

# The Post-treatment Impact on Quality of Life, Body Image, and Occupational Concerns among Head and Neck Cancer Patients

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## ABSTRACT

**Introduction:** Head and Neck Cancer (HNC) is the sixth most common cancer across globe, more common in Asian countries. HNC patients are at a significant risk of developing body image and functionality-related concerns, which in turn impact their overall Quality of Life (QoL). This study provides factual insights into the QoL of Indian male HNC patients three months after completing their treatment.

**Aim:** To assess patients' perceptions of self and overall QoL in context of body image and occupation.

**Materials and Methods:** This mixed-method study included 32 male HNC patients and was conducted at a tertiary cancer centre in Ahmedabad, India, from March 2022 to April 2022. Patients who underwent surgery, with or without radiation therapy or chemotherapy, were included. The Functional Assessment of Chronic Illness Therapy-Head and Neck version (FACT-HN) and the Body Image Scale (BIS) were used as assessment tools. Qualitative responses were also recorded by the interviewer. Statistical analysis was performed using Statistical Package for Social Sciences (SPSS) version 23.0, including both parametric and non parametric tests.

**Results:** The mean age was 45.50 years. The overall QoL of the HNC population was found to be positive, with a mean score of  $117.88 \pm 12.72$ . Higher scores indicated better QoL (total score range: 0-148). Similar trends were observed across all domains. Analysis of variance was conducted for three groups: '3-11 months', '1-3 years', and 'more than three years'. A significant difference in mean HNC scores between these groups ( $p$ -value=0.004) was observed, with '3-12 months' (mean=108) and 'more than three years' (mean=124.6) showing notable differences. QoL between these two groups was compared using the Kruskal-Wallis test, revealing significant differences in their physical, social, and HNC-specific index (HNCS). Approximately 43% of patients reported returning to work within 3-4 months post-treatment, while 46% experienced reduced work hours due to concerns related to functionality and appearance.

**Conclusion:** This data highlights the subjective impact of physical, social, and head and neck-specific QoL issues on patients, particularly in the immediate post-treatment phase, which may persist for upto three years in some cases. Over time, patients' overall QoL improves post-treatment.

**Keywords:** Follow-up study, Head and neck surgery, Occupation

## INTRODUCTION

HNC is among the top 10 leading cancers worldwide [1]. HNC includes different subsites such as the parotid gland, buccal mucosa, pharynx, voice, tongue, skin of the region, and paranasal sinuses [1,2].

Asian countries bear 57.5% of the total global burden of HNC, with about 30% occurring in India [3]. The incidence of oral cavity cancer is particularly high in Gujarat [4]. According to the report from the state institute Gujarat Cancer Research Institute, mouth and tongue cancers accounted for 30.77% of cases in urban Ahmedabad, slightly higher than global rates [5]. There is a significantly greater number of males affected by HNC compared to females, with a ratio ranging from 2:1 to 4:1. The incidence rate is 20 males detected with HNC per 100,000 cases in the Indian subcontinent, Hong Kong, and European countries like France and Spain [6]. Cancer patients are primarily concerned about survival but often remain unaware of the possibilities for achieving optimal functioning post-treatment, which can impact their overall QoL [7].

QoL is defined as a "global concept, conceived to reflect the totality of human well-being, including (but not limited to) physical, psychological, social, economic, and spiritual domains." The concept of Health-Related QoL focuses on the impact of disease and treatment on patients' QoL. Preservation of QoL is important for patients treated with both curative and palliative intents. There is no universally accepted questionnaire as a benchmark for measuring QoL [8].

Cancer treatment can bring about changes such as visible scars and dysfunctionality in mouth-related functions, including speech and limitations in eating. These changes can pose a threat to body image [9,10]. Body image disturbance can lead to low self-confidence, difficulties with sexual well-being, depressive mood, and deteriorating personal and social relationships. Therefore, body image issues significantly impact patients' ability to regain their normal lives and overall QoL [11].

