Body Image Distress among Cancer Patients: Needs for Psychosocial Intervention Development

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Research Article

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Abstract

Objectives: This study examines the body image associated distress among patients with head and neck cancer visiting a tertiary care hospital for follow-ups.

Design: An exploratory, cross-sectional design enrolled 170 patients with head and neck cancer purposively undergone cancer surgery at a newly established tertiary care hospital, North India.

Methods: A structured pre-tested socio-demographic and clinical profile checklist and the Derriford Appearance Scale 24 (DAS-24) were used to collect information. An appropriate descriptive and inferential statistic was applied to compute the findings.

Results: The mean age of the participants was 47.98 (SD=12.1) years, and 80% of the participants were unemployed. The mean body image distress score was 57.95 (SD=10.3, 47-66.75, range 42-77). The body image distress found a significant association with age ($p<.001$), gender ($p=0.003$), and working status of the patients ($p=0.032$). Multilinear regression reported gender as an independent predictor (95% CI: 0.615 - 8.646, $p=0.025$) for body image distress in patients.

Conclusions: Patients with head and neck cancer have significant psychosocial distress due to changes in body appearance. Female patients who had undergone surgery at young age reported higher distress. We should include body image and rehabilitation in the daily care of patients. Recommending the use of cosmetic surgery on routine follow-ups is another strategy to improve facial appearance to overcome the negative impact of body image.

Introduction

Head and neck squamous cell carcinoma (HNC) is the sixth, most common cancer worldwide accounts 30-40% of all cancer sites in India [1, 2]. Mouth and tongue cancers are more common in India, with a higher incidence in the North-East region [1]. However, extensive use of tobacco, pan masala, and gutkha are common and may be linked to the higher incidence of HNC in the geographical area [3].

Patients with head and neck cancer undergo long, physically demanding, and multimodal treatment approaches, including surgery, radiotherapy, and chemotherapy or combination sometimes[1]. These treatment modalities sometimes result in significant alterations and debilitating changes in the body involving loss of a body part, disfigurement, scars development, and skin changes, leading to overall disturbed body image [4]. Unlike other forms of cancer, the disfigurement after surgical excision for head and neck cancer cannot be hidden and can enormously influence the individual's identity [5, 6]. These surgical treatment modalities may spoil the appearance of completeness of an individual and leads to psychological distress among patients [6]. Likewise, radiotherapy may cause fibrosis, swelling, and changes in skin pigmentation and may disturb normal skin integrity and tone [7].

Furthermore, a person's identity is an intricate construction that extends beyond their physical appearance. Body image is a similar yet multifaceted concept involving perceptions, thoughts, feelings, and behaviors towards his body and its different domains [7]. Body image is a subjective perception of one's physical outlook perceived by both selves and by sensing the viewpoint of others[8].

Body image in a patient with head and neck cancer refers to an individual's identity as a by-product of their social and psychological experiences shaped by their impressions and sense of the bodily appearance every day [9]. The evidence suggested that 75% of patients face innumerable problems related to acknowledgment and embarrassment about unwanted physical changes and body image concerns which further evoke painful experiences and constantly remind of body disfigurement [10]. Furthermore, body image-induced stress is common in patients with HNC, with prevalence rates ranging from 25–77% [11]. However, the prevalence of body image distress found varies in different types of oral and oropharyngeal cancer [12]. Further, these psychosocial issues may be linked with relationship conflict, social isolation, damage to self-image, disfigurement, stress, and moderate levels of anxiety and depression experienced by an individual[12, 13].

The first aim of the present investigation is to study the body image-related distress among patients with head and neck cancer and whether socio-demographic and clinical factors are associated with body image distress. The present study's findings will develop more insight into other body image or identity-associated issues, facilitating emotional needs targeting HNC patients with distress.

Material And Methods

An exploratory, cross-sectional survey research design was used to body image distress among patients who underwent head and neck cancer surgery. Patients with head and neck cancer surgery with six weeks of follow-up were purposively recruited in the study. A sample size considering 75% expected prevalence and 5% margin of error was used to calculate the survey and came out to be 288. However, the study sample size was limited to 170, considering restriction and decreased patients' load during the COVID-19 pandemic. The data collection was completed between Dec 18, 2020, to Jan 18, 2021. Patients equal to or more than 18 to 65 years of age and converse in Hindi and English languages are included in the study. Patients with other types of malignancies and unwilling to write consent were excluded from the study.

