Oncology Section

Factors Affecting Quality of Life among Caregivers of Cancer Patients in Rishikesh, Uttarakhand, India: A Quantitative Study

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ABSTRACT

Introduction: Cancer impacts not only people living with cancer but also their caregivers. In hospital, caregivers always have pressure on them and their personal and private lives are disrupted during the caring process.

Aim: To identify the various factors affecting the Quality of Life (QoL) among caregivers of cancer patients.

Materials and Methods: This quantitative study with an exploratory research design was conducted in Oncology Outpatient Department (OPD) of All India Institute of Medical Sciences, Rishikesh, India, from November 2019 to February 2020. A total of 256 caregivers of cancer patients, who were visiting various oncology units were included. Data regarding caregiver's sample characteristics, clinical variables and Caregiver's Oncology Quality of Life questionnaire (CarGOQoL) were collected. Statistical analysis was done using Chi-square test and Fischer's-exact tests were used to study variables.

Results: Majority, 94 (37%) belonged to 41-50 years age group, 143 (56%) were females, and 142 (56%) lived in rural areas. Patients' diagnoses were breast cancer in 94 (37%), Stage-III in 133 (52%), symptoms lasting more than 6-12 months in 103 (40%), and were partial dependent in 172 (67%). A total of 123 (48%) of caregivers scored less in the CarGOQoL questionnaire, so about half of the caregivers had a poor QoL. Caregiver coping (43%) and the private life domain were enormously affected in 193 (37%). Significant relationships with caregivers' QoL were seen for variables like female gender (p-value=0.037), educational level of patients (p-value=0.018), caregivers with co-morbidities (p-value=0.05), and the number of earning members in the family (p-value=0.022).

Conclusion: Care burden always has an impact on the caregiver's overall QoL. It mainly affects their psychological well-being, burdens, and private lives. Therefore, comprehensive attention should be given to patients as well as caregivers.

Keywords: Health, Physical well-being, Psychological burden, Self-esteem

INTRODUCTION

As a result of advancements in technology and improvements in cancer diagnosis and care, the number of cancer survivors is increasing, statistical data from the International Agency for Research on Cancer (IARC), shows that there are currently 17.0 million new cancer cases worldwide, with predictions of upto 27.5 million new cancer cases by 2040 [1]. It is estimated that more than 19.3 million new cancer cases would be detected by 2020 [2]. There are approximately 43.5 million caregivers in the world, with one out of every four caregivers spending 41 hours per week caring for an adult or a kid [3,4].

Cancer patients require long-term care and assistance because of prolonged treatment, poor tolerance to treatment, and physical issues due to disease burden. Assistance is provided by family members who are caregivers and play a dynamic role in the recovery and recuperation of cancer patients. Taking care of their patients gives them a positive attitude but may also affect their QoL [5,6].

The majority of caregivers may suffer from financial burden, stress, increased anxiety, depression, decreased health-related QoL, or the responsibility of other family members [7,8]. Also, it can affect caregiver health in a multidimensional way, e.g., mental, psychological, social, financial, and emotional response. There have been unclear results regarding various burden faced by caregivers and their QoL [5,6]. QoL of cancer caregivers is dependent on multiple factors and lot of variations are seen in previous studies [2,4,5]. Therefore, present study was conducted in the sub-Himalayan region to assess if there was some variation from other studies or results are similar.

Hence, present study was conducted to assess the QoL of caregivers of cancer patients and to identify factors affecting the QoL of caregivers.

MATERIALS AND METHODS

This quantitative study with exploratory research design was conducted in Oncology OPD of All India Institute of Medical Sciences, Rishikesh, Uttarakhand, India, from November 2019 to February 2020. Ethical approval for this study was obtained from the Institute's Ethics Committee (AIIMS/IEC/19/1102). Written informed consent was obtained from each study participant and individual confidentiality and anonymity were maintained during the whole study.

Inclusion criteria: Caregivers, aged >18 years, who were primarily involved in the care of cancer patients for >3 months and, who were either parents, spouses, or in-laws of cancer patients were included in the study.

Exclusion criteria: Caregivers who were caring of patients less than three months, paid caregivers and caregiver with any mental illness, were excluded from this study.

Sample size calculation: A total enumeration technique for data collection was used, in which study participants, who fulfilled the eligibility criteria and were willing to participate were included in study. Cochrane formula:

$(n=Z^2 (p \times q) \div d^2)$

was used for the sample size calculation [9] in which 'n' means sample size; 'N' stands for the size of the eligible population;

t²=Square value of the standard deviation score that refers to the area under a normal distribution of values; p=Percentage category for which the authors are computing the sample size, q=(1-p); d²=Square value of one half to the precision internal around the sample estimate. 15% was considered for estimated dropout, so 301 patients were to be recruited.