Body image is a complex construct that extends beyond how one views their physical appearance. It is often defined as a multifaceted concept that encompasses individuals' perceptions and attitudes about their own body, particularly its appearance, but not exclusively [11]. It involves compulsive self-inspection in mirrors, efforts in dressing and grooming to conceal perceived defects, and seeking reassurance from others without feeling satisfied. According to the cognitive-behavioral model, body image satisfaction or dissatisfaction is determined by the level of attachment and significance one gives to their body in daily life [12]. The prevalence of distress related to body image ranges from 25-77% [13].

The increase in survival rates for HNC has led to an increase in the number of HNC survivors who are of working age. However, there are implications for these survivors and, to some extent, their employers due to compromised physical and functional well-being. The factors that determine a cancer survivor's return to work

have been categorised as the organisation's work environment, interactions with colleagues and employers, support received, job characteristics, personal coping strategies, and abilities to deal with the altered situation [14]. In high-income countries, the return to work rate after cancer treatment completion is 63.5% (range: 24%-94%). On average, 40% of individuals return to work within six months post-treatment completion, and 89% return within two years [14]. Unfortunately, there has been little attention given to this issue in low or middle-income countries, with only a few studies addressing the topic [15]. As a developing nation, India can only provide minimal economic resources for these patients. The loss of work can contribute to feelings of inadequacy, social loneliness and deprivation for these survivors. In Indian society, which relies heavily on interdependence, the impact can be particularly adverse for patients with dependent families compared to Western societies [15]. Studies on the psychosocial impact of HNC have predominantly used qualitative, quantitative, and mixed-method approaches in literature from various parts of the world [8,14-27].

There are limited studies on the body image issues, functionality, and QoL of Indian HNC patients undergoing cancer treatment and how they cope with these challenges [12,16,28,29]. This study aims to primarily investigate the relationship between HNC treatment and its impact on overall QoL. The secondary objective was to gain insights into the qualitative aspects of the impact on body image and patients' return to work post-treatment.

## MATERIALS AND METHODS

This mixed-method study was conducted from March to April 2022 at a premier tertiary cancer centre with an interdisciplinary HNC treatment team in Ahmedabad, Gujarat, India. Consent to conduct the study in a hospital setting was obtained from the hospital authorities. Informed consent was obtained from the participants under study and their caretakers as necessary. The study was conducted in accordance with the ethical standards outlined in the 1975 Declaration of Helsinki and its later amendments or comparable ethical standards.

**Inclusion criteria:** Patients who underwent surgery, with or without radiation therapy or chemotherapy, had completed at least three months post-treatment, and had no evidence of any psychiatric condition.

**Exclusion criteria:** Patients with laryngeal and thyroid cancers, those who did not undergo surgery as one of the modalities of treatment, and those with distant metastasis or who were unaware of their cancer diagnosis were excluded from the study.

**Sample size:** Thirty-three individuals were initially interviewed for the study; however, as there was only one female participant, she was excluded from the data analysis for statistical convenience and to maintain homogeneity. Therefore, the analysis was performed on 32 male participants, aged 18 years or older, who visited the clinic for post-treatment follow-up with their primary consultant. Data collection was continued until thematic saturation was reached, ensuring that no new information would be added by continuing to collect data.

**Measures:** The FACT-HN is a validated tool used to assess QoL and symptom severity in HNC [18]. It is available in multiple Indian languages. For the current study, translations in Gujarati, Hindi, and English were used based on patient preference. The FACT-HN (Version 4) consists of 39 items, with scores ranging from 0 to 4 on a Likert-type scale. It assesses 5 domains of QoL and has a maximum total summary score of 148, representing the best possible QoL.

The BIS by Hopwood is a 10-item scale that assesses concerns related to body image. This tool was previously validated only on breast cancer patients, but there are studies that have used it for head and neck cancer as well. It has been found to have satisfactory internal consistency and adequate correlation with other body image

scales [19]. As there were no available Indian language translations for the tool, each question was pretranslated into Hindi and Gujarati with the help of language specialists, and back translation was performed to ensure accuracy before administration. The maximum total score for the BIS is 30, indicating higher levels of body image concerns. All questionnaires were administered using the interview technique to accommodate the literacy and understanding levels of the patients under study and to address the limitations of the Likert scale in this context.