Self-reported Questionnaires

The data collection tools consisted of a clinical and socio-demographic sheet, and Derriford Appearance Scale (DSA-24) is used to measure body image-related distress among patients with head and neck cancer.

Socio-demographic and clinical profile sheet consists of information on age, gender, religion, working status, marital status, family type, education, residential area, and monthly income. Further, a brief clinical profile was obtained using a pre-tested clinical profile sheet consist information on the duration of cancer,

tumor site, tumor site, types of surgery and treatment, comorbidities, and history and duration of alcohol and tobacco use.

The Derriford Appearance Scale 24 (DAS-24)[14] is a 24 items psychometric scale designed to measure adjustment to problems of visible difference and disfigurement in the body after undergoing different types of surgery in cancer patients. Participants were asked to respond to the scale using a 5-point rating scale; 'almost always (4)' to 'never/almost never (0)'. Some of the items in the scale are rated on 'extremely (4)' to 'not at all (0)'. The scale has a total score of 11-96 (min.-max.). The scale is continuous, and getting a high score indicates more psychological distress due to poor or dissatisfaction with body image. The tool reliability is calculated using the split-half test and reported 0.82 ($r = 0.82$) for the present study. The scale's internal consistency was tested using Cronbach alpha and reported 0.86 ($\alpha = 0.86$). The scale was translated into Hindi, and back translation was used to measure the scale's consistency. The scale is validated and pre-tested before using it for final use.

Ethical Considerations

The study was approved by the Institutional Ethics Committee (ICE, 43/IEC/M.Sc./2020). However, written informed consent was obtained from each patient after giving a due explanation of the purpose of the study. Participants were ensured for privacy and confidentiality at each point of data collection and during publication.

Statistical Analyses

Descriptive statistics are used to analyze the frequency, percentages, and other relevant statistics for socio-demographic and clinical profiles. Independent sample t-test and one-way ANOVA were applied to find the association of socio-demographic variables with body image-related distress among patients. Odds ratio (ORs) with 95% confidence interval (CI) were used to quantify the strength of association between socio-demographic characteristics and body image concerns of patients. Data analysis was completed in SPSS Window, Version 23.0 Armonk, NY: IBM Corp. The level of significance was set at $P < 0.05$ (two-sided).

Results

Descriptive analysis and preliminary analyses

Table 1 describes the demographic characteristics of the patients. The mean age of the patients was 47.98 (12.1) years. Around an equal number of patients were in a category of 41-50 years (26.46%) and 51-60 years (27.06%). One-third of the patients were male (72.35%) and belonged to the Hindu religion (81.18%). More than two-thirds of the patients were not working (80%) and were married (88.24%). More

than half of patients (52.36%) belonged to urban areas, completed secondary education (54.12%), and had monthly family income of 10,002-29,972 rupees (82.95%).

Table 2 present the clinical profile of the patients. More than half (58.24%) of the patients have oral cancer, followed by nasopharynx (14.11%) and nasal cavity (13.53%) with a mean duration of 11.55 (SD:6.91) years of cancer. More patients (38.24%) undergoing a combination of treatment including radiotherapy, surgery, and chemotherapy (38.24%) and underwent mouth angle scarified surgery (27.06%) and glossectomy (21.76%). Approximately half of the patients have one or another comorbidity, including hypertension and diabetes along with cancer. More patients report alcohol use (42.94%) than tobacco (20%), with a mean duration of 13.43(SD:6.56) years and 12.82 (SD:5.06) years, respectively.

Further, body image associated distress was found significantly higher in females ($p=0.003$) and younger patients ($p<.001$) visiting the outpatient department for follow-ups. Additionally, this distress was reported higher in patients staying at home or not working ($p=0.032$) Table 1.

Table 1
Socio-demographic variables and body image distress in cancer patients
(n=170)

Socio-demographic variable	f (%)	Mean±SD	p-value
Age (years, Mean±SD)	47.98 ±12.1		
≤40	51(7.05)	67.81±5.63	<.001
41-50	45(26.46)	56.69±8.59	
51-60	46(27.06)	47.83±5.51	
>60	28(16.48)	59.82±9.80	
Gender			
Female	47(27.65)	62.49±9.76	0.003*
Male	123(72.35)	56.22±10.02	
Religion			
Hindu	138(81.18)	57.98±10.62	0.956
Others#	32(18.82)	57.64±9.03	
Working status			
Not working	136(80.00)	61.32±10.07	0.032*
Working	34(20.00)	57.11±10.08	
Marital status			
Married	150(88.24)	57.91±10.31	0.887
Unmarried/widow	20(11.76)	58.10±10.83	
Family type			
Joint family	72(42.35)	57.62±10.27	0.627
Nuclear family	98(57.65)	58.4 ±10.44	
Education			
Up to Primary	48(28.23)	58.05±9.76	0.932
Secondary	92(54.12)	57.62±10.24	
Graduate and above	30(17.65)	59.03±11.37	
Residential area			
Rural	26(15.29)	55.42±9.53	0.942

