Quality of Life and Its Correlates among Cancer Caregivers

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Cancer is a chronic disease that causes patients and caregivers to lose control over their lives, has an adverse effect on their personal, social, and professional lives. Cancer patients can require a lot of care, and those who provide it face the danger of experiencing physical and mental discomfort. This study aims to identify the relationship between Quality of life (QOL), Caregiver Burden and Resilience among cancer caregivers and further aims to study the role of gender among cancer caregivers. A correlational as well as cross-sectional study was designed to obtain a sample of 100 cancer caregivers from Kerala. All the scales including the Socio-Demographic data sheet, WHOQOL-BREF, Burden Assessment Schedule and Resilience Scale were used to collect data. A significant correlation among study variables and significant differences in these variables between male and female Caregivers, were found. The present study has practical implications for acknowledging and improving the QOL of cancer caregivers and planning intervention programs for them to help them learn to deal with psychological issues like burden and stress.

Keywords: Cancer Caregiver, Quality Of Life, Caregiver Burden and Resilience.

Despite the medical advancement and global consideration, pronouncing the word cancer is associated with a life-threatening situation which is growing as a major cause of morbidity and mortality in the present time across the world including India. According to estimates from the International Agency for Research on Cancer (IARC), in 2018 there were 17.0 million new cancer cases and 9.5 million cancer deaths worldwide. The impact of cancer often reaches beyond the diagnosed individual to family members and friends. Individuals within a cancer patient's social network often provide critical care and assist with many supportive tasks, such as administering medication and helping with postsurgical care. These informal cancer caregivers (typically a family member, friend, or neighbor) provide unpaid care and support for individuals with cancer. It impacts not only on the patient, but the whole family, especially when a family member assumes the role of the family caregiver, leading to an

additional emotional, social and financial strain on them. In the process of caregiving, the social ecological model describes various factors such as intrapersonal factors, interpersonal factors, institutional factors, community factor and policy or environmental factors, which influence informal cancer caregiving in a great extent (Molassiotis & Wang, 2022). With advances in cancer diagnosis and breakthroughs in cancer treatment, palliative care is introduced early in the care continuum. Cancer patients survive longer, and the length of the caregiving period gets extended from days or weeks to months or years. These developments in the field of cancer care shows that family caregivers are facing new responsibilities in medical, emotional, and practical domains (Alexander, 2010; Hudson & Payne, 2009; Kristjanson). Many aspects of cancer care fall to family caregivers, including organizing visits, providing lodging, monitoring treatment, compliance, symptom

management, emotional support, food preparation, cleaning, and financial assistance (Given et al., 2011), but this usually occurs with insufficient preparation or training in the provision of care. Caregivers often neglect their own needs, and are even often required to give up their usual daily activities due to their caregiving responsibilities (Molassiotis & Wang, 2022).

A caregiver sometimes called an informal caregiver who is an unpaid individual (a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks. Caregiving can include everything from assisting with everyday chores to providing direct care to the care recipient. The domains of the caregiving role include: assistance with household tasks, self-care tasks, and mobility; provision of emotional and social support; health and medical care; advocacy and care coordination; and surrogacy. Each domain has multiple tasks and activities (Spillman, 2014; Wolff, 2007). A cross-sectional study from a cancer research centre in South India was conducted and findings indicated that the prevalence of depression in caregivers was 52.5%. Moreover this study revealed that spousal caregivers, those who resided with the patient, those providing financial support and those with non-caring domestic responsibilities appeared as vulnerable determinants (Sahadevan et al., 2019). A study also suggested that informal caregivers of cancer patients are always at risk of deterioration of their quality of life (QOL) in terms of physical, psychological, social and environmental health due to less time for self-care and extra burden (Mishra et al., 2021).

