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Attributes of Psychosocial Distress from the Perspectives of Head-and-Neck Cancer Patients – A Thematic Analysis

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ABSTRACT

Objectives: Patients diagnosed with head-and-neck cancer (HNC) face unique challenges in comparison to other types of cancers. Sources of psychosocial distress (PSD) are multifactorial and recognising the key attributes would facilitate better understanding of the experienced distress, potentially enabling directed intervention strategies. The present research was conducted to explore the key attributes of PSD from HNC patients' perspective to develop a tool.

Material and Methods: The study adopted a qualitative approach. The data were collected from nine HNC patients receiving radiotherapy through focus group discussion. Data were transcribed, read and reread through for searching the meanings and patterns, to familiarise with the data and obtain ideas on experiences related to PSD. Similar experiences identified across the dataset were sorted and then collated into themes. Detailed analysis of themes and related quotes of the participants are reported with each theme.

Results: The codes generated from the study are grouped under four major themes; '*Irksome symptoms are distressing*', '*Distressing physical disability inflicted by the situation*', '*Social Curiosity – a distressing element*' and '*Distressing uncertainty of future*'. The attributes of PSD and the magnitude of psychosocial problems were reflected in the findings.

Conclusion: Psychosocial health of HNC patients is greatly impacted due to disease and/or treatment. Dynamic patterns of attributes identified from the study contributed to developing a tool on PSD. The findings of this study also necessitate the need for constructing an intervention for reducing PSD based on the attributes from the HNC patient's perspective.

Keywords: Head-and-neck cancer, Psychosocial distress, Thematic analysis, Radiotherapy

INTRODUCTION

Annually, worldwide head-and-neck cancer (HNC) accounts for more than 650,000 cases and 330,000 deaths.^[1] In developing countries including India, Bangladesh, Taiwan, Pakistan and Sri Lanka, high rates of HNC have been reported. HNCs account for around 30–40% of all cancers in India.^[2] HNC patients' specific needs and challenges are beyond the needs and challenges of most other cancer patients. Notable alterations in the appearance, and profound changes in speech, hearing, swallowing and sight among HNC patients can have a significant impact.^[3]

Even in modern medicine, cancer continues to be one of the most emotionally distressing conditions,^[4] despite steady

improvement in survival rates.^[5] Psychosocial distress (PSD) among cancer patients is caused by several psychological and social issues in addition to the disease stage, age of the patient, physiologic effects of cancer and treatment modalities.^[6] Untreated severe depression may significantly shorten the survival time and increase the death rate.^[7,8] Patients with HNC experience varying degrees of PSD, an important factor affecting their quality of life (QOL).^[9] Population with HNC will have psychosocial issues with significant impact^[10] and a high level of baseline distress which requires special attention.^[11]

Evidence shows high rates of PSD among HNC patients.^[12] Despite this, the attribute of distress is poorly recognised.

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In a study conducted by Chen *et al.*, HNC patients showed mild-to-severe depression (58%) before the initiation of radiotherapy, which worsened (67%) by the end of the treatment.^[8] Findings of another study on screening of PSD among HNC patients showed the presence of distress in 29%, among whom 82% had increased levels of distress and had not received any mental treatment.^[13] Findings of another study by Ichikura *et al.* reported 52.5% of HNC patients with persistent psychological distress, with a significant association between physical and emotional functioning.^[14] In the clinical management of patients with cancer, psychosocial care is growingly being recognised as an essential component.^[6] Thus, there is ample evidence of HNC patients' suffering from PSD. To the best of our knowledge, no studies have so far examined the patients' PSD qualitatively. There is a stressed need to conduct preparatory qualitative research before developing measures of population health. Qualitative researches are useful particularly in elucidating and contextualising the determinants of variance in health state valuations in an extremely diverse cultural setting to address the number of needs. It would also precede or complement psychometric and econometric work by assisting in the understanding and development of conceptual domains and culturally appropriate scale items.^[15] Hence, the focus group discussion (FGD) was conducted to understand the PSD in detail from the HNC patients' perspectives. The objective was to develop a research instrument to assess the PSD appropriate to the context based on the experiences of HNC patients along with an extensive literature review. The operational definition of PSD was 'global discomfort experienced by the HNC patients due to the restrictions imposed by the disease condition'.