Study Procedure

Data collection tools include three sections. Section-I included a datasheet of socio-demographic profile including age, gender, residence, marital status, educational level of patient and caregiver, type of family, relationship with family and distance from health facility. Section-II included a datasheet of clinical variables including cancer site, stage, symptom duration, patient dependency, nature of treatment and nature of caregiver sharing responsibilities and Section-III included the CarGOQoL, 2011 tool [10,11].

The CarGOQoL is a standardised research tool that mainly consists of 29 items which are categorised into ten domains i.e., psychological well-being (4), burden (4), relationship with healthcare (3), administration and finances (3), coping (3), physical well-being (4), self-esteem (2), leisure time (2), social support (2), and private life (2). 0-100 (for each domain and the global score). Each item is scaled on a 5-point Likert scale (ranging from 1=Never/Not at all to 5=Always/Very Much). The score of each domain was obtained by computing the mean of the item scores for that domain. Cut-off value for the domains was decided based on the mean values of the scores of the participants. A CarGOQoL score of more than 50% was considered good. Data collection tools were translated in Hindi and interview was conducted by researcher [11].

STATISTICAL ANALYSIS

Statistical analysis was done using International Business Machines (IBM) Statistical Package for the Social Sciences (SPSS) version 23.0. For socio-demographic variables and clinical variables frequency and percentage were calculated. Caregiver QoL questionnaire scoring was done by frequency, percentage, and ranking. The Chi-square and Fisher-exact tests were used to calculate the association of the caregiver QoL questionnaire scores with socio-demographic variables and clinical variables. A p-value <0.05 was considered to be statistically significant.

RESULTS

A total of 256 participants completed the QoL questionnaire out of 301 participants. The majority of the participants 94 (37%) belonged to the 41-50 years' age group and were females 143 (56%). The majority of the respondents were from rural areas 142 (56%). The majority of caregivers had nuclear families 131 (51%) and the majority were children 108 (42%) taking care of their patients. A total of 199 (77.5%) of caregivers did not have any diseases. The majority of respondents 110 (43%) lived 10-100 km away from healthcare facilities [Table/Fig-1].

Socio-demographic variables		n (%)
	31-40	60 (23)
	41-50	94 (37)
Age (years)	51-60	74 (29)
	61-70	28 (11)
Gender	Male	113 (44)
	Female	143 (56)
Residence	Urban	114 (44)
Residence	Rural	142 (56)
Marital status	Married	244 (95)
	Single	9 (3.5)
	Widowed	3 (1.5)

	Illiterate	122 (48)		
Educational level of	8 th standard	77 (30)		
patients	12 th standard	18 (7)		
	Higher education	39 (15)		
	Illiterate	41 (16)		
Educational level of	Primary schooling	87 (34)		
caregiver	Complete schooling	64 (25)		
	Higher education	64 (25)		
—	Nuclear	131 (51)		
Type of family	Joint	125 (49)		
	Spouse	95 (37)		
	Parent	5 (2)		
	Children	108 (42)		
Relationship with patient	Sibling	31 (12)		
patient	In-laws	13 (5)		
	Cousin/Nephew	2 (1)		
	Friend	2 (1)		
	Diabetes	12 (4.5)		
	Hypertension	10 (4)		
Caregiver having any	COPD	12 (5.0)		
disease	Any other diseases i.e. hypothyroidism and asthma			
	None	199 (77.5)		
	Patient	59 (23)		
Earning member	Spouse	103 (40)		
	Children	80 (31)		
	Parents	10 (4)		
	Brother/Sister	2 (1)		
	In-law	2 (1)		
	<10 km	48 (19)		
Distance from health facility	10-100 km	110 (43)		
lacinty	>100 km	98 (38)		
	Service	95 (37)		
	Business	85 (33)		
	Agriculture	43 (17)		
Occupation	Housework	18 (7)		
	Unemployed	14 (5.5)		
	Pension	1 (0.5)		
Dationt owars shout	Yes	213 (83)		
Patient aware about his/her disease	No	43 (17)		
Table/Fig-11: Socio d	emographic variables of the particip			

Majority of patients 94 (37%) had breast cancer diagnoses and had symptoms for more than 6-12 months. In present study, 172 (67%) were partially dependent on their caregivers. The majority of patients, 125 (49%), were getting chemotherapy and 35 (13.5%) were receiving care for symptom management without any active oncology treatment. The number of caregivers sharing responsibilities was mainly three in majority of the cases 85 (33%) [Table/Fig-2].