Quality of Life is an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns ("The World Health

Organization Quality of Life (WHOQOL)-BREF (No," 2004). In caring for family members, caregivers often neglect their own health care needs, posing a risk of deterioration in their own quality of life (QOL). While cancer caregiving is a meaningful experience, it is also associated with deteriorating quality of life (QOL), greater psychiatric squeal, and an increased risk of mortality for the caregiver. It is therefore essential to identify, understand and support family caregivers and, by extension, their care recipients. A study was conducted on 23 cancer survivors and their family caregivers and it was found that the cancer survivors report significantly higher quality of life, less fear of cancer recurrence, and more support than their family caregivers (Mellon.S., et al., 2006). Quality of Life of Family Caregiver of Patients with Cancer was studied and it was indicated in the results that majority of family caregivers of patients with cancer had moderate QOL and there is a strong association between the caregiver QOL with their own demographic variables as well as the patients' demographic variables such as age, religion, marital status, gender, education and region etc. Family caregivers of patients with cancer unconsciously tend to neglect their own quality of life by putting the patient's needs first. They report various problems from their care giving role that include physical health problems, psychological distress, conflict among their social roles, restriction of activities, and strain in marital and family relationship. These negative experiences would negatively impact on the general wellbeing and the quality of life of those informal caregivers (Araki et al., 2023). It shows that caregiving individuals experience a lot of burden in the form of physical and psychological imbalances. Cancer caregiving is a rigorous process, which increases the caregiver's burden and related strain. In order to reduce it, psychoeducation, support intervention and other caregiver training are

very essential and recommended (Jadalla et al., 2020).

Caregiver burden is the stress that comes with taking care of a family member who is aged, disabled, or chronically ill. A complex reaction to the financial, social, psychological, emotional, and physical strains that come with providing care, caregiving burden takes many forms. It has been stated that caregiver burden is both perceived and observed. The influence on the caregiver's life is determined by how they perceive the burden, and not by other family members or medical professionals. It was seen in many studies that the level of perceived burden was found to be correlated with higher risks of depression and lower quality of life for caregivers. It was found that there is no significant difference in caregiver burden between intervention and usual care conditions. Further it was seen that higher objective caregiver burden and stress burden were associated to lower patient quality of life, higher symptom intensity, and higher depressed mood which the follow-up analysis indicated (O'Hara R.E. et al., 2010). A study was conducted and findings of this study revealed that there was significant difference in cancer caregiver burden based on education level, family income, only child status, and participation in a patient support group on social media. Further results of the structural equation modeling indicated that QOL is strongly impacted by cancer caregiver burden, anxiety, and depression; these associations are mediated by individual resilience (Chen X. et al., 2023). A study was done and its findings suggested that there is a positive correlation was found between patients' family resilience and caregivers' family resilience as well as between patients' family resilience and caregivers' psychological resilience. Furthermore, the family resilience of caretakers was negatively correlated with the patients' symptom burden (Cui P. et al., 2023). It was suggested by a

previous study that 56.5% caregivers of overall sample, reported no or minimal burden while 37.5% caregivers reported mild to moderate burden. Moreover, marital status, education and type of family of caregivers, occupation of cancer patients and type of treatment facility were found to be the predictors of burden on caregivers (Lukhmana S. et al., 2015). Caregivers often have feelings of pronounced isolation and effectively grieve for their previous vibrant and active lifestyles. It was found that lack of time for self-care and continued focus on the cancer patients' well-being typically deplete their energy and contribute to an increased caregiver burden. Further findings indicated that resilience is the one of the factors that impacts on caregiver burden in different ways to reduce it (Ruisoto P et al., 2020)

Resilience is the ability to mentally or emotionally cope with a crisis or return to precrisis status quickly. Originally, resilience was referred to as a personality trait that moderates the negative effect of stress and promotes adaptation. Through the developmental and psychosocial process of psychological resilience, people who are subjected to ongoing adversity or potentially catastrophic situations eventually show positive psychological adaptation. Resilience is defined as an important psychological resource that is characterized by the capacity to adapt actively to adversities and "bounce back" effectively from stressful situations (Block & Kremen, 1996; Bonanno, 2005). A study was conducted on the relation between patients' resilience and quality of life after treatment for cancer of the head and neck shows that there was a significant correlation between overall QOL and resilience. As higher resilience scores had a significant correlation with a better QOL, strengthening a patient's resilience might in turn help to improve their quality of life (Clarke et al., 2019). Similarly another research study findings also revealed that there was

substantial positive correlation between resilience and quality of life among people with physical disability and resilience emerged as good predictor for QOL (Nishi Srivastava et al., 2023). After reviewing various research studies, it is visible that resilience would be the best psychological construct for the caregiving recipients. A research study was conducted on building resilience through role adjustment and mutuality and findings suggested that the new patterns of role adjustment and mutuality can assist with making meaning and finding benefits and these patterns contribute to dyadic resilience when moving through a cancer experience (Gibbons R et al., 2019). Another research study findings revealed that the degree of self-care, age, and spouse relationship with patients were all associated with caregiver burden. Furthermore, family resilience mediated the relationship between perceived social support and caregiver burden, and both variables were negative predictor of caregiver burden (Zhang,Y. et al., 2023).