## Procedure

This study used mixed-method approach. Patients who had completed their outpatient consultation were approached by the doctor coordinators. Only those who provided consent were subsequently interviewed by a Psycho-Oncologist. Each interview lasted approximately one hour. Any significant distressing concerns raised by the patients were addressed and appropriate follow-ups were arranged as needed. However, the focus of the current study was to understand and analyse concerns in context of occupation and appearance, along with their impact on QoL in the context of HNC diagnosis and treatment.

## STATISTICAL ANALYSIS

The quantitative data collected for the study was manually transferred to an Excel spreadsheet (Microsoft, USA). Normality, descriptive statistics, confidence intervals, and t-tests were used for statistical analyses. Additionally, correlation, Mann-Whitney, and Kruskal-Wallis tests were applied using the SPSS version 23.0 software (IBM, Chicago, USA). Qualitative research encompasses various methods, and one conventional approach is narrative inquiry. Since narratives and thematic analysis provide valuable insights into understanding the topics beyond quantitative information, they were chosen for this study.

## RESULTS

The sample comprised 32 participants with an average age of 45.50 years [Table/Fig-1]. The mean total score on the FACT-HN for these 32 participants was 118.75, with a range of 90 (lowest) to 142 (highest). The maximum possible score was 148 [Table/Fig-2]. The maximum total scores for physical, social, emotional, and functional well-being are 28, 28, 20, and 28, respectively [Table/Fig-3]. Differences in mean scores were observed between the three groups. The group with a treatment completion period of 3-11 months had a mean score of 108.00, the group with 1-3 years had a higher mean of 116.38, and the group with three years or more had the maximum mean of 124.60. The overall mean score for all participants was 117.88 [Table/Fig-4].

Parameters	n (%)
Gender-Men	32 (100)
Age (years) Min-Max	30-63
<b>Education</b>	
Illiterate	2 (6.3)
Primary	6 (18.8)
High school	13 (40.6)
Undergraduate and above	11 (34.4)
<b>Marital status</b>	
Married	31 (96.9)
Separated	1 (3.1)
<b>Treatment modality</b>	
Chemotherapy	26 (81.3)
Radiation Therapy	23 (71.9)
Surgery	32 (100)

Type of work	
Job	6 (18.8)
Business	16 (50)
Self-employed	10 (31.3)
<b>Cancer recurrence</b>	<b>5 (15.6)</b>
Treatment completion period	
3-11 months	9 (28.1)
1-3 years	8 (25)
3 years and more	15 (46.9)

[Table/Fig-1]: Demographic and clinical characteristics of sample (n=32).

Questionnaire	Mean	Highest possible score	Range
FACT-HNC	118.75	148	90-142

[Table/Fig-2]: General QoL and functional status scores for post-treatment patients following major surgery.

Subscale	Mean±Std. Dev	Range
Physical well-being	25.91±2.08	20-28
Social well-being	21.38±4.36	9-28
Emotional well-being	22.16±2.73	13-20
Functional well-being	21.09±3.77	11-28

[Table/Fig-3]: FACT-HN subscale score.

Time	N	Mean±Std. Deviation	95% Confidence interval for mean		Minimum	Maximum
			Lower bound	Upper bound		
3-11 months	9	108.00±11.576	99.10	116.90	90	123
1-3 years	8	116.38±11.463	106.79	125.96	93	127
3 years and more	15	124.60±10.183	118.96	130.24	110	142
Total	32	117.88±12.722	113.29	122.46	90	142

[Table/Fig-4]: Comparison of means between treatment completion group.

The overall QoL for the HNC population appears to be above average (117.88±12.72). A similar trend was observed across all domains: physical, social, emotional, functional, and head and neck specific. Analysis of Variance was conducted for the three groups: '3-11 months', '1-3 years', and 'more than 3 years'. A significant difference in the mean HNC scores between these groups was observed, with a p-value of 0.004 [Table/Fig-5]. The Bonferroni correction was used to adjust for the increased chance of making a Type-I error when conducting multiple comparisons. The results indicate that a significant difference in the outcome variable was seen between the group that completed treatment within 3-12 months and the group with three years or more. However, no significant differences were observed between the other pairs of groups (p-value=0.05) [Table/Fig-6].

