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A Cross-Sectional Study On Impact Of Shame and Stigma in Post Operative Head and Neck Cancer Survivors

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Abstract

Background: *Management of Head and neck cancers (HNCs) often require extensive surgical resection and reconstructions that can lead to disfigurement, difficulties with speech and swallowing and various functional impairments, which can have lasting psychosocial effects. Survivors frequently report feelings of shame and stigma, especially in rural areas where cultural attitudes may heighten psychological distress. Even though there have been improvement in clinical outcomes, the emotional and social aspects of survivorship are still not fully addressed.*

Objectives: *To assess the impact of shame and stigma on emotional and social well being in long term head and neck cancer survivors following major resection, reconstruction and adjuvant treatment using the Shame and Stigma Scale (SSS).*

Methods: *We conducted a cross-sectional descriptive study involving 113 HNC survivors after a minimum of 12 months after completion of treatment in tertiary care area. Participants filled out validated version of the 20-item Shame and Stigma Scale translated in local language. We analyzed the data using SPSS version 25 to understand the distribution of stigma levels and the contributions from different domains.*

Results: *Most participants (60.2%) reported experiencing moderate levels of stigma, while 21.2% indicated high levels. The changes in appearance and aesthetics were the biggest contributors (40.5%) to the overall stigma score, followed by feelings related to stigma, regret, and issues with speech, difficulty in swallowing, dribbling of saliva, dependency on tracheostomy tube. These findings underscore the persistent psychosocial challenges that survivors face even a year after their treatment.*

Conclusion: *There is a significant burden of shame and stigma among long-term HNC survivors, highlighting the need for psychological support to be integrated into routine survivorship care, particularly in culturally sensitive rural environments.*

Keywords: *Head and neck cancer, stigma, shame, psychosocial impact, rural health, resection and reconstruction, adjuvant treatment*

INTRODUCTION

Head and neck cancers (HNCs) are a major global health issue and often require extensive surgical procedures. While these surgeries can be life-saving, they can also lead to significant physical changes, including facial disfigurement, difficulties with speech and swallowing, dribbling of saliva, long term dependency on tracheostomy tube and various functional limitations [1]. Though advancements in cancer treatment have improved survival rates, the psychological effects of these treatments—especially feelings of shame and stigma—are still not fully addressed by present treatment protocols[2].

Patients recovering from HNC surgery frequently deal with both internalized and societal stigma, which often arises from changes in their aesthetic appearance and challenges in communication [3]. These psychological hurdles can result in emotional distress, social isolation, lower self-esteem, and a diminished quality of life. Additionally, stigma has been linked to a lack of adherence to crucial follow-up care and rehabilitation, which can jeopardize long-term health outcomes and survival rates [4,5].

Current research falls short in providing a thorough quantitative assessment of how stigma affects quality of life and self-confidence, especially in rural and culturally sensitive developing country[6]. In developing countries, where there is a heightened sensitivity to physical appearance and social norms, the stigma surrounding HNC may have an even greater impact on survivors. Most existing studies tend to focus on Western populations, failing to capture these regional and cultural differences [7].

This study aims to address these gaps by utilizing the Shame and Stigma Scale (SSS) to evaluate the prevalence and intensity of stigma among postoperative HNC patients in a rural setting in developing country [8]. It also seeks to investigate how shame and stigma might influence treatment compliance and long-term survival, underscoring the critical need to incorporate psychosocial support into cancer care strategies.

OBJECTIVES

To assess the impact of shame and stigma on emotional and social well being in long term head and neck cancer survivors following major resection, reconstruction and adjuvant treatment using the Shame and Stigma Scale (SSS).

METHODOLOGY

Study Design

The study utilized a cross-sectional descriptive design to delve into the feelings of shame and stigma faced by long-term survivors of head and neck cancer in a rural area during their recovery phase. This approach allowed researchers to evaluate both psychological and social aspects at a specific moment in time, using a standardized and validated tool tailored for the local community.