MATERIAL AND METHODS

Participants

This analysis was part of FGDs conducted to develop a measuring tool to assess the PSD of HNC patients. In this study, we used a single-centre cross-sectional design in which two FGDs were conducted among nine HNC patients receiving radiotherapy. Participants were recruited using 'purposive sampling technique'^[16] that is, selecting the cases that benefit the most for the study since they are rich in information as they have experienced the phenomenon. The inclusion criteria for choosing the patients were adult participants ranging in age between 40 and 70 years receiving radiotherapy with or without chemotherapy able to speak English or the regional languages (Kannada or Tulu), attending the radiotherapy regularly, and willing to participate in FGD. Patients with a history of mental illness, observable neurological disorders and radiotherapy followed by surgery with difficult communication were excluded from the study. Patients in the 5th week of radiotherapy and able to articulate the experience were selected, considering that

they are rich in experience associated with disease and effects related to radiotherapy.

Data collection procedure

FGDs were conducted in a private room adjacent to the radiotherapy department after obtaining informed consent from the participants. The study was approved by the Institutional Research Committee and Institutional Ethics Committee. In depth, open-ended interviews were conducted to elicit and explore the perception of PSD of patients with HNC using a pre-prepared FGD guide. The FGD guide was validated by subject experts from the field of radiotherapy, oncology, nursing, psycho-oncology, psychology and palliative care. An open ended broad question '*Describe the psychosocial problems you faced during the course of disease and treatment*', was posed to encourage and elicit broad responses by communicating participant's own experiences, understanding and their perspectives of PSD. Based on the responses obtained for the broad question, a set of subsequent questions were also posed to the participants for obtaining in-depth information. The FGDs lasted for 35–45 min and the data were audiotaped.

Analysis

The recorded data were transcribed initially. Initially, the data were read and reread through for searching the meanings and patterns, to familiarise with the data and obtain ideas on experiences related to PSD. Working through the entire dataset was systematically performed, paying equal and full attention to every data item. Similar experiences identified across the dataset were sorted and then collated into themes. Themes were refined by reflecting on their accuracy of meaning in the dataset, pattern and coherence. Clear distinction between the themes and coherence of data within the themes was ensured. Detailed analysis of each theme was written and researchers tried to fit-in the entire data under themes by considering the research question of PSD among HNC patients. Direct quotes from the participants are reported under each theme.

RESULTS

Demographic and clinical characteristics

Sample consisted of male preponderance that is, 7 (77.8%), and 5 (55.6%) were in the age group of 56–70 years (mean = 56.7 years) and all were married and living with family. Four were diagnosed with cancer of the oropharynx and another three were with buccal mucosa cancer. Five were in stage IVA and all were scheduled for radiotherapy with curative intent.

In this study, the analysis of data generated four major themes, namely, the distress experienced by the annoying and irritating symptoms, inability to perform the routines due to physical disability, unpleasant experiences associated with social curiosity, and uncertainty about the future. The themes

with related verbatim and the relevant items generated for the PSD scale are described below.

Theme 1: Irsome symptoms are distressing

This theme describes the distress experienced by patients with physical symptoms. Irritating and uncomfortable symptoms such as pain, painful eating, loss of taste, inability to chew and swallow, loss of control over saliva, mouth sores, bad mouth odour, fatigue and inability to communicate freely were regarded as distressing, greatly restricting the routines and limited interaction with others. Symptom burden was found to be the major contributor to distress in our study.

'I have severe pain, here (opens mouth). I have difficulty in eating, ulcers here (opens mouth), I cannot eat properly, and the mouth has a bitter taste. I feel like eating and I wish to eat the rice. But no taste in the mouth. I can't eat vegetables and curry. I feel tired, with No energy at all.' (FGD 2-R1). *'I can't talk, pain, severe pain, lot of ulcers in the mouth. Too difficult to eat. I can't go out. I feel dizzy, too much dizziness. I feel tired, weak, lot of weakness. Don't have any energy in my body, I lost my voice. I can't talk'* (FGD 2-R2). *'I am tired, I get giddiness, I have ulcers in the mouth and I am unable to eat. I have severe pain'* (FGD 2-R3). *'Now finding difficult eat. The mouth is swollen, very much pain while swallowing. No taste, can't eat spicy food, Lot of saliva drooling from the mouth and pain, lot of ulcers also. Feel hungry but unable to eat. Very painful.'* (FGD 2-R5).