The evolution of cancer in India mimics the pattern of growth in other European and American countries. The National Cancer Registry of India states the causation of cancer to be multi-factorial, the burden to be multi-dimensional, and the treatment to be multi-disciplinary. A diagnosis of cancer begins a long journey that can affect physical health, mental well-being, and relationships with loved ones. Having a cancer patient at home makes the family as a whole go through a series of changes and adjustments, from kids to the elderly. Carers of patients suffering from cancer have to go through a transition where their responsibilities, lifestyle and way of life have to change in order to accommodate the needs of their loved ones. In our society, caregiving is a cultural obligation and an expected role for women. However, due to the high demands associated with providing care, it may eventually lead to burnout, exhaustion, caregiver burnout, and a general reduced health-related quality of life and strain on the caregivers. Cancer treatments are improving, and thus, caregiving for cancer patients continues for longer periods now than in the past, when deaths occurred rapidly. In a state like Kerala, where literacy rate is high, the knowledge about Cancer, its treatment and course is very clear to the Caregivers. The experience of caregiving affects both males and females spouses and non-spouses in the family. Therefore, the current study is aiming to explore the impacts of cancer caregiving on the Quality of life, Caregiver Burden and Resilience among cancer caregivers.

Aim and Objectives

The present study was intended to ascertain the relationship between Quality of life, Caregiver Burden and Resilience among Cancer Caregivers. Further it aims to find the difference in Quality of life, Caregiver Burden and Resilience among male and female Cancer Caregivers. The objectives of the study are as follow:

- To assess the relationship between Quality of life, Caregiver Burden and Resilience among male cancer caregivers.
- To assess the relationship between Quality of life, Caregiver Burden and Resilience among female cancer caregivers.
- To assess the difference between male and female cancer caregivers on their Quality of life, Caregiver Burden and Resilience.

Hypotheses

• *Ha1:* There will be a significant relationship between Quality of life, Caregiver Burden and Resilience among male cancer caregivers.

- *Ha2:* There will be a significant relationship between Quality of life, Caregiver Burden and Resilience among female cancer caregivers.
- *Ha3:* There will be a significant difference between male and female cancer caregivers on Quality of life, Caregiver Burden and Resilience.

Method

Sample

The target population of the study was the caregivers of patients with cancer who were undergoing treatment of Cancer from different districts of Kerala (Pathanamthitta, Kollam, and Kottayam) such as Muthoot Cancer Centre located at Pathanamthitta district in Kerala. The sample comprised of 100 participants (N=100). Purposive sampling method was used to select sample from the population of Cancer Caregivers in Kerala. The sample consists of 50 male and 50 female caregivers each.

Inclusion Criteria

Participants within the age group of 25-55 years and were caregivers of family members suffering from cancer were included for the study. Participants who can read and understand English and has no hearing or visual impairment, and no previous or current record of any psychological illness were included. Also, the participants had no previous or current treatment history of cancer.

Exclusion Criteria

Participants below 25 years and above 55 years of age were excluded from the study. Participants who cannot read and understand English, as well as participants having hearing or visual impairment were excluded. Participants with a previous or current record of any psychological illness or having previous or current treatment history of cancer treatment were excluded. Participants' caregiving for Relatives and close friends were excluded.

Measures

Socio-demographic and personal data sheet: Socio-demographic data sheet developed by the researcher was used to collect the socio demographic data of the participants.

Quality of life: QOL was assessed using the WHOQOL-BREF which was developed by WHO (2004). It consists of 26 items. It is a self-reporting scale. On each item respondents provide their answer on fivepoint scale. It is a tool to measure Quality of life of individuals under four dimensions includes physical health (7 items and á =0.82), psychological health (6 items and á =0.81), social relationships (3 items and á =0.68), and environmental health (8 items and á =0.80).