Study Setting and Duration

The research was conducted in the outpatient departments of ENT, Head and Neck Surgery, and Radiation Oncology at a rural tertiary care center. Data was gathered over a two-month span, from April2025 to May 2025.

Ethical Considerations

The study protocol received approval from the Institutional Ethics Committee(approval number SDUAHER/R&D/CEC/SDUMC-PG/78/NF/-2025-26) prior to data collection. Written informed consent was taken from all participants and confidentiality was strictly upheld throughout the research process with all data stored securely.

Participants

The study focused on long-term survivors of head and neck cancer who had under gone major resection, reconstruction followed by adjuvant treatment least 12 months before the study began. Eligible participants were 18 years or older, could understand the local language, and were willing to take part voluntarily. Those with preexisting psychiatric conditions, cognitive impairments, or serious health issues that might have affect their ability to respond accurately were excluded.

Instrument for Data Collection

When it comes to gathering data, we relied on the Shame and Stigma Scale (SSS), which was first created by Kissane and colleagues in 2013. For our study, a group of experts took the time to translate and culturally adapt the scale into local language. The SSS consists of 20 items that aim to capture different dimensions of shame and stigma experienced by cancer survivors, including feelings of internalized shame, perceived stigma, social rejection, and concerns about body image.

Sample Size Determination

To determine our sample size, we used the following formula:

$n = (Z^2 \times \sigma^2) / d^2$,

where Z is 1.96 for a 95% confidence level, σ is 16.22 (the standard deviation), and d is 3 (the margin of error). With these figures, we calculated that we needed 113 participants.

Data Collection and Analysis

For data collection and analysis, participants filled out the translated Shame and Stigma Scale during their regular follow-up visits. We gathered their responses and organized them in Microsoft Excel Sheet using SPSS version 25. Continuous variables were summarized using mean, standard deviation, median (Q1–Q3), as well as minimum and maximum values. Meanwhile, categorical variables were presented in terms of frequencies and percentages, giving us a well-rounded view of the response distribution and demographic details.

RESULT

In this study, we enrolled 113 long-term survivors of head and neck cancer who had undergone surgery. These participants filled out the validated Kannada version of the Shame and Stigma Scale (SSS), which evaluates various aspects of the psychosocial challenges they faced after treatment. We analyzed the data to uncover how common and intense feelings of shame and stigma were in four main areas: changes in appearance, feelings of stigma, feelings of regret, and difficulties with speech.

Demographic and Clinical Characteristics

Table 1 provides a summary of the demographic details of the participants.The mean age was 54.2 years old (±10.6), with a notable majority being male (68.1%). Most of the participants hailed from rural regions, and a significant number had received both surgery and radiation therapy. The time since they completed their treatment varied between 12 to 36 months.

Table 1: Demographic and Clinical Characteristics of Study Participants (N = 113)

Variable	**Frequency (%) / Mean ± SD**
Age (years)	54.2 ± 10.6
Gender	
- Male	77 (68.1%)
- Female	36 (31.9%)
Education Level	
- No formal education	31 (27.4%)
- Primary education	44 (38.9%)
- Secondary and above	38 (33.6%)
Type of Treatment	
- Surgery only	28 (24.8%)
- Surgery + Radiation	54 (47.8%)
- Surgery + Radiation + Chemo	31 (27.4%)
Time Since Treatment (months)	18.7 ± 6.4

Shame and Stigma Scale Scores

The overall SSS scores ranged from 12 to 76, with a mean score of 41.5 (±14.8), indicating a moderate level of perceived shame and stigma among the participants. Domain-wise analysis revealed that appearance-related changes contributed the most to the overall stigma, followed by speech-related impairment.

