Mohamed Saini, S., Ahmad, S. N. A., Midin, M., Sidi, H. et. al. (2014). Clinical depression while caring for loved ones with breast cancer. Comprehensive Psychiatry, 55, S52–S59. doi: https://doi.org/10.1016/j.comppsych. 2013.03.003
- 7. Ullrich, A., Ascherfeld, L., Marx, G., Bokemeyer, C., Bergelt, C., Oechsle, K. (2017). Quality of life, psychological burden, needs, and satisfaction during specialized inpatient palliative care in family caregivers of advanced cancer patients. BMC Palliative Care, 16 (1). doi: https://doi.org/10.1186/s12904-017-0206-z
- 8. Pettersson, A., Modin, S., Wahlström, R., af Winklerfelt Hammarberg, S., Krakau, I. (2018). The Mini-International Neuropsychiatric Interview is useful and well accepted as part of the clinical assessment for depression and anxiety in primary care: a mixed-methods study. BMC Family Practice, 19 (1). doi: https://doi.org/10.1186/s12875-017-0674-5
- 9. Sreedevi, A., Cherkil, S., Kuttikattu, D. S., Kamalamma, L., Oldenburg, B. (2015). Validation of WHOQOL-BREF in Malayalam and Determinants of Quality of Life Among People With Type 2 Diabetes in Kerala, India. Asia Pacific Journal of Public Health, 28, 62S–69S. doi: https://doi.org/10.1177/1010539515605888
- 10. Swaroop, N., Ravi, S., Ramakrishna Goud, B., Archana, M., Pius, T. M., Pal, A. et. al. (2013). Caregivers burden of mentally ill patients. International Journal of Research and Development of Health, 1 (2), 29–35. Available at: https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.403.8585&rep=rep1&type=pdf
- 11. Mohd Saleem, S. (2020). Modified Kuppuswamy socioeconomic scale updated for the year 2020. Indian Journal of Forensic and Community Medicine, 7 (1), 1–3. doi: https://doi.org/10.18231/j.ijfcm.2020.001
- 12. Santre, M. S., Rathod, J., Maidapwad, S. (2014). Prevalence of emotional distress in caregiver's of cancer patients. International Journal of Medical Research & Health Sciences, 3 (3), 675. doi: https://doi.org/10.5958/2319-5886.2014.00416.0

- 13. Govina, O., Kotronoulas, G., Mystakidou, K., Katsaragakis, S., Vlachou, E., Patiraki, E. (2015). Effects of patient and personal demographic, clinical and psychosocial characteristics on the burden of family members caring for patients with advanced
- cancer in Greece. European Journal of Oncology Nursing, 19 (1), 81–88. https://doi.org/10.1016/j.ejon.2014.06.009
 14. Caregiving in the U.S. 2015 Report. Chicago (IL). Available at: https://www.caregiving.org/wp-content/uploads/2020/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf
- 15. Borges, E. L., Franceschini, J., Costa, L. H. D., Fernandes, A. L. G., Jamnik, S., Santoro, I. L. (2017). Family caregiver burden: the burden of caring for lung cancer patients according to the cancer stage and patient quality of life. Jornal Brasileiro de Pneumologia, 43 (1), 18–23. doi: https://doi.org/10.1590/s1806-37562016000000177
- 16. Costa-Requena, G., Cristófol, R., Cañete, J. (2011). Caregivers' morbidity in palliative care unit: predicting by gender, age, burden and self-esteem. Supportive Care in Cancer, 20 (7), 1465–1470. doi: https://doi.org/10.1007/s00520-011-1233-6
- 17. Muliira, J. K., Kizza, I. B. (2019). The other untold burden of cancer in sub-Saharan Africa: Anxiety and depressive symptoms among family caregivers of adult cancer patients. International Journal of Africa Nursing Sciences, 11, 100166. doi: https://doi.org/10.1016/j.ijans.2019.100166
- 18. Tippani, A., Kandakatla, A., Srinath, K., Bhavana, G., Reddy, V. M., Gouthami, A. (2018). Assessment of Quality of Life and Strain Burden on Cancer Caregivers. IOSR Journal of Dental and Medical Sciences (IOSR-JDMS), 17 (1), 45–48. Available at: https://www.iosrjournals.org/iosr-jdms/papers/Vol17-issue1/Version-2/J1701024548.pdf
- 19. Hacialioglu, N., Özer, N., Yilmaz karabulutlu, E., Erdem, N., Erci, B. (2010). The quality of life of family caregivers of cancer patients in the East of Turkey. European Journal of Oncology Nursing, 14 (3), 211–217. doi: https://doi.org/10.1016/j.ejon.2010.01.017
- 20. Kim, H., Chang, M., Rose, K., Kim, S. (2011). Predictors of caregiver burden in caregivers of individuals with dementia. Journal of Advanced Nursing, 68 (4), 846–855. doi: https://doi.org/10.1111/j.1365-2648.2011.05787.x
- 21. Seven, M., Yılmaz, S., Şahin, E., Akyüz, A. (2014). Evaluation of the Quality of Life of Caregivers in Gynecological Cancer Patients. Journal of Cancer Education, 29 (2), 325–332. doi: https://doi.org/10.1007/s13187-013-0606-6
- 22. Ahmad Zubaidi, Z. S., Ariffin, F., Oun, C. T. C., Katiman, D. (2020). Caregiver burden among informal caregivers in the largest specialized palliative care unit in Malaysia: a cross sectional study. BMC Palliative Care, 19 (1). doi: https://doi.org/10.1186/s12904-020-00691-1
- 23. O'Hara, R. E., Hull, J. G., Lyons, K. D., Bakitas, M., Hegel, M. T., Li, Z., Ahles, T. A. (2010). Impact on caregiver burden of a patient-focused palliative care intervention for patients with advanced cancer. Palliative and Supportive Care, 8 (4), 395–404. doi: https://doi.org/10.1017/s1478951510000258
- 24. Li, Q., Lin, Y., Xu, Y., Zhou, H. (2018). The impact of depression and anxiety on quality of life in Chinese cancer patient-family caregiver dyads, a cross-sectional study. Health and Quality of Life Outcomes, 16 (1). doi: https://doi.org/10.1186/s12955-018-1051-3
- 25. Heidari Gorji, M. A., Bouzar, Z., Haghshenas, M., Kasaeeyan, A. A., Sadeghi, M. R., Ardebil, M. D. (2012). Quality of life and depression in caregivers of patients with breast cancer. BMC Research Notes, 5 (1). doi: https://doi.org/10.1186/1756-0500-5-310
- 26. Karabekiroğlu, A., Demir, E., Aker, S., Kocamanoğlu, B., Karabulut, G. (2018). Predictors of depression and anxiety among caregivers of hospitalised advanced cancer patients. Singapore Medical Journal, 59 (11), 572–577. doi: https://doi.org/10.11622/smedj.2018066
- 27. Palacio, C., Krikorian, A., Limonero, J. T. (2017). The influence of psychological factors on the burden of caregivers of patients with advanced cancer: Resiliency and caregiver burden. Palliative and Supportive Care, 16 (3), 269–277. doi: https://doi.org/10.1017/s1478951517000268

Received date 04.05.2022 Accepted date 21.06.2022 Published date 30.09.2022

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