

## QUALITY OF LIFE AMONG CAREGIVERS OF CANCER PATIENTS ATTENDING TERTIARY CARE CENTRE IN SOUTHERN TAMILNADU- A CROSS-SECTIONAL STUDY

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### ABSTRACT:

**Background:** Cancer, a chronic disease, often demands prolonged treatment, lifelong follow-up, and uncertainty of cure. This affects patients' quality of life and burdens family, particularly caregivers. The acknowledged role of caregivers is significant, but their challenges and quality of life determinants remain unclear.

**Aim:** The aim of this study is to determine the quality of life of cancer patient's caregivers and to find out the different socio-demographic factors and their impact on the lives of cancer caregivers.

**Materials and methods:** A cross-sectional study was done among 100 family caregivers of cancer patients. A semi-structured proforma was administered to collect the socio-demographic details. Quality of life of caregivers were assessed using the WHO-Quality of life (QOL) BREF scale. Data analysed using SPSS version 20.0.

**Results:** QOL in caregivers was assessed in four domains according to the WHO-QOL BREF scale. All domains of quality of life were affected in this study. The Physical domain of QOL was the most affected. Following statistically significant association (P value< 0.05) were`

found. Physical health domain exhibited association with variables such as literacy, occupation. Psychological health domain was associated with variables such as relation of the patient to caregivers, Marital status, literacy, occupation and socio-economic class. Social relationship exhibited association with occupation. Environment domain is associated with variables such as literacy, socio economic class, occupation. overall health was associated with variable such as marital status, literacy, occupation and socio- economic class. Positive Pearson correlations were observed between Socioeconomic status score, educational level, and occupation with all domains of QOL.

**Conclusion:** The education, occupation, and socioeconomic status of care givers of cancer patients affect their quality of life. Healthcare providers should prioritize caregivers well-being and should give them recommended support.

**Key words:** Burden, cancer caregivers, quality of life.

## INTRODUCTION:

According to National cancer registry of India reports that there are multiple contributing factors to cancer, a multifaceted cancer burden, and a multidisciplinary cancer treatment regimen.<sup>1</sup> Cancer is a chronic illness that has no known cure and requires treatment for practically a lifetime. This has a negative impact on patients quality of life and puts a psychological strain on family members, particularly those who provide patient care.<sup>2</sup>

Studies on care givers perceptions on health have been conducted in industrialized nations. Still, developing nations have a dearth of the same. Numerous studies have demonstrated the correlation between the caregiver's burden and factors such as age, gender, relationship to the patient, unemployment, caregiver income, absence of family and social support, length and stage of illness, prior experience providing care, and caring for another sick patient<sup>3</sup>. In Indian culture, families, extended families, and other caregivers provide the majority of the patient care<sup>4</sup>. The strain this caregiver bears has an indirect impact on the patient's health in addition to their behaviour, physical condition, and emotional state.

More patients are receiving ambulatory care on an outpatient basis as a result of recent advancements in treatment methods. This increases patient's reliance on caregivers for therapy, symptom management, medication monitoring and adverse reaction monitoring, other daily routines, and emotional support.<sup>5,6</sup> On the other hand, the caretakers are not

emotionally ready to provide the care. They become more susceptible to financial, social, and physical stresses that have an impact on their individual health dimensions as a result. As a result, caregivers disregard their own health in favour of their sick relatives wants and well-being. A number of factors, including age, gender, relationship to the patient, unemployment, the caregiver's income, the length and stage of the illness, prior caregiving experience, and caring for another sick patient, might affect the stress experienced by caregivers.<sup>7,8,9</sup> The stress on caregivers influences not only their actions, physical and mental well-being, but also the health of their patients inadvertently.<sup>9</sup> Few studies evaluating caregiver's burden and quality of life were conducted in India. The aim of the study is to assess the quality of life and burden in caregivers of cancer patients.