HNC patients were avoiding social functions and gatherings as eating was difficult in such gatherings. *'I can't eat anything. I eat only porridge. They feel sad if I come without eating anything. They feel that they are eating and I am not eating. So, I feel bad'* (FGD 1-R4). *'I feel like eating when I see others eating. But I can't eat'* (FGD 2-R1). Perception of changes in the mouth odour was unpleasant and restricting social interactions. *'Mouth is smelling, I can't brush, and I myself can feel the bad smell. I myself can't bear the smell. I wear this (shows the mask), so others don't get the smell, so I don't go out and talk to people'* (FGD 2-R3).

These findings contributed to developing the items of PSD associated with 'inability to talk', 'inability to eat or drink', 'in eating/drinking in social gatherings' and 'keeping oneself away from family/friends/neighbours'.

Theme 2: Distressing physical disability inflicted by the situation

The theme describes the distressing experience with the notion of being incapacitated that is, the belief of loss of power and strength, and inability to help oneself and perform the activities which were done regularly before disease onset. *'My mother and aunty are with me. I have to take care of them. But now they are taking care of me'* (FGD1-R1). *'My family members don't allow me to go out. Because they are worried that I may fall due to giddiness, I can't do anything. I can't lift anything. I have a granddaughter, she wants me to lift her but I can't do that. No energy to do it. I wish I could do the*

household activities, but I am tired, so can't do it' (FGD2-R1). *'Unable to attend the family functions due to weakness, lot of weakness'* (FGD 2-R2). *'I am unable to go out of my house. I am tired. I get giddiness; even if I feel like going out, they (family members) are worried that I may fall due to giddiness. Even I am scared of going out of the house, I can't do anything, I am helpless. I am scared, don't know why, Can't explain. (pause...cries....eyes full of tears)'* (FGD 2-R3).

'I am not attending the functions, there were a few functions and I was invited, but I did not go. I can't eat anything. Then why to go? I am not comfortable to go there and return without eating anything. I can't sit there for a long time, if I don't eat I feel dizzy and tired' (FGD 2-R5). *'There was a wedding in two of their houses. They invited me to the functions. I did not go to the wedding'* (FGD1-R4).

Items generated from these findings are distress associated with 'inability to go out to public places,' 'inability to attend family function,' 'inability to perform the activities which were done before' and 'feeling helpless/worthless'.

Theme 3: 'Social curiosity' - A distressing element

Repeated exposure to inquisitive behaviours and the desire of people to acquire information about the patient, the inquiring nature of people and their reactions were distressing. The curiosity of the people about changes in physical appearance, changes in routines and expressing negative comments was distressful.

'People around me at my place question me that, I was strong before and I don't have previous charm now when they ask me that I was good before and now I am not so, I feel psychologically down' (FGD1-R1). *'People ask me why I go to the hospital every day. I don't tell them. They may treat me differently. They are curious to know'* (FGD1-R2). *'When I come out of my house, when I go to a shop, people ask me why it has turned black (shows the neck). They talk among themselves that I have lost weight. What to do? They say that I have lost my charm. I feel sad when I hear such things. Rich people can safely stay inside the flat and avail the treatment and no one will get to know about it'. 'People talk on my back that it's my karma'* (FGD2-R5).

Perception of being treated differently by society because of a cancer patient was a distressing experience. *'It was the disease once upon a time without treatment. People in the villages still think that it is the same today as well. Awareness has not reached all... people in the villages say, Oh! That person got this disease. Then I feel bad'* (FGD1-R2).

The above findings were useful in developing the items related to the PSD associated with 'the way people around are treating' and 'restriction of activities due to physical appearance'.

Theme 4: Distressing uncertainty of future

Being unsure of what would come next, worries and fear of more bad things soon that bothered the participants are

described under this theme. Uncertainty of the future was mainly related to the disease prognosis and inability to perform roles as a responsible person in the family.

'How long do I have to take the treatment like this? In life, if everything is alright, there is fun, otherwise what is there? Nothing' (FGD2-R2). *'I am scared, scared what will happen in future' (eyes filled with tears....pause for few seconds)* (FGD2-R3). *'I am tense, I feel that it shouldn't have happened to me. I have two daughters, both are not yet married, I wish at least one of my daughters could have married'* (FGD2-R4).

'I was involved in rituals related to spiritual activities, and prayers and I have to talk more and fluently. I have to call out many names, I worry about that, and will I be able to do that again? Now I am feeling sad about this disease occurrence. I have not gone for such rituals after this (diagnosis)' (FGD 2-R5).