Table 2: Domain-wise Mean Scores of Shame and Stigma Scale

Domain	**Item Numbers**	**Mean Score ± SD**	**Score Range**
Appearance-related Changes	1–8	16.8 ± 5.9	4–32
Stigma Feelings	9–13	10.2 ± 3.8	1–20
Regret Feelings	14–17	7.4 ± 3.2	0–16
Impaired Speech	18–20	7.1 ± 2.9	0–12
Total SSS Score	1–20	41.5 ± 14.8	12–76

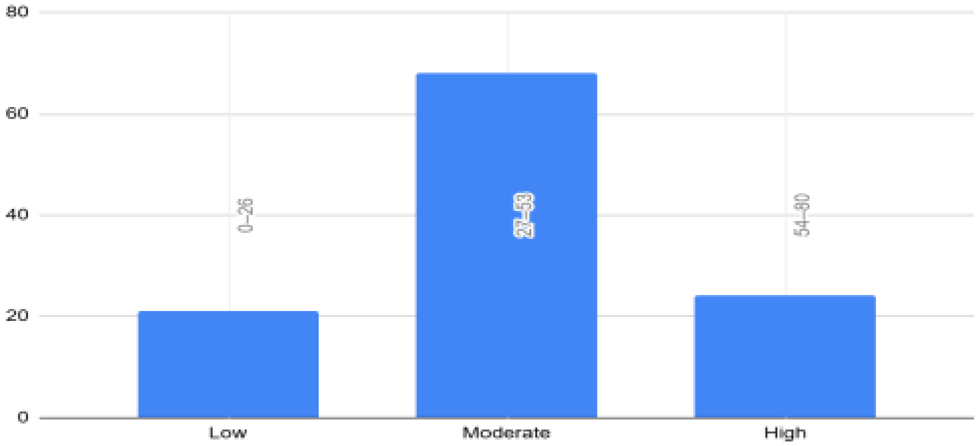

Figure 1: Distribution of Total Shame and Stigma Scale Scores Among Participants

Figure 1 depicts the frequency distribution of total SSS scores categorized into low (0–26), moderate (27–53), and high (54–80) levels of stigma perception. The majority of participants scored within the moderate range.

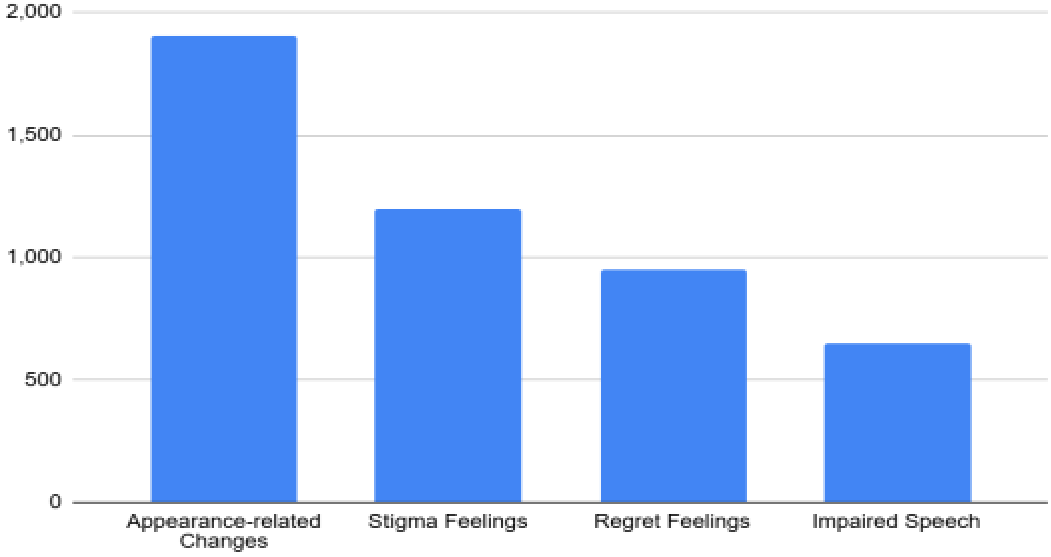

Figure 2: Domain-wise Contribution to Overall Shame and Stigma Score

Figure 2 represents the proportionate contribution of each domain (appearance-related changes, stigma feelings, regret feelings, and impaired speech) to the overall stigma score. Appearance-related changes were the predominant *contributor, accounting for approximately 40% of the total score.*