Socio-demographic variable	f (%)	Mean±SD	p-value
Semiurban	55(32.35)	58.51±10.04	0.089
Urban	89(52.36)	58.31±10.71	
Monthly Income#			
≤10,001	09(05.29)	54.78±10.77	0.089
10,002-29,972	141(82.95)	57.52±10.35	
29,973-49,961	20(11.76)	62.41±9.05	

#-Classification based on Kupuswami scale updated in 2020; #- Muslim & Sikh; * p-value<0.05

Table 2
Clinical profile of cancer patients (n=170)

Clinical Profile	f (%)
Tumor Site	
Nasal cavity	23(13.53)
Nasopharynx	24(14.11)
Oral cavity	99(58.24)
Hypopharynx	07(04.12)
Others*	17(10.00)
Duration of Cancer (Yrs, Mean±SD)	11.55±6.91
Type of treatment	
Surgery + Chemotherapy	26(15.29)
Surgery + Chemotherapy + Radiotherapy	65(38.24)
Surgery + Radiotherapy	46(27.06)
Surgery only	33(19.41)
Type of Surgery	
Facial skin- sacrificed	30(17.65)
Mouth angle-sacrificed	46(27.06)
Glossectomy	37(21.76)
Inferior maxillectomy	01(00.59)
Other types	56(32.94)
Comorbidity (Yes)	76 (44.70)
Type of Comorbidity	
Diabetes mellitus	03(3.89)
Diabetes mellitus & hypertension	36(46.75)
Hypertension	37(49.35)
History of alcohol consumption (Yes)	73(42.94)
Alcohol consumption duration (Yrs, Mean±SD, n=73)	13.43 ± 6.56
≤10	23(31.52)

Clinical Profile	f (%)
11-15	42(68.48)
History of tobacco consumption (Yes)	34(20.00)
Tobacco consumption duration (Yrs, Mean $\pm$ SD, n=34)	12.82 $\pm$ 5.06
≤ 10	13(38.23)
≥ 11	21(61.75)

*** Paranasal cavity, larynx, salivary glands**

Table 3
Response to the Derriford (DAS 24) Questionnaire

Derriford Appearance Scale (DAS-24) items	Significant problem on DAS-24	Significant problem on DAS-24	
		F	%
How confident do you feel	Not at all/slightly	41	24.0
How distressed do you get when you see yourself in the mirror/ window	Extremely/moderately	139	81.3
My self-consciousness makes me feel irritable at home	Almost always/often	164	95.6
How hurt do you feel	Extremely/moderately	102	59.7
At present, my self-consciousness has an adverse effect on my work	Almost always/often	168	98.3
How distressed do you get when you go to the beach	Extremely/moderately	117	68.4
Other people misjudge me because of my feature	Almost always/often	132	77.2
How feminine/masculine do you feel	Not at all/slightly	166	99.4
I am self-conscious of my feature	Almost always/often	169	98.6
How irritable do you feel	Extremely/moderately	72	42.1
I adopt certain gestures (e.g., folding my arms in front of other people, covering my mouth with my hand)	Almost always/often	138	80.7
I avoid communal changing rooms	Almost always/often	144	82.5
How distressed do you get by shopping in department stores/ supermarkets	Extremely/moderately	153	89.5
How rejected do you feel	Extremely/moderately	22	12.9
I avoid undressing in front of my partner	Almost always/often	26	15.2
How distressed do you get while playing sports/games	Extremely/moderately	00	0.00
I close into my shell	Almost always/often	10	5.8
How distressed are you by being unable to wear your favorite clothes	Extremely/moderately	102	5.8
How distressed do you get when going to social events	Extremely/a fair amount	127	59.7
How normal do you feel	Extremely/moderately	127	74.3
At present, my self-consciousness has an adverse effect on my sex life	Almost always/often	63	36.8