#### **AIMS AND OBJECTIVES:**

- To determine the quality of life of cancer patient's caregivers.
- To find out the different socio-demographic factors and their impact on the lives of cancer caregivers

**METHODOLOGY:** A hospital-based cross-sectional study was conducted over one month, from April 1, 2024, to April 30, 2024, at Sree Mookambika Institute of Medical Sciences (Cancer Centre), Kulasekharam, involving caregivers of cancer patients. Caregivers present at the time of data collection and willing to participate were included in the study, while those who were illiterate, hearing defects excluded. The study involved 100 family caregivers, study details were explained and informed consent obtained. Socio-demographic details were collected using a semi-structured proforma, and the quality of life of caregivers was assessed using the WHO-QOL BREF scale.

Variables	Criteria	Frequency	Percentage
Gender distribution	Male	54	54%
	Female	46	46%
	Total	100	100%
Marital status	married	85	85%
	unmarried	17	17
Type of family	Nuclear family	64	64%
	Joint family	33	33%
	5 Family members	68	68%
Occupation	Professional	21	21%
	Semi professional	13	13%
	Clerical/Shop/Farm	17	17%
	Skilled Worker	17	17%
	Semi Skilled Worker	13	13%
	Unkilled Worker	7	7.0%
	Unemployed Worker	12	12%
Your relationship with spouse	Spouse	25	25%
	Parent	20	20%
	Children	18	18%
	sibling	14	14%
	Friend	12	12%
	Relative	11	11%
Education	Professional degree	13	13 %
	Graduate	23	23%
	Intermediate/ Diploma	20	20%
	High school	28	28%
	Middle school	7	7%
	Primary school	4	4%
	Illiterate	5	5%
Overall quality of health			
How would you rate your quality of life	Very poor	2	2%
	Poor	9	9%
	Neither Poor nor good	32	32%
	Good	48	48%
	Very good	9	9 %
How satisfied are you with your health?	Very Dissatisfied	0	0
	Dissatisfied	16	16 %
	Neither satisfied nor dissatisfied	21	21%
	Satisfied	56	56%
	Very satisfied	7	7%
Physical Domain			
To what extent do you feel that physical pain prevents you from doing what you need to do?	Not at all	29	29 %
	A little	15	15%
	A moderate amount	33	33%
	Very much	22	22%
	An Extreme Amount	1	1%
How much do you need any medical treatment to function in your life?	Not at all	26	26%
	A little	15	15 %
	A moderate amount	38	38 %
	Very much	18	18%
	An Extreme Amount	3	3%
Do you have enough energy for everyday life ?	Not at all	8	8%
	A little	14	14%
	A moderate amount	30	30%
	Very much	35	35%
	An Extreme Amount	13	13%