Time	Sum of squares	df	Mean square	F	Sig.
Between groups (3-11 months and 3 years and more)	1574.025	2	787.012	6.628	0.004
Within groups (3-11 months and 3 years and more)	3443.475	29	118.741		
Total	5017.500	31			

[Table/Fig-5]: One-way Analysis of Variance between treatment completion groups.

Significant differences in scores for physical well-being, social well-being, and the HNC-specific domains were found between the two groups (3-11 months and 3 years or more). However, no significant differences were observed in the emotional well-being and functional well-being domains between these two groups (p-value=0.05) [Table/Fig-7].

Treatment complete		Sig.
3-11 months	1-3 years	0.374
	3 years and more	0.003
1-3 years	3-11 months	0.374
	3 years and more	0.286
3 years and more	3-11 months	0.003
	1-3 years	0.286

[Table/Fig-6]: Post-hoc comparisons-Bonferroni.

Subscale	Chi-square	Asymp. Sig.
Physical well-being	11.322	0.003
Social well-being	6.202	0.045
Emotional well-being	5.319	0.070
Functional well-being	4.751	0.093
HNCS score	7.498	0.024

[Table/Fig-7]: QoL comparison of two groups (3-11 months and 3 years and more) using Kruskal Wallis test.

Approximately 40.63% of the participants were able to sustain their similar work and continue their usual routine as earlier. A 46.88% of participants opted for reduced work, which involved intermittent rest time or fewer hours. Around 9.37% of participants modified their previous work to a different form of work due to treatment-related changes. Only 3.12% of participants preferred to stop working and take premature retirement. This table offers a perceptive into the time duration it took for participants to return to their work circumstances after their cancer treatment [Table/Fig-8].

Work classification	n (%)
Same work- normal routine work as before	13 (40.63)
Reduced work- intermittent breaks, reduced work hours	15 (46.88)
Adapted work- switched to another form of work	3 (9.37)
Quit work- early retirement	1 (3.12)
Total	32 (100)

[Table/Fig-8]: Return to work post-cancer diagnosis.

The patient expressions in the table shed light on several significant concerns experienced by the participants during the post-treatment phase, in the context of various aspects of QoL such as physical, psychological, social, occupational, and spiritual well-being. The themes that emerged from the narratives include:

**Change of appearance:** Participants reported both visible and non visible changes resulting from their treatment. They mentioned changes in the shape of their mouth, jaw region, and significant weight loss, which led to an altered sense of appearance.

**Psychological functioning:** Participants expressed concern about how others perceived them due to changes in their appearance and speech, often associated with dryness of the mouth. These changes posed challenges to their identity and social roles, leading to a decreased sense of confidence, and feelings of depression and distress. They also reported issues with eating, such as drooling and chewing in public, which further exacerbated feelings of shame.

**Physical and daily functioning:** Some participants experienced limitations in their daily functioning due to low energy levels and postoperative discomfort. This made it challenging for them to engage in activities that required physical strength.

These themes highlight the multifaceted impact of head and neck cancer treatment on various aspects of the participants' lives, underscoring the need for comprehensive support and interventions to address their concerns and enhance their overall well-being.

**Social functioning and response from others:** Participants experienced feelings of awkwardness, embarrassment, isolation,

and frustration in social settings due to changes in speech and eating. These challenges led them to avoid social gatherings. Modifying speech and voice made effective communication difficult, causing others to avoid and stare at them.

**Occupational functioning:** Changes in appearance, speech, and voice affected interactions in the workplace. Some customers were unable to recognise them based on their faces. Participants adapted their work to less physically demanding tasks.

**Impact on intimate relationship:** Participants reported concerns about their ability to engage in sexual activity due to reduced energy and confidence. In some cases, participants or their partners maintained distance due to a belief that cancer was contagious. Participants felt hesitant to approach their spouse to discuss these concerns. Rejection, stigma, and difficulties in engaging in sexual activity impacted their QoL [Table/Fig-9].

These responses reflect the various constructs of BIS, including affective, cognitive, and behavioral aspects, in relation to cancer treatment. They highlight the psychological distress individuals experience as a consequence of changes in appearance [Table/Fig-10].