Burden Assessment Schedule: It was developed by Thara, Padmavati, Kumar and Srinivasan (1999). The Burden Assessment Schedule (BAS) was developed at the Schizophrenia Research Foundation (SCARF) India, to assess the burden on FCG's of PWCMI. 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. Scores range from 40 to 120 with higher scores indicating greater burden i.e. mild burden (0-40), moderate burden (41-80) and severe burden (81-120). The BAS has been validated against the 'Family Burden Schedule' by Pai & Kapur (1981) and the correlations ranged from 0.71 to 0.82 for most items. Inter-rater reliability for the scale is 0.80.

Resilience Scale: This scale was developed by Wagnild & Young (1993). Resilience scale aims to assess the level of

resilience of the individual as a positive feature of the personality that promotes individual adaptation. It consists of 25 items, each item rated on a 7-point Likert scale. Total score ranges between 25 and 175 points. The RS indicated good psychometric properties, with respect to internal validity and content validity. A Cronbach's alpha of .91 was found and item-total correlations ranged between .37 and .75. It is composed of a unifactorial structure that includes items referring to aspects related to self-esteem, independence, mastery, resourcefulness, perseverance, adaptability, balance, flexibility and a balanced perspective on life.

Data Collection Procedure:

Step 1: Due permission from the concerned authority was obtained. The study was sanctioned by the Ethical and Scientific Supervisory Committee of the institute. Informed consent from all the participants was obtained before initiating the data collection.

Step 2: The collection of sociodemographic and personal datasheets of the participants was especially designed for the study. *Step 3*:The data was collected by administering the respective questionnaires:

- WHOQOL-BREF questionnaire used for the assessment of Quality of Life.
- Burden Assessment Schedule used for the assessment of Caregivers Burden.
- Resilience Scale used for the assessment of Resilience.

The data collection process took approximately 4-5 weeks period. Data was collected and analyzed for testing the hypotheses of the study.

Results

The present study intended to find out the relationship between Quality of life, Caregiver Burden and Resilience among male and female Cancer Caregivers. Also, examine whether there is a difference in Quality of life, Caregiver Burden and Resilience among male and female Cancer Caregivers. Mean age of cancer caregivers was 33.33 years (age range: 25-55 years, SD=2.01years). The gender wise percentage distribution of participants shows that 50% of the participants were male respondents and the other 50% consisted of female respondents.

Variables	Caregiver	Resilience	Quality of life				
	Burder		Physical Health	Psychological Status	Social Support	Environment	
Caregiver Burden							
Resilience	468**						
Physical health	713**	099					
PsychologicalStatus	465**	.526**	.081				
Social support	376**	.638**	.027	.089			
Environment	043	.139	.166	158	.073		

Table1. The correlation among male Cancer Caregivers' Quality of life-domains, Caregivers Burden and Resilience.

**significant at 0.01 level

The results indicate that Caregivers Burden shows significant negatively correlation with, physical health, psychological status and social support domain of Quality of life. Resilience is negatively correlated with caregiver burden and physical health domain of QOL. Also, Resilience shows significant positive correlation with psychological status and social support domain of QOL. Therefore, from the results it is seen that hypothesis 1 is accepted, indicating there is a significant relationship between Quality of life domains, Caregiver Burden and Resilience among male cancer caregivers.

Table2: The correlation among female Cancer Caregivers' Quality of life-domains, Caregiver Burden and Resilience.

Variables	Caregiver	Resilience	Quality of life				
	Burder		Physical Health	Psychological Status	Social Support	Environment	
Caregiver Burden							
Resilience	414**						
Physical health	468**	.583**					
PsychologicalStatus	465**	.526**	.612**				
Social support	298**	.491**	.638**	.376**			
Environment	.010	161	032	.746**	171		

**.significant at 0.01 level

Finding shows that in female cancer caregivers, Caregiver's Burden shows significant negatively correlation with Resilience, physical health, psychological status and social support domain of quality of life. Resilience has significant negative correlation with Caregiver Burden and significant positive correlation with physical health, psychological status and social support domain of Quality of life. Therefore, from the results it is seen that hypothesis 2 is accepted, indicating there is a significant relationship between Quality of life domains, Caregiver Burden and Resilience among female cancer caregivers.

Table3: Descriptive statistics and t-value for Quality of life-domains, Caregiver Burden and Resilience among male and female Cancer Caregivers.