<b>How well are you able to get around?</b>	<b>Not at all</b>	4	4%
	<b>A little</b>	12	12%
	<b>A moderate amount</b>	35	35%
	<b>Very much</b>	32	32%
	<b>An Extreme Amount</b>	17	17%
<b>How satisfied are you with your sleep?</b>	<b>Not at all</b>	1	1%
	<b>A little</b>	21	21%
	<b>A moderate amount</b>	34	34%
	<b>Very much</b>	38	38%
	<b>An Extreme Amount</b>	6	6%
<b>How satisfied are you with your ability to perform your daily living activities?</b>	<b>Not at all</b>	5	5%
	<b>A little</b>	8	8%
	<b>A moderate amount</b>	24	24%
	<b>Very much</b>	59	59%
	<b>An Extreme Amount</b>	4	4%
<b>How satisfied are you with your capacity for work?</b>	<b>Not at all</b>	0	0%
	<b>A little</b>	14	14%
	<b>A moderate amount</b>	28	28%
	<b>Very much</b>	50	50%
	<b>An Extreme Amount</b>	8	8%
<b>Psychological domain</b>			
<b>How much do you enjoy life</b>	<b>Not at all</b>	5	5%
	<b>A little</b>	23	23%
	<b>A moderate amount</b>	37	37%
	<b>Very much</b>	27	27%
	<b>An Extreme Amount</b>	8	8%
<b>To what extent do you feel your life to be meaningful?</b>	<b>Not at all</b>	1	1%
	<b>A little</b>	10	10%
	<b>A moderate amount</b>	41	41%
	<b>Very much</b>	34	34%
	<b>An Extreme Amount</b>	14	14%
<b>How well are you able to concentrate ?</b>	<b>Not at all</b>	2	2%
	<b>A little</b>	11	11 %
	<b>A moderate amount</b>	35	35%
	<b>Very much</b>	38	38%
	<b>An Extreme Amount</b>	14	14%
<b>Are you able to accept your bodily appearance</b>	<b>Not at all</b>	0	0%
	<b>A little</b>	11	11%
	<b>A moderate amount</b>	24	24%
	<b>Very much</b>	43	43%
	<b>An Extreme Amount</b>	22	22%
<b>How satisfied are you with yourself?</b>	<b>Not at all</b>	0	0%
	<b>A little</b>	10	10%
	<b>A moderate amount</b>	28	28%
	<b>Very much</b>	53	53%
	<b>An Extreme Amount</b>	9	9%
<b>How often do you have negative feelings, such as blue mood, despair, anxiety, depression?</b>	<b>Not at all</b>	34	34%
	<b>A little</b>	22	22%
	<b>A moderate amount</b>	27	27%

	Very much	17	17%
	An Extreme Amount	0	0%
<b>Social relationship domain</b>			
<b>How satisfied are you with your personal relationships?</b>	Not at all	1	1%
	A little	11	11%
	A moderate amount	26	26%
	Very much	54	54%
	An Extreme Amount	8	8%
<b>How satisfied are you with your sex life?</b>	Not at all	0	0%
	A little	15	15%
	A moderate amount	33	33%
	Very much	50	50%
	An Extreme Amount	2	2%
<b>How satisfied are you with the support you get from your friends?</b>	Not at all	3	3%
	A little	10	10%
	A moderate amount	21	21%
	Very much	51	51%
	An Extreme Amount	15	15%
<b>Environment Domain</b>			
<b>How safe do you feel in your daily life?</b>	Not at all	5	5%
	A little	12	12%
	A moderate amount	29	29%
	Very much	40	40%
	An Extreme Amount	14	14%
<b>How healthy is your physical environment?</b>	Not at all	3	3%
	A little	8	8%
	A moderate amount	35	35%
	Very much	38	38%
	An Extreme Amount	16	16%
<b>Have you enough money to meet your needs?</b>	Not at all	11	11%
	A little	12	12%
	A moderate amount	39	39%
	Very much	29	29%
	An Extreme Amount	9	9%
<b>How available to you is the information that you need in your day-to-day life?</b>	Not at all	5	5%
	A little	13	13%
	A moderate amount	32	32%
	Very much	31	31%
	An Extreme Amount	19	19%
<b>To what extent do you have the opportunity for leisure activities?</b>	Not at all	10	10%
	A little	15	15%
	A moderate amount	41	41%
	Very much	22	22%
	An Extreme Amount	12	12%
<b>How satisfied are you with the conditions of your living place?</b>	Not at all	0	0%
	A little	10	10%
	A moderate amount	27	27%
	Very much	56	56%

	An Extreme Amount	7	7%
<b>How satisfied are you with your access to health services?</b>	Not at all	0	0%
	A little	8	8%
	A moderate amount	22	22%
	Very much	62	62%
	An Extreme Amount	8	8%
<b>How satisfied are you with your mode of transportation?</b>	Not at all	2	2%
	A little	13	13%
	A moderate amount	19	19%
	Very much	56	56%
	An Extreme Amount	10	10%

### Tools Used

**A semi-structured intake Proforma** containing Socio-demographic details of CGs like age, gender, religion, education, occupation, type of family, family income, relationship with the patient and type of cancer the patient is suffering from.

