

# Study of Psychological Well-Being and Quality of Life of Caregivers of Patients with Head and Neck Cancers: A Comparative Study with Normal Controls

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## ABSTRACT

**Background:** Head and neck cancer (HNCs) usually begin in oral or nasal cavity, throat, salivary glands, sinuses, muscles/nerves in head and neck. Oral cavity cancer accounts for highest number of cases in Indian males and thyroid lesions as the third most common. Diagnosis of cancer creates a certain amount of burden on caregivers. Caregivers often hide their concerns and worries, and prefer not to disclose it. **Aim:** To assess and compare the psychological well-being, and quality of life of caregivers of HNCs patients. **Methods:** Total of 65 caregivers of patients diagnosed with HNCs referred from Radiotherapy OPD were taken. Those fulfilling the inclusion and exclusion criteria were selected. 41 normal controls were taken from general population to compare variables with caregivers of clinical group. All participants were assessed with the General Health Questionnaire-12, Ryff's Psychological Well-Being Scale and WHO Quality of Life-BREF. **Result:** Comparison of psychological well-being and quality of life among caregivers and normal control revealed significant differences across different dimensions. **Conclusion:** Results explain psychological well-being and quality of life are important factors that negatively impact caregivers of HNCs patients. There is a need for early therapeutic intervention for caregivers.

**Keyword:** Cancer; psychological well-being; quality of life; caregivers

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## Introduction

Originating in squamous cells of mucosal surfaces, the head and neck cancer (HNCs) usually begin in oral or nasal cavity, throat, salivary glands, sinuses, muscles/nerves in head and neck. Reported prevalence in Indian population is 30% in males and 11-16% in females [1]. The causes of cancer include consumption of tobacco, alcohol, slaked lime, betel quid, etc. In India, tobacco accounts for 86.5% of HNCs and alcohol 23.2% [2]. Oral cavity cancer accounts for highest number of cases in Indian males and thyroid lesions as the third most common [3].

Diagnosis and treatment of cancer impacts immensely not only the patients but their family members as well, particularly

the caregivers. In Indian settings, caregivers are often the near family members, such as spouse, children, extended family or friends; known as informal caregivers. Whatever may be the type of cancer, caregiving creates a certain amount of burden. Caregivers often hide their concerns and worries, and prefer not to disclose it in the presence of their family members.

Extensive evidence indicates that caregivers are more prone to deteriorating psychological well-being; in particular, women are at a greater vulnerability with more burden of care and less coping strategies [4-6]. The burden of caregiving includes all aspects of physical, psychological, social and financial aspects. Similarly, the deteriorating quality of life (QoL) has also been linked with caregiving. Following the

cultural norms of piety and expectations of responsibility, QoL of Asian population is specifically poor. The burden of caregiving also leads to social withdrawal, isolation and loneliness. Caregivers often give-up on their hobbies, leisure times and avoids socialization, which in turn impacts their psychosocial well-being and quality of life. The current investigation thus was designed to analyze the impact of cancer on caregivers by comparing psychological well-being and quality of life of caregivers of patients with HNCs and controls.

## Materials and Method

A total of 65 caregivers of patients diagnosed with HNCs, referred from Radiotherapy department and 41 normal controls were taken to compare variables with caregivers of clinical group. Patients fulfilling inclusion as well as exclusion criteria were included in the study.

### Inclusion Criteria

- 1) Caregivers between ages 18-60 years
- 2) Caregivers of middle and advanced staged patients of HNCs
- 3) Caregivers of patients receiving chemotherapy/ radiation therapy
- 4) Caregivers who gave consent for participation

### Exclusion Criteria

- 1) Caregivers not falling under the age range
- 2) Caregivers of patients having severe medical and psychiatric condition
- 3) Caregivers having physical and intellectual disability
- 4) Caregivers of patients who were not receiving chemotherapy/radiation therapy
- 5) Caregivers who did not give consent for participation

## Tools Used

### Socio-Demographic and Clinical Data Sheet

In order to collect clinical information, a self-prepared data sheet was designed. This sheet contained questions pertaining age of the patient, their marital status, their occupation, their residential area, duration of the illness, etc.

### General Health Questionnaire-12 (GHQ-12)

This questionnaire was developed by Goldberg, et al. (1997). This questionnaire screens presence or absence of minor psychiatric illness or psychological morbidity. It consists of 12 items [7].

### Ryff's Psychological Well-Being (PWB)

There is total 42 items, rated on 6-point scale. It has acceptable reliability and validity [8].

### WHO Quality of Life- BREF

This widely used 26 items scale has 4 domains. It has adequate acceptable reliability and validity [9].

### Procedure

Total of 65 caregivers of patients diagnosed with HNCs referred from Radiotherapy OPD were taken. Those fulfilling the inclusion and exclusion criteria were selected. 41 normal controls were taken from general population. All the caregivers were explained about the purpose of the present study and written consent was obtained. Socio-demographic and clinical details was gathered and assessment was done using GHQ-12, PWB and WHO-QoL-BREF.

### Statistical Analysis

Using SPSS version 26, comparison was done between caregivers of patients with HNCs and normal control using appropriate statistical tests.