Items related to the PSD associated with 'uncertainty about the future', 'inability to perform the roles and responsibilities' and 'managing the family finances' were developed based on the above findings.

The results of this study helped in the preparation of the tool for assessing the PSD of patients with HNC. After obtaining the attributes of PSD from HNC patients, the next process was the preparation of the PSD scale. This stage involved discussion with experts from oncology, psycho-oncology, radiotherapy and nursing. The prototype of the tool was validated with subject experts, pretested and reliability ($r = 865$) were established.

DISCUSSION

PSD is a multidimensional concept for patients suffering from HNCs. The themes are drawn from the understanding and words of patients diagnosed with HNCs. In the present study, findings showed that HNC patients experienced distress mainly because of uncomfortable and lingering signs and symptoms and associated difficulty to meet basic needs such as chewing, swallowing and communication. The notion of getting incapacitated, loss of power and strength, inability to perform activities, social curiosity and future uncertainty were the prominent attributes of PSD. These attributes of PSD identified from qualitative research from HNC patients were beneficial in developing the PSD scale relevant to the context along with the quantitative research findings from published literature.

Qualitative research findings in the published literature on attributes of PSD from the HNC patients' perspective are meagre. However, quantitative researches aimed at exploring PSD and its correlating factors also show related findings. A study conducted in Tokyo by Ichikura *et al.* to assess the persistence of PSD among HNC showed better physical and emotional wellbeing with reduced distress in comparison with continued distress.^[14]

Similarly, a high level of distress exceeding the definition of clinically significant distress according to National

Comprehensive Cancer Network guidelines was found in 51% of patients. Significantly greater distress was found among HNC patients with family concerns ($P = 0.030$), physical concerns ($P = 0.014$) and emotional concerns ($P = 0.001$).^[11]

However, our study did not elicit a lot of attributes of PSD from the perspective of family concern, compared to the Western counterparts. Indian families' support systems and family dynamics have always proved to be an excellent resource for the care of the ill. Families form a valuable support system, which could be helpful in managing various stressful situations though the resources are not appropriately utilised.^[17] Furthermore, invasion of privacy and repeated inquiry might be more common in our region, whereas might be lesser in some regions such as metropolitan cities, or their Western counterparts. Keeping the private facts and not disclosing them to others is an individual's right, whereas in many societies, such curiosity would be considered as ill-mannered and offensive according to the law.

Economic burdens are common and disproportionately impact the socioeconomically disadvantaged patients with cancer affecting the QOL and treatment adherence.^[18] The present study findings did not demonstrate evident financial/economic distress though the futuristic concern in managing the roles and responsibilities was expressed by a few of the participants. This could be due to the introduction of several health insurance programs by the governments both at the central and state level with ensuring the goal of universal health coverage to all citizens. The coverage of the poor under health insurance schemes is increasing and are succeeded in reducing the extent of out-of-pocket expenditures on hospitalisation and treatments in India.^[19]

Results of this study also necessitate the need for constructing an intervention for reducing PSD based on the attributes from the HNC patient's perspective. Although the causality of PSD is multifactorial, the major contribution was from symptom burden. Addressing all these attributes is required to effectively reduce distress and improve the QOL of HNC patients.

Implications

Suffering among HNC is more compared to any other cancer type. The symptoms burden attributed due to the disease or treatment will have a huge impact on QOL and PSD. The present study is the first of its kind which explored the PSD from the HNC patients' perspectives in our context. The findings of the study further can be used to assess the PSD of HNC patients and provide appropriate care.

Limitations

The data were collected among those HNC patients, able to articulate their experiences and receiving radiotherapy during the 5th week, considering that they are rich in experience associated with disease and effects related to radiotherapy. However, there may be differences in the

experience of PSD across the course of the disease and treatment. The scale also was administered to a smaller group to establish the psychometric properties and needs to be administered to a larger group of HNC patients across the disease and treatment course.

CONCLUSION

Cancer and cancer-related treatments impact the psychosocial health of HNC patients to a great extent. The concept of psychosocial health is also important to the nursing discipline. Identifying the root themes underlying the distress experienced by HNC patients helped in developing the tool relevant to the context. These findings would help in adopting best-suited strategies to decrease the PSD and eventual well-being of HNC patients.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

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Conflicts of interest

There are no conflicts of interest.

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