## DISCUSSION

In a recent study, it was found that overall QoL significantly decreases during Radiation Therapy (RT). There was a significant improvement in QoL from the completion of RT to three months after RT; however, no major change in overall QoL was observed at three months compared to baseline scores [8]. Another study found that overall QoL improved more rapidly during the six months after completion of RT. QoL domains that had lower scores during treatment showed significant improvement from the end of RT to three months after

Topic	Key issues	Transcript
Appearance changes	Visible changes	"I compare with my previous appearance, now I do not get dressed like before."
		"My jaw area appears dented and mouth shape looks different."
		"There is significant weight loss it makes me look very different."
	Non visible changes	"After radiation therapy there are more changes in my appearance."
Psychological functioning	Identity – role threat	"It feels sad that I do not look like before, people do not even recognise me, despite me sitting in front of them they will come and ask me where is this person."
		"I am losing confidence in my body, I cannot do things as before."
	Shame	"When I eat in public, people must be getting disgusted of me, there is drooling, so I feel hesitant in public."
		"I do not want to meet and face people after changed appearance."
	Sadness, depression	"I feel depressed that I am unable to eat food of my choice."
		"I feel lonely, as wife keeps things separate and children away, as people say cancer is contagious. Despite of telling her that it is not she still does that."
	Feeling bad and ugly	"What must be my karma that I am going through this."
		"My life is only for four years now others will live longer than I will."
Physical and daily functioning	Low energy level	"It takes much time to be able to function normally again, I get tired easily."
		"Pulling sensation at the operated site makes me uncomfortable."
		"I cannot engage into physical activities like before, the ones which require more strength."
Social functioning	Eating (in public)	"It is embarrassing situation, food drips from the side of the mouth."
		"I avoid social gatherings due to problems with eating and drinking."
		"Difficulties with social activities due to problematic combination eating and talking."
		"It takes longer to eat, I cannot eat spicy or oily food like before. So I carry my food from home."
	Talking (in public)	"Talking is uncomfortable due to change in voice."
		"I get frustrated when others cannot understand the pronunciations."
		"I have to be accompanied by a close family member outsiders cannot understand what I say."
		"I prefer wife attending social gathering, I avoid going unless necessary."
		"I sense that people avoid talking to me as well, they cannot understand my speech."
		"My voice becomes hoarse and there is dryness if I do not take water in between while talking."
	Reaction from others	"I know I am now being ignored because of cancer related changes, they judge, else earlier they will come and talk to me themselves."
		"Others do not know how to respond to my situation, so they avoid me."
		"I feel that people stare at me."
		"I do not eat or drink at others place as some think that cancer may be contagious."
	Going on holiday	"Earlier I had lot of command over people, now they look at me as a disabled."
Occupational functioning	Changes at work	"People are unable to recognise my face at work, I do not like going there anymore."
		"I do not engage in any strenuous work now. Used to do labour work, now whatever work is possible at home, I engage in that only."
		"Being a teacher, I have to deal with students, feels that they may get scared with change in appearance, hence use a cloth to cover mouth while teaching."
Functioning in intimate relationships	Rejection and stigma	"My lip area has undergone change, it looks slanted, I do not feel that attractive. Feel tired so it is difficult to engage in any sexual activity. I feel bad for my wife, she is younger than I am, she may have such desires, we haven't talked about it, but we cannot engage in it. Is it contagious? Can it have an impact on my wife?"
		"My wife does not come close to me after I got my surgery she thinks she may get cancer". "Others tell her to stay away, she doesn't listen to me."

[Table/Fig-9]: Patient narratives on the post-treatment changes.

S. No.	BIS item and response	0	1	2	3
1	Self-conscious about appearance	16	10	5	1
2	Felt less physically attractive	18	6	8	0
3	Dissatisfied with appearance when dressed	24	6	2	0
4	Felt less masculine	32	0	0	0
5	Found difficult to look at self-naked	32	0	0	0
6	Felt less sexually attractive	28	4	0	0
7	Avoided people	23	4	5	0
8	Felt that treatment has left body less whole	16	9	7	0
9	Dissatisfied with your body	16	8	8	0
10	Dissatisfied with the appearance of scar	22	7	3	0

**[Table/Fig-10]:** BIS response frequency for individual items.

treatment. However, there was no significant change in functional domain scores at three months compared to baseline scores [20]. Another study also pointed out that the mean score of the functional domain declined during treatment and then improved [20,21]. This could be attributed to the fact that in present study, 43% of patients returned to work within 3-4 months after completing their treatment. A decline in social functioning throughout the treatment period and no improvement in social function until 12 months after treatment has been observed [22]. However, according to Lohith G et al., [23], there seems to be an improvement in social functioning at one and three months after treatment.