### Results

Table 1 shows the socio-demographic details of caregivers and normal controls. The two groups were comparable apart from occupation. Comparison of psychological well-being among caregivers and normal control revealed significant difference across six dimensions: autonomy ( $t=31.46$ ), environmental mastery ( $t=27.5$ ), personal growth ( $t=28.87$ ), positive relations with other ( $t=30.51$ ), purpose in life ( $t=29.61$ ) and self-acceptance ( $t=29.54$ ) (Table 2).

Comparison between caregivers and normal control on four different dimensions of quality of life showed significant differences in physical ( $t=53.36$ ), psychological ( $t=52.22$ ), social relationships ( $t=59.7$ ) and environment ( $t=63.66$ ). This difference was significant at 0.05 level (Table 3).

### Discussion

Cancer has the capacity to turn one's life upside down. The patient, the family members, friends, all are significantly impacted. However, it's the main (primary) caregivers who suffer the most. The process of diagnosis and treatment of cancer perse creates stress both on the patient and caregiver particularly in psychological well-being and quality of life. The present study aimed to examine this effect and compare it with normal population.

The results of the present investigation showed that caregivers of HNC patients have poor psychological well-being in comparison to normal control (Table 2). This impairment was found across all the six domains of the scale. Similarly, quality of life was also found impaired among the caregivers, across all four dimensions; physical, psychological, social relationships and environment (Table 3). These results found support from the previous researches

**Table 1: showing Socio-Demographic Details of Participants**

Variables	Characteristics	Caregivers (n=65) %	Normal Control (n=41) %	p value
<b>Age</b>	18-31	(19) 29.23	(10) 24.39	0.853
	32-44	(26) 40	(17) 41.46	
	45-60	(20) 30.77	(14) 34.14	
<b>Sex</b>	Males	(27) 41.53	(20) 48.79	0.465
	Females	(38) 58.47	(21) 51.21	
<b>Marital status</b>	Married	(44) 67.7	(26) 63.41	0.651
	Unmarried	(21) 32.3	(15) 36.59	
<b>Education</b>	Illiterate	(22) 33.85	(12) 29.26	0.574
	Metric	(8) 12.3	(7) 17.08	
	Inter	(15) 23.08	(13) 31.70	
<b>Occupation</b>	Graduate	(20) 30.77	(9) 21.96	0.027
	Unemployed	(7) 10.77	(11) 26.82	
	Business	(24) 36.92	(6) 14.64	
	Farmer	(16) 24.61	(14) 34.14	
<b>Residence</b>	Labour	(18) 27.7	(10) 24.4	0.749
	Rural	(36) 55.39	(24) 58.53	
	Urban	(29) 44.61	(17) 41.47	

**Table 2: Shows the Comparison of Psychological Well-Being (PWB) of all the Participants**

Psychological Well-Being (PWB)	Group	M	p value
<b>Autonomy</b>	Caregivers	23.28±1.71	0.000*
	Normal Control	36.43±2.62	
<b>Environmental Mastery</b>	Caregivers	23.5±1.76	0.000*
	Normal Control	35.8±2.83	
<b>Personal Growth</b>	Caregivers	23.61±1.63	0.000*
	Normal Control	36.29±2.88	
<b>Positive Relations with Others</b>	Caregivers	23.27±1.69	0.000*
	Normal Control	36.07±2.63	
<b>Purpose in Life</b>	Caregivers	23.46±1.64	0.000*
	Normal Control	36.41±2.85	
<b>Self-Acceptance</b>	Caregivers	23.43±1.74	0.000*
	Normal Control	36.07±2.65	

\*Sig. at 0.05

**Table 3: Shows the Comparison of Quality of Life (QoL) of all the Participants**

Quality of Life (QoL)	Group	Mean±SD	p value
Physical	Caregivers	35.93±2.35	0.000*
	Normal Control	85.17±6.83	
Psychological	Caregivers	36.03±2.83	0.000*
	Normal Control	86.41±6.92	
Social Relationships	Caregivers	35.44±3.39	0.000*
	Normal Control	86.8±5.46	
Environment	Caregivers	36.58±2.41	0.000*
	Normal Control	86.41±5.54	

\*Sig. at 0.05

conducted over the years. Comparison of the QoL of oral cavity cancer patients and their wives revealed that both have poor quality of life [10]. Another study reported that caregivers showed deteriorating QoL (health) [11]. A study of the caregivers of HNCs found that in comparison to non-spouse caregivers, spouse caregivers have poor psychological well-being and quality of life [12]. Similar result was reported in a recent study [13]. In another study comparison was made to analyze caregiver's perspective of patient's quality of life and found that caregivers who agree with their patients had better quality of life in comparison to those who negatively view their patient's quality of life [14].

Cancer, of any type, causes significant distress in lives of patients and their caregivers. But for better management of this condition, a healthy support system is needed. Therefore, it is important to address the states of caregivers and their psychological well-being as well as their quality of life. Psychosocial interventions should be devised to overcome these issues.

## Conclusion

Caregivers of cancer patients have lower psychological well-being and quality of life as compared to control subjects. Psychosocial interventions for both patients and their caregivers should be initiated early.

## Limitation

The sample size was small and variables like resilience, self-esteem were not assessed.

**Conflict of Interest:** All authors declare no COI

**Ethics:** There is no ethical violation as it is based on voluntary anonymous interviews

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