The majority, i.e., the 1st 76 (30%) ranked caregiver received a QoL questionnaire score in the range of 73-82, the 2nd 67 (26%) in the range of 63-72, the 3rd 43 (16.5%) in the range of 83-92, and the 4th 30 (12%) in the range of 53-62 [Table/Fig-3].

Caregivers' psychological well-being was affected a little bit in 446 (44%). The majority of caregivers (25% of all caregivers) were heavily burdened. For the majority of caregivers 340 (44%), administration and finances were not at all affected. The majority 329 (43%) of caregivers used coping strategies extensively. For the majority of caregivers, physical well-being 386 (38%) and self-esteem

Socio-demographic vari	ables	n (%)			
	Head and neck	49 (19)			
	Lung	12 (4.5)			
	Gastrointestinal	56 (22)			
Cancer site	Gynaecological	28 (11)			
	Breast	94 (37)			
	Genitourinary	10 (4)			
	Others	7 (2.5)			
	I	8 (3)			
Stage (According to	Ш	36 (14)			
clinical diagnosis)	Ш	133 (52)			
	IV	79 (31)			
	<3 months	28 (11)			
O mante an al matien	3-6 months	69 (27)			
Symptom duration	6-12 months	103 (40)			
	>12 months	56 (22)			
	Partial	172 (67)			
Patient dependency	Total	69 (27)			
	Independent	15 (6)			
	Biopsy/Investigation	25 (10)			
	Chemotherapy	125 (49)			
Nature of treatment	Radiotherapy	54 (21)			
	Surgery	17 (6.5)			
	Palliative care	35 (13.5)			
	One	72 (28)			
Number of caregiver	Тwo	79 (31)			
sharing responsibilities	Three	85 (33)			
	Four	20 (8)			
[Table/Fig-2]: Clinical variables of participants (N=256).					

Score	Category	n (%)	Ranking	
33-42	1	02 (1)	7 th	
43-52	2	24 (9)	5 th	
53-62	3	30 (12)	4 th	
63-72	4	67 (26)	2 nd	
73-82	5	76 (30)	1 st	
83-92	6	43 (16.5)	3 rd	
93-102	7	12 (4.5)	6 th	
103-112	8	0	9 th	
113-122	9	02 (1)	8 th	
[Table/Fig-3]: Caregiver Quality of Life (QoL) questionnaire score (N=256).				

407 (80%) were not at all affected. A 48% of caregivers did not had leisure time, and 49% of caregivers did not have any social support system. The majority 193 (37%) of caregivers said this had enormously affected their private lives [Table/Fig-4].

Variables	Responses	n (%)
	Not at all	263 (25)
	A little	446 (44)
Psychological well-being (4 Items)	Moderately	31 (04)
(*******)	A lot	132 (13)
	Enormously	152 (14)
	Not at all	236 (23)
	A little	219 (21)
Burden (4 Items)	Moderately	70 (07)
	A lot	246 (25)
	Enormously	253 (24)

	Not at all	498 (64)
Relationship with health care (3 items)	A little	244 (32)
	Moderately	8 (01)
	A lot	8 (01)
	Enormously	10 (02)
	Not at all	340 (44)
	A little	212 (28)
Administration and finance (3 items)	Moderately	35 (04)
	A lot	77 (10)
	Enormously	104 (14)
	Not at all	163 (21)
	A little	147 (19)
Coping (3 items)	Moderately	20 (02)
	A lot	109 (15)
	Enormously	329 (43)
	Not at all	386 (38)
	A little	194 (19)
Physical well-being (4 items)	Moderately	20 (02)
(4 (16)	A lot	126 (12)
	Enormously	298 (29)
	Not at all	407 (80)
	A little	45 (08)
Self-esteem (2 items)	Moderately	9 (1.5)
	A lot	27 (06)
	Enormously	24 (4.5)
	Not at all	246 (48)
	A little	94 (18)
Leisure time (2 items)	Moderately	24 (05)
	A lot	66 (13)
	Enormously	82 (16)
	Not at all	250 (49)
	A little	85 (16.5)
Social support (2 items)	Moderately	4 (0.5)
	A lot	69 (14)
	Enormously	104 (20)
	Not at all	175 (35)
	A little	75 (14.5)
Private life (2 items)	Moderately	7 (1.5)
	A lot	62 (12)

Variables such as gender, educational level of patients, caregivers with any disease, and earning members of the family, all showed a significant association with caregiver QoL scoring (p-value=0.037, p-value=0.018, p-value=0.05, p-value=0.022, respectively). Female caregivers had lower QoL scores than males. Many factors, like site and stage of cancer, duration of symptoms, patient dependency, type of treatment, and sharing responsibilities, were associated with the QoL of caregivers. All the clinical variables of patients did not have any significant association with the caregiver oncology QoL score [Table/Fig-5].