**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.

Data was collected through a pretested questionnaire, entered into an MS Excel sheet, and analysed using IBM SPSS version 20.0 software.

Based on study done by sanjeevani et al<sup>10</sup>,  $p=83\%$ ,  $Z_{1-\alpha/2} = 1.96$  for absolute precision  $\alpha 5\%$ , sample size - 78.68, so 100 caregivers of cancer patients included.

**RESULTS:** Below are the analysis report of the various parameters considered and the frequency / percentage response from various respondents are analyzed here under.

Mean age of the study participants: Mean +/- SD = 45.80 +/- 15.837.

$$\text{Transformed Scale} = \left[ \frac{(15 - 4)}{16} \right] \times 100 = 68.75$$

This formula used to transform.

### WHO Domain

Sl.	Domain	Mean +/- SD
1	Physical	60.60 +/- 16.70
2	Psychological	63.37 +/- 16.55
3	Social Relationship	63.41 +/- 16.97
4	Environmental	61.28 +/- 16.22

### Association between Socio-demographical Variables and QOL Domains

#### ANOVA Tests

Sl.	Domain	D1 (Physical)	D2 (Psychological)	D3 (Social)	D4 (Environment)	Over all health
1	Relation with Patient	F = 0.88 P = 0.49	F = 2.55 <b>P = 0.03</b>	F = 1.45 P = 0.21	F = 0.54 P = 0.74	F= 1.60 P= 0.16
2	Marital status	F = 0.67 P = 0.41	F = 7.03 <b>P = 0.001</b>	F = 0.84 P = 0.36	F = 2.18 P = 0.14	F= 4.20 <b>P= 0.04</b>
3	Occupation	F = 4.67 <b>P = 0.001</b>	F = 2.47 <b>P = 0.02</b>	F = 2.18 <b>P = 0.05</b>	F = 4.63 <b>P = 0.001</b>	F = 2.74 <b>P = 0.01</b>
3	Literacy	F = 3.08 <b>P = 0.001</b>	F = 2.51 <b>P = 0.02</b>	F = 1.59 P = 0.15	F = 3.02 <b>P = 0.01</b>	F = 3.30 <b>P = 0.001</b>
4	Socio economic status	F = 8.85 <b>P = 0.001</b>	F = 5.46 <b>P = 0.001</b>	F = 0.56 P = 0.63	F = 8.25 <b>P = 0.001</b>	F = 6.83
5	Type of Family	F = 1.30 P = 0.27	F = 1.88 P = 0.15	F = 1.53 P = 0.22	F = 0.36 P = 0.69	F = 0.19 P = 0.82
6	Type of cancer the patient suffers from	F = 1.09 P = 0.37	F = 1.09 P = 0.37	F = 0.91 P = 0.54	F = 0.75 P = 0.69	F= 0.60 P= 0.83

### Quality of life in CGs of cancer Patients

QOL in CGs was assessed in four domains according to the WHO-QOL BRIEF scale.



The highest mean score was seen in the Social Relationship domain, which indicates good QOL in this domain, and the least mean score was scored in the Physical domain indicating poor QOL in this domain.

#### **Association between the QOL 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 ( $P < 0.5$ ) was found,

- Between the Physical domain of QOL with literacy ( $F = 3.08$ ,  $P = 0.00$ ), the occupation
- Between the Psychological domain of QOL with relation to the patient of CGs ( $F = 2.55$ ,  $P = 0.03$ ), Marital status ( $F = 7.03$ ,  $P = 0.00$ ), literacy ( $F = 2.51$ ,  $P = 0.02$ ), occupation ( $F = 2.47$ ,  $P = 0.02$ ), socio economic class ( $F = 5.46$ ,  $P = 0.02$ )
- Between the Social domain of QOL and occupation ( $F = 2.18$ ,  $P = 0.05$ )
- Between the Environment domain of QOL and the literacy ( $F = 3.02$ ,  $P = 0.01$ ), socio economic class ( $F = 8.25$ ,  $P = 0.00$ ), occupation ( $F = 4.63$ ,  $P = 0.00$ ),
- Between the overall health and marital status ( $F = 4.20$ ,  $P = 0.04$ ), literacy ( $F = 3.30$ ,  $P = 0.001$ ), occupation ( $F = 2.74$ ,  $P = 0.01$ ), socio economic class ( $F = 6.83$ ,  $P = 0.001$ )

Correlation: pearson correlation.