Derriford Appearance Scale (DAS-24) items	Significant problem on DAS-24	Significant problem on DAS-24	
		F	%
I avoid going out of the house	Almost always/often	128	74.0
How distressed do you get when other people make remarks about your feature	Extremely/a fair amount	101	59.1
I avoid going into pubs/restaurants	Almost always/often	96	56.2

Significant problems measured by DAS-24

Significant problems are measured by the DAS-24 are summarized in Table 3. We have considered the significant issues reported as worst outcomes (e.g., extremely/moderately, almost always or often). 98.9% of patients were self-conscious about their features and believed (98.3%) that surgical treatment had an adverse effect on work. Similarly, 95.9% of patients responded that self-consciousness makes them irritable at home and (81.3%) distressed while watching a mirror or window. A more than two-thirds of patients (80.7%) express folding arms and covering their face while facing other people. Likewise, 82.5% said to avoid using communal changing rooms and avoid going (89.5%) shopping at departmental stores and supermarkets. An equal number of patients (74.3%) refused to attend a social event and reported adverse effects on sexual life (74.8%) after surgical excision.

Table 4
Body Image distress and selective socio-demographic variables of patients. (n=170)

Item	Age/gender/ working status	Mean±SD	p- value
Feeling distressed while shopping in department stores/supermarkets.	≤40 years	3.43±0.57	0.035*
	41-50 years	3.20±0.55	
	51-60 years	3.07±0.74	
	>60 years	3.29±0.60	
Feeling of rejection	≤40 years	2.00±0.63	0.016*
	41-50 years	1.96±0.42	
	51-60 years	2.37±0.90	
	>60 years	2.00±0.72	
Feeling distressed while playing sports/games	≤40 years	0.80±0.83	0.006*
	41-50 years	1.29±0.82	
	51-60 years	0.78±0.84	
	>60 years	0.71±0.81	
Avoiding communal changing rooms	Female	2.91±0.69	0.025*
	Male	3.17±0.65	
Avoid going to pubs/restaurants	Female	3.13±0.99	0.028*
	Male	2.76±0.97	
I feel close into my shell	Female	1.51±0.55	0.025*
	Male	1.28±0.59	
I feel close into my shell	Not working	1.31±0.60	0.048*
	Working	1.53±0.51	
*- <i>p-value significant <0.05</i>			

Further, findings reported that patients aged less than 40 years were feeling more distressed while going shopping in departmental stores/supermarkets than their counterparts (p=0.035). In contrast, feelings of rejection were significantly higher in patients 51-50 years of age than older and younger patients (p=0.016). However, the feelings of distress were significantly higher in the patients who belonged to the 41-50 years of age category in contrast to the younger cohort (p=0.006). Findings reported that females were significantly more concerned with body image issues after surgical excision Table 4.

Table 5
Multilinear regression to identify predictors of body image distress (n=170)

Variable	B	SE	β	t-value	p-value	95% CI
Constant	58.295	3.074		18.962	0.000	52.040-64.550
Age	0.437	0.754	.093	.579	0.566	-1.098-1.971
Gender	4.630	1.974	0.393	2.346	0.025*	0.615-8.646
Working status	-3.044	2.073	-.248	-1.469	0.151	-7.260-1.173
<i>Model fit calculated from valid cases F (2.205), p=0.106, Adjusted R²= 0.091; SE- Standard error; CI- Confidence interval; *-p value<0.05</i>						

Further, multilinear regression was applied to quantify the strength of association of variables that shows significant association with DAS-24. Findings represent that gender as female has a significant impact (p=0.025) on body image distress among head and neck cancer patients. The model explained 91% of (Nagelkerke R²) variance on the body image concern.

Discussion

The present study was conducted to identify body image distress among patients with head and neck cancer attending follow-up services at a newly established tertiary care hospital, North India. The mean age of patients was 47.98 (± 12.1) years, with a higher proportion of male patients than female patients. These demographics were found in concurrence with the previous epidemiological study, which reported higher head and neck cancer incidence in the age group of 40-60 years and sixteen times higher in the male population conducted in Western Uttar Pradesh[15]. Likewise, these demographic trends were found similar in other work conducted in southern states of India [16]. Demographics trends further supported with other relevant literature emphasizing 2-4 times higher risk of head and neck cancer in men than women [17].