DISCUSSION

A cancer diagnosis is stressful not only for the patient but also for the family caregiver [12]. Both the patient and the caregiver usually struggle psychosocially and financially to fight this disease. Present study evaluated the quality of caregivers of cancer patients and identified factors affecting their QoL. In previous studies, various

	Caregiver Quality of Life (QoL) questionnaire score		Chi- square		
Variables	Low N=123	High N=133	value	df	p-value
Age (years)					
31-40	29	30			
41-50	48	46			
51-60	34	40	0.695	3	0.874
61-70	12	16			
Sex					
Male	46	67			
Female	77	66	4.365	1	0.037*
Residence				I	
Urban	52	62			
Rural	71	71	0.487	1	0.485
Marital status					
Married	118	126			
Single	3	6	1.207	2	0.547
Widowed	2	1			
Educational level of		1			
Illiterate	. 56	66			
8 th standard	36	43			0.018*
12 th standard	15	3	10.012	3	
Higher education	16	23			
Educational level of	spouse				
Illiterate	19	22			
Primary schooling	39	48			0.346
Complete schooling	37	27	3.313	3	
Higher education	28	36			
Type of family					
Nuclear	61	70			
Joint	62	63	0.236	1	0.627
Relationship with pa	atient				
Spouse	49	46			
Parent	0	5		6	0.063
Children	56	52			
Sibling	9	22	11.962		
In-laws	8	5	11.302		
Cousin/Nephew	1	1			
Friend	1	1			
Caregiver having an				I	
Diabetes	4	8			
Hypertension	2	9		3	0.05*
COPD	2	7	7.775		
Any other diseases	12	11			
None	98	101			
Earning member				I	
Patient	21	38			
Spouse	59	44	13.139	5	0.022*
Children	39	44			
Parents	39	7			
Brother/Sister	0	2			
In-law	2	0			
Distance from healt		00			
<10 km	27	22	4.203		o
10-100 km	45	65		2	0.122
>100 km	51	47		1	

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Stage-III7459Image: Product Section	Stage-II	12	24	7 058	3	0.070
Symptom duration Symptom duration <3 months	Stage-III	74	59	7.000		
<3 months1315 $<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<<$	Stage-IV	33	46			
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Patient dependencyPartial8686Total29401.43220.489Independent871.43220.489Independent871.43220.489Nature of treatmentBiopsy/Investigation1510	6-12 months	50	53	0.200		
Partial 86 86 86 7 2 0.489 Total 29 40 1.432 2 0.489 Independent 8 7 1.432 2 0.489 Nature of treatment 7 68 7 68 7 68 7 6607 5 0.252 0.253 0.253	>12 months	26	30			
Total 29 40 1.432 2 0.489 Independent 8 7 1.432 2 0.489 Nature of treatment 8 7 1.432 2 0.489 Nature of treatment 8 7 1.432 2 0.489 Nature of treatment 8 7 10 7	Patient dependency	,				
Independent87INature of treatmentBiopsy/Investigation1510Chemotherapy5768Radiotherapy3024Surgery512Palliative care1619Number of caregiver sharing responsibilitiesOne3537Two3643Three3946Four137	Partial	86	86			
Nature of treatment Image: Stream of treatment Stream of treatmen	Total	29	40	1.432	2	0.489
Biopsy/Investigation 15 10 Chemotherapy 57 68 Radiotherapy 30 24 Surgery 5 12 Palliative care 16 19 Number of caregive sharing responsibilities One 35 37 Two 36 43 Three 39 46 Four 13 7	Independent	8	7			
Chemotherapy 57 68 6.607 5 12 6.607 5 0.252 <td>Nature of treatment</td> <td></td> <td></td> <td></td> <td></td> <td></td>	Nature of treatment					
Radiotherapy 30 24 6.607 5 0.252 Surgery 5 12 <td>Biopsy/Investigation</td> <td>15</td> <td>10</td> <td></td> <td></td> <td></td>	Biopsy/Investigation	15	10			
Surgery 5 12 Paliative care 16 19 Number of caregive sharing responsibilities Second Sec	Chemotherapy	57	68			
Palliative care 16 19 Number of caregiver sharing responsibilities Image: Constant of Care	Radiotherapy	30	24	6.607	5	0.252
Number of caregive sharing responsibilities One 35 37 Two 36 43 Three 39 46 Four 13 7		5	12	4		
One 35 37 Two 36 43 Three 39 46 Four 13 7						
Two 36 43 2.585 3 0.460 Three 39 46 7 3 0.460 Four 13 7 7 3 0.460	Number of caregive		sibilities	1		
Three 39 46 2.585 3 0.460 Four 13 7 2 3 0.460 10				4		
Three 39 46 Four 13 7				2.585	3	0.460
				4		
[Table/Fig-5]: Factors affecting Quality of Life (QoL) of caregiver.						