	<b>Physical domain</b>	<b>Psychological Domain</b>	<b>Social relationship</b>	<b>Environment domain</b>	<b>Overall health</b>
Age	$r = -0.21$ $p = 0.03$	$r = -0.426$ $p = 0.00$	$r = -0.26$ $p = 0.00$	$r = -0.30$ $p = 0.00$	$r = -.176$ $p = .081$
Overall health	$r = 0.55$ $p = 0.0001$	$r = 0.56$ $p = 0.0001$	$r = 0.439$ $p = 0.0001$	$r = 0.50$ $p = 0.0001$	—
PHYSICAL DOMAIN	—	$r = 0.739$ $p = 0.0001$	$r = 0.496$ $p = 0.0001$	$r = 0.729$ $p = 0.0001$	$r = -0.21$ $p = 0.0001$
PSYCHOLOGICAL DOMAIN	$r = 0.739$ $p = 0.0001$	—	$r = 0.523$ $p = 0.0001$	$r = 0.762$ $p = 0.0001$	$r = -0.426$ $p = 0.0001$
SOCIAL RELATIONSHIP	$r = 0.496$ $p = 0.0001$	$r = 0.523$ $p = 0.0001$	—	$r = 0.522$ $p = 0.0001$	$r = 0.439$ $p = 0.0001$

ENVIRONMENT DOMAIN	r=0.729 p= 0.0001	r=0.762 p= 0.0001	r=0.522 p= 0.0001	_____	r=0.500 p= 0.0001
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In pearson correlation, except age all domain shows positive correlation on other domains. Age shows negative correlation.

## DISCUSSION:

The quality of life of caregivers is influenced by their work, education, and socioeconomic level. In addition to offering information and counselling, healthcare professionals should put the wellbeing of caregivers first. To enhance the quality of life for family caregivers, health workers at all levels in developing country cancer hospitals should be made aware of the different responsibilities they confront. In our study, Mean age of the study participants is 45.80 +/- 15.837, similar study by Mishra s et al, the mean age is 38.98±10.53<sup>12</sup>.

In this study, WHO quality of life domains such as physical health, psychological domain, social relationship, environment domains (mean with standard deviation) were 60.60 +/- 16.70, 63.37 +/- 16.55, 63.41 +/- 16.97, 61.28 +/- 16.22 compared to a study done by sanjeevani et al physical health, psychological domain, social relationship, environment domains (mean with standard deviation) were 23.25±9.026, 26.5±13.38, 62.09±22.83, 18.22±15.40<sup>10</sup>. In this study moderate amount of distress (27%) present compared to study done by Rajeswari A et al<sup>4</sup> emotional distress about 30.7%.

**LIMITATION:** Low sample size.

**GENERALIZABILITY:** Not Generalizable.

## CONCLUSION:

Caregivers; education, occupation, and socioeconomic status impact their quality of life. Healthcare providers should prioritize caregiver's well-being and provide education and counseling. All levels of health-staff in cancer hospitals in developing countries should be sensitized to the various burdens faced by family caregivers in order to improve the quality of life in this group of people.

## RECOMMENDATIONS:

We recommend the establishment of counselling centre within all cancer hospitals, accompanied by the creation of tailored interventions and support groups. These resources are

essential for assisting caregivers in managing and addressing the challenges they face. Moreover, healthcare providers must prioritize the caregivers' both physical and mental well-being. To achieve this, comprehensive education and counseling services should be readily available and integrated into their care framework

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