The analysis demonstrates that a significant portion of long-term HNC survivors in the rural setting continue to face psychosocial challenges, particularly related to physical appearance and communication difficulties. These findings underscore the need for holistic post-treatment care that includes psychosocial support alongside medical follow-up.

DISCUSSION

This study shines a light on the significant feelings of shame and stigma experienced by long-term survivors of head and neck cancer (HNC) in a rural area of India. By using the culturally adaptedlocal language version of the Shame and Stigma Scale (SSS), we gained valuable insights into the psychological effects following surgical treatment, especially regarding concerns about appearance and speech difficulties. Most participants reported moderate levels of perceived stigma, with changes in appearance being the biggest factor. This findings were similar to Pirola et al. (2017), who found that disfigurement and changes in appearance after HNC treatment were key triggers for stigma among Brazilian patients using the adapted SSS, highlighting the universal importance of appearance in feelings of shame and social withdrawal [9].

Our findings also back up previous research showing that stigma isn't just an emotional weight; it can also hinder treatment adherence and social reintegration. As pointed out by Nigro et al. (2017), in a multidisciplinary care approach, addressing the psychosocial aspects is just as vital as treating the cancer itself to enhance long-term outcomes [10]. This study emphasizes the necessity of integrating psychological support services into regular follow-up care, particularly in resource-limited rural areas where stigma may be intensified by cultural norms and a lack of mental health resources.

The global impact and outlook of HNC, as discussed by Sankaranarayanan et al. (1998), reveal differences based on location and access to healthcare. This research contributes to that conversation by offering region-specific data and highlighting that survivors in low-resource settings encounter distinct psychosocial challenges that can influence their recovery and overall quality of life [11].

While this study didn’t specifically measure anxiety or depression, it’s clear that there’s a strong link between stigma and emotional distress, which has been well-established in previous research. Tools like the Hospital Anxiety and Depression Scale (HADS) and the EORTC QLQ-C30 have shown that patients who perceive higher levels of stigma are more likely to suffer from psychological issues (Bjelland et al., 2002; Aaronson et al., 1993) [12,13]. Moreover, qualitative studies, such as the one by Chapple et al. (2004), have highlighted that cancer patients often internalize feelings of blame and shame, leading them to hide their struggles and isolate themselves socially. This pattern was also evident in our findings, where participants mentioned avoiding social situations and feeling a sense of responsibility for their illness [14].

Longitudinal research by Rapoport et al. (1993) showed that psychosocial distress in head and neck cancer (HNC) survivors can live longer after treatment has ended, underscoring the importance of ongoing psychological evaluation and support [15]. Our cross-sectional data backs this up, revealing that even a year after treatment, many survivors still grapple with significant emotional distress linked to feelings of shame and stigma.

In summary, this study highlights the critical need to incorporate stigma-reduction strategies into survivorship care, especially in culturally sensitive and resource-limited environments. Future research should aim to develop longitudinal assessment and intervention models that specifically address the emotional and social hurdles faced by HNC survivors.

CONCLUSION

This study following major resection, reconstruction and adjuvant treatment in long term head and neck cancer survivors had substantial impact on their social interactions there by affecting psychological well being and resulted in low esteem. It was moderate in 60.2% of the survivors and high in 21.2% of survivors using Shame and Stigma Scale which significantly affected their lifestyle and social interaction and led to depression. Tackling stigma through early psychological help and community awareness could be key to enhancing the overall well-being and long-term recovery of patients who have undergone surgery for head and neck cancer.

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