Other studies that have compared the QoL of HNC patients with individuals who have not undergone such diagnosis and treatment have reported a worsened overall QoL for HNC patients. This is due to the impact of treatment, which can lead to various issues such as loss of appetite, difficulty with mouth opening, weight loss, chewing problems, the use of feeding tubes, reliance on dietary supplements, sticky saliva, frequent dryness of the mouth, swallowing difficulties, challenges with social eating, cognitive difficulties, issues with speech clarity and communication, and sexual concerns [23-25].

After completing treatment, the focus of HNC patients shifts from survival to living well and maintaining a good QoL. Dental restoration is believed to address some of these issues post-treatment; however, it often requires significant out-of-pocket expenditure, making access to such care difficult for many patients. As a result, patients' QoL is further compromised in this context, in addition to other challenges they may face [13,24].

Another objective of the study was to examine the impact of body image on return to work among HNC patients. In a recent study conducted in North India, which included 170 HNC patients of both genders, a significant relationship was found between body image and distress, as well as with the ability to return to work. The findings revealed that younger patients (<40 years) experienced higher body image issues, and 80% of the participants in the study were unemployed. The reasons cited for unemployment included quitting or changing jobs due to physical dysfunction, discomfort related to appearance, fatigue, symptom management, and the need for long-term cancer treatment [12]. These findings align with the qualitative remarks provided by participants in the current study.

Further analysis of the qualitative responses from the body image questionnaire revealed that certain items related to sexual impact due to body image issues were scored as zero by respondents, with no further qualitative explanations provided upon inquiry. In contrast, participants provided additional information for other items. It is important to consider cultural comfort in answering such questions, as discussions about sexuality may not be openly addressed in some developing nations. Therefore, patients may not have felt comfortable reporting their concerns about these specific items to the interviewer. Sexual concerns have been reported as unmet needs among patients globally [26].

The measure used to assess body image-related concerns holds significant importance in its ability to capture these overlooked aspects of a patient's life. The BIS has been widely used in studies involving cancer populations, including the current study. However, there is a need to use more sensitive measures that can effectively capture this important aspect. The paucity of concrete measures to assess body image concerns has been reported worldwide, and although various studies have utilised different measures, their validity for the Indian population may be questionable due to cultural sensitivity surrounding discussions about these issues.

### Limitation(s)

The study primarily focused on a small sample of male participants, which suggests the need for future studies to include a larger and more diverse sample size.

### CONCLUSION(S)

This data provides valuable insights into the impact of physical, social, and head and neck-specific QoL issues on patients, particularly during the immediate treatment completion phase, which can last up to three years for some patients. However, over time, the overall QoL of patients tends to improve post-treatment. Based on the emerging narratives from patients, it is important to recognise the need for sensitising healthcare providers and the general public to understand the emotions of cancer patients and dispel myths and misconceptions surrounding cancer. This can help prevent cancer-related stigma and enable survivors to live their post-treatment lives with greater confidence. These findings can also assist in setting realistic patient expectations regarding the recovery process, which may ultimately reduce frustration arising from unrealistic treatment expectations and enhance confidence in medical care.

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#### PLAGIARISM CHECKING METHODS: [Jan H et al.]

- Plagiarism X-checker: Jun 22, 2023
- Manual Googling: Oct 28, 2023
- iThenticate Software: Oct 31, 2023 (6%)

#### ETYMOLOGY: Author Origin

EMENDATIONS: 8

#### AUTHOR DECLARATION:

- Financial or Other Competing Interests: None
- Was Ethics Committee Approval obtained for this study? Yes
- Was informed consent obtained from the subjects involved in the study? Yes
- For any images presented appropriate consent has been obtained from the subjects. Yes

Date of Submission: Jun 21, 2023

Date of Peer Review: Aug 15, 2023

Date of Acceptance: Nov 02, 2023

Date of Publishing: Dec 01, 2023