[Table/Fig-5]: Factors affecting Quality of Life (QoL) of caregiver.

demographic and medical characteristics of the caregivers of patients have been reported. Another study reported that patients undergoing curative or palliative cancer treatment in which caregivers of patients with various cancers at different stages were included [13,14]. In present study, most of the caregivers were middle-aged females. Most of the caregivers belonged to rural backgrounds with primary school education only.

About 48% scored less on the QoL questionnaire, so about half of the caregivers had poor QoL. A study conducted in Hong Kong also showed the QoL of caregivers had significantly low scores [11]. In the present study, caregivers' coping and private life domains were enormously affected. The caregiver felt a lot in the burden domain. The psychological well-being domain was also a little bit affected. Physical well-being, self-esteem, and leisure time were not at all

>100 km

51

affected. A study conducted on the domains of QoL expressed by caregivers found that their family, leisure time, and personal health were the most commonly expressed in the QoL domains [15,16].

Female caregivers showed a significant relationship with caregiver burden and similar findings were noted in Wong DF et al., study, which reported that lower QoL was seen in females because of their traditional gender role [17]. Present study finding was in contrast with Lim HA et al., in which the male gender showed poorer QoL than females in terms of physical or practical issues and self needs [18].

As the educational level of patients decreased, so did the caregiver burden scale. This indicated that less-educated caregivers felt a greater burden during patient care, while as education increased, they felt less burden. A study conducted in Iran showed a significant association between the age of caregivers and their burden, so as the age of the caregiver increases, the caregiver burden also increases [19]. Caregiver education and care burden were also found to have a significant relationship which implies that higher education levels reduced the care burden. Similarly, a study done by Cameron JI et al., showed a lower education level was associated with a lower physiological QoL score [20]. If the caregiver had any disease or co-morbidity, then their QoL was very poor in the present study. This was in accordance with the study of Jafari H et al., which showed that the health status of the caregiver was associated with better QoL in the caregivers [21].

It is a well-known fact that the relationship between patients and caregivers of family members had a profound impact on their QoL. In present study, the children of the patients showed poorer QoL than other relationships. This was in line with the findings of Cameron JI et al., [20]. Apart from this, one more factor was that an earning member in the family showed a significant relationship with caregiver QoL. The spouse, as the earning member of the family, showed poor QoL compared to other relations. Similar observations were made in the study by Hughes SL et al., in their study caregivers who were spouses stated the greatest amount of objective burden [22]. The findings of present study demonstrated that the majority of the patients were in Stage-III of cancer. The caregivers' QoL was poor while caring for these patients. These findings were consistent with Kim H and Yi M they stated that early cancer stages and successful treatment outcomes were found to be favourably correlated with carers' QoL [23].

In the present study, most of the patients were receiving chemotherapy and were found to have low QoL in their caregivers. In a review study, the QoL of caregivers was low during treatment and improved after completing treatment [24]. A similar observation was seen in the present study. Patient dependency in daily life was partially or completely correlated with the caregiver's QoL. In present study, partial patients' dependency on the caregiver was reported to have low QoL. This was in contrast to the findings of Vrettos I et al., they showed that caregivers' QoL was highly correlated with the complete patients' dependency [25]. In present study, caregivers' QoL was measured, in which each individual were allowed to express their feelings in a non predefined domain.

Limitation(s)

Current study was limited by its cross-sectional design and which delimit present study findings not to compare caregiver's QoL in home care, hospices and other curative and palliative settings.

CONCLUSION(S)

In the present study, most of caregiver's has low QoL and cancer patients' overall QoL is always impacted by the care burden. It mainly affects their psychological well-being, burdens, and private lives. So, complete consideration should be given to patients as well as caregivers. Comprehensive care, including all social, economic, physical, and psychological domains should be provided. This can be done by explaining and providing a unique care situation specific to them. In every healthcare scenario, the caregivers always need more awareness and need additional counselling sessions to cope with the situation. In future, a further study can be planned to assess caregiver burden during home care setting or other palliative care settings.

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