In clinical profile, oral cancer reported more frequent cancer in the head and neck with a mean duration of 11.55 (± 6.91) years. Further, a greater number of patients were undergoing a combination of treatment, including chemotherapy, radiation, and surgery. These demographics are in line with the study from India reported 40% of oral cancer, where cancer of the tongue and mouth contributed more than one-third of total cancer [18]. However, a decline in trends for oral cancer was observed in men above 40 years of age during 1986-2000, but this trend remains unchanged in adult men below the age of 40 [19]. The possible reason for the sudden decline of oral cancer in a group may be postulated with the declining use of tobacco. However, a very higher incidence of cancer indicates continued use of tobacco and alcohol in the population. Excessive alcohol use (42.9%) and tobacco use (20%) were observed in the current cohort, higher in female patients. Besides tobacco use, the harmful effects of alcohol and other paan products are clear risk factors for oral cancer in India and elsewhere [20, 21]. Further, it has been attributed that regular alcohol use increases the risk of oral cancer [18]. Likewise, smoking and alcohol use further intensify the incidence of oral cancer compared to alcohol use only [22, 23].

Further, the mean scores of body image distress were 57.95 ± 10.3 , ranging from 42-77, suggesting higher distress among head and neck cancer patients. The higher distress in patients shall be correlated with dissatisfaction with personal appearance or disfigurement after surgery [24]. A similar result was found in earlier work on a head and neck cancer patient [25]. Likewise, other concerns noticed among surgically treated head and neck cancer patients were negative body image and overall poor quality of life [12, 25]. The incidence of negative self-evaluation about the health dimension of body image, appearance, and not being attractive or embarrassed about bodily changes is very well documented in cancer patients [26]. In a qualitative investigation, disfigurement reported a constant reminder for ruptured self-image and other dysfunctions in cancer patients [27]. However, the prevalence of body image distress varies, which ranges 25-77%, higher in newly diagnosed younger patients [10].

Age, gender, and working status of patients with head and neck cancer reported a significant association with body image associated distress. Findings said that younger patients (<40 years) felt more distress while shopping in a departmental store. Conversely, the adult cohort reported a feeling of rejection and distress while playing sport. These findings on distress are consistent with the work conducted at Netherland said higher distress among younger age cohort while having social interactions [6]. Likewise, male patients were more embarrassed while using communal changing rooms, and refraining from visiting restaurants and public places is more frequently observed in the female cohort. A qualitative investigation reported that patients with this kind of cancer face more problems while eating in public places or restaurants while holding the fluid in their mouth, starring people, and prosthesis-related issues that further potentiate frustration and embarrassment [28].

Body image distress is more common in young patients with cancer considering being more apprehensive and feeling isolated and rejected [26]. Patients expressed negative body image experiences related to the asymmetric appearance of the face and created an older look. However, it has been reported by the patients that it will take a longer time for them to restore normalcy in working, living, or sports [27]. Saying that anxiety before joining the work after facial surgery and different attitude of supervisors or colleagues after surgery may potentiate to quit a job [9]. Further, disfigurement associated with poor self-esteem and higher body image-related distress may also impede the normal grieving process and may take a longer time for patients to restore everyday living [29].

Females cancer cohort reported higher body image-related distress than male counterparts. Facial disfigurement has a higher negative impact on female patients than male patients and may have a negative effect on body image [30]. In general, women are more sensitive about their appearance and appreciate and associate beauty as their emotional strength [28, 31], This could be a probable reason for higher body identity-related stress in the female cohort, similar to earlier findings on a female with head and neck cancer.

However, the study should be appraised under many limitations. First, a one-time cross-sectional survey may not attribute cause and effect relationships. Secondly, the response to body identity associated self-distress was self-reported and hence may carry subjective reporting bias and should be extrapolated

carefully. Third, the study was conducted in a single center; even though one of the largest institutes in the regions consequently, the findings' generalizability might be limited to the area only. Finally, the phenomenological approach would best explore the cause of body identity-associated distress in a real-time scenario in the study cohort.

Conclusions

The body identity associated stress was predominately observed in young female and working patients with head and neck cancer. For clinical practice, it is necessary to identify the patients with higher body image distress when visiting the clinic. Evidence on effective supportive care targeting body image distress in head and neck cancer patients is scarce, indicating more research.

Declarations

- **Funding:** No funding source to declare
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- **Authors' contribution:** Included in Title page
- **Ethics approval:** Ethical approval obtained, Letter No mentioned under heading 'Ethical Considerations'
- **Consent to participate:** Informed Written Consent obtained from each subject
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