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	Variables	Groups	Mean	Standard deviation	t-value
Quality ofLife	Physical health	Male	50.800	14.83796	3.906**
		Female	50.060	28.5853	
	PsychologicalStatus	Male	44.620	18.7060	3.841
		Female	61.660	25.1871	
	Social support	Male	36.320	20.6679	2.501
		Female	48.180	26.4017	
	Environment	Male	71.400	18.0543	.028

	Female	71.500	17.1348	
CaregiverBurden	Male	74.1250	7.71674	4.177**
	Female	84.7250	14.07305	
Resilience	Male	118.0250	16.85913	4.123**
	Female	101.6000	18.72308	

**Significant at 0.01 level

From the perusal of the above table, it is revealed that the t-value between male and female Cancer Caregivers on physical health domain of Quality of Life is 3.906, which is statistically significant. However on Psychological Status, Social Support and Environmental dimensions of Quality of Life t-value comes to be 3.841, 2.501 and .028 are statistically respectively which insignificant. The t-value between male and female Cancer Caregivers on Caregiver Burden is 4.177, which is statistically significant. The t-value between male and female Cancer Caregivers on Resilience is 4.123, which is also statistically significant. From the results, it is seen that hypothesis 3 is partially accepted. There is a significant difference among male and female cancer caregivers on the Psychological Status domain of Quality of life, Caregiver burden and Resilience.

Discussion

Regarding the first two hypotheses, the result of the correlational study revealed that, caregivers' burden was negatively correlated with Resilience, Quality of life including its domains in both male and female caregivers. As Caregivers' Burden increases, the resilience, and Quality of life tends to decrease for an individual (Clarke et al., 2019; Chen X. et al., 2023). Caregivers Burden tends to decrease as the overall Quality of life of an individual increase. Earlier research studies report that the majority of caregivers experience health issues, domestic problems, and poor quality

of life (Bostancý et al., 2007; Mystakidou et al., 2007). Further it was seen that Quality of life including its domains (psychological status and social support) showed positive correlation with Resilience in male caregivers and QOL with its domains (physical health, psychological Status and social support) showed positive correlation with resilience in female caregivers. This implies that as Resilience increases the Quality of life tends to increase. Apart from that Psychological Status showed positive correlation with Social Support and Environmental domain. This shows that an increase in one of these domains would constitute to an increase in the other domains, thus making the individual's Quality of Life better.

The result of this present study further revealed, regarding the third hypothesis, that gender has a significant role in the Quality of life, Caregiver Burden and Resilience of cancer caregivers. Resilience was seen higher in male caregivers than in female caregivers. Men are asked to be strong in our society. But the overall Quality of Life was seen to be higher in females than in males. Previous studies supported the primary findings of the present study that gender had its specific role in caregiving process (Sims-Gould & Martin-Matthews, 2010). Men have to deal with a wide range of social stress situations and they might not be able to open up to others about these dilemmas. The study reveals that the Caregivers Burden experienced by women is higher than that experienced by men (Chellappan & Rajkumar, 2016). It suggests that as

Caregivers Burden increases, the Resilience, Physical Health, Psychological status and Social support domain of Quality of life decrease. The female caregivers are in constant requirement of meeting the needs of the family, cancer patient at home and their own needs. In female caregivers, it was seen that as Quality of life decreased as the Caregivers Burden experience increased. As roles and responsibilities change, caregivers may feel they are losing their self-sufficiency and independence too (Freydberg et al., 2010). In Indian society, women are portrayed as weak and vulnerable as so, they are more likely to receive better social support from their families as they are assigned with taking care of their families and loved ones. This indeed results in female caregivers showing better quality of life. Women are seen more psychologically strong than men, as women are trained from a very young age to take care of the family and meet family needs.

Conclusion

Cancer caregiving may be associated with high caregiver burden, low resilience and low Quality of life in both male and female caregivers. Female caregivers experience more caregivers' burden than male caregivers. The quality of life of caregivers is low, but there is no significant difference between male and female caregivers in its all domain. Given the multifaceted and complex nature of the caregiving role, as described above, preparedness for caregiving is essential. The effects of caregiving are not all negative. Numerous surveys suggest that, for some, caregiving instills confidence, provides lessons on dealing with difficult situations, brings them closer to the care recipient, and assures them that the care recipient is well-cared for. The results of the study emphasize the necessity of expanding government initiatives and policies in order to enhance caregiver's resilience and overall quality of life while

diminishing the caregiver burden on them. Further investigation is also required to fully comprehend the special requirements and difficulties associated with caregivers in various social and cultural contexts.

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