

# “Personified as Paragon of Suffering..... Optimistic Being of Achieving Normalcy:” A Conceptual Model Derived from Qualitative Research

Shalini G Nayak, Mamatha Shivananda Pai<sup>1</sup>, Linu Sara George<sup>2</sup>

Departments of Medical Surgical Nursing, <sup>1</sup>Child Health Nursing, <sup>2</sup>Fundamentals of Nursing, Manipal College of Nursing, Manipal Academy of Higher Education, Manipal, Karnataka, India

## Abstract

**Background:** Conceptual models developed through qualitative research are based on the unique experiences of suffering and individuals' adoptions of each participant. A wide array of problems are faced by head-and-neck cancer (HNC) patients due to disease pathology and treatment modalities which are sufficient to influence the quality of life (QOL). Men possess greater self-acceptance and are better equipped with intrapersonal strength to cope with stress and adequacy compared to women. **Methodology:** A qualitative phenomenology study was conducted among seven women suffering from HNC, with the objective to understand their experiences of suffering and to describe the phenomenon. Data were collected by face-to-face, in-depth, open-ended interviews. Data were analyzed using Open Code software (OPC 4.0) by following the steps of Colaizzi process. **Results:** The phenomenon that emerged out of the lived experiences of HNC women was “Personified as paragon of suffering, optimistic being of achieving normalcy,” with five major themes and 13 subthemes. **Conclusion:** The conceptual model developed with the phenomenological approach is very specific to the women suffering from HNC, which will be contributing to develop strategies to improve the QOL of women.

**Keywords:** Conceptual model, head, lived experience, neck cancer, phenomenology, qualitative research, quality of life, self-image

## INTRODUCTION

In oncology nursing, quality of life (QOL) is a relevant concept. The concept QOL has been discussed by many authors. In oncology, Ferrell *et al.* and Ferrans described conceptual models on four domains of QOL (<http://www.hs.jgr/medicine/definitions-and-conceptual-models-of-quality-of-life-in-cancer-patients.pdf>). Models are developed and tested based on the individual experiences since individuals are the only proper judges for expressing their QOL.<sup>[1]</sup> Hence, the qualitative research is the most apt methodology to develop the conceptual models based on the individual experiences.

Head-and-neck cancer (HNC) patients experience a variety of psychosocial problems in addition to physical problems. The psychosocial problems mainly include loss of self-esteem, uncertainty about the future, anxiety, and depression. These psychosocial problems may lead to isolation from friends and social and sexual tensions within families.<sup>[2]</sup>

Diagnosis of cancer and its treatment modalities have an effect

on facial figure and functional capabilities. This will have a direct influence on clients' self-concept and psychosocial well-being.<sup>[3]</sup> Different domains of self-image such as body image, self-esteem, and integrity are affected as a result of suffering from HNC.<sup>[4]</sup>

A person's physical, emotional, and mental states are significantly impacted by cancer. QOL among cancer survivors is also at risk of decline up to several years after diagnosis. Maximizing the QOL for patients, their caregivers, and their families is primarily based on understanding and responding to the full impact of cancer and cancer-related well-being.<sup>[5]</sup>

Men also reflect feelings of personal worth, greater overall

**Address for correspondence:** Dr. Mamatha Shivananda Pai, Department of Child Health Nursing, Manipal College of Nursing, Manipal Academy of Higher Education, Manipal - 576 104, Karnataka, India. E-mail: mamatha.spai@manipal.edu

This is an open access article distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as the author is credited and the new creations are licensed under the identical terms.

**For reprints contact:** reprints@medknow.com

**How to cite this article:** Nayak SG, Pai MS, George LS. “Personified as paragon of suffering..... Optimistic being of achieving normalcy:” A conceptual model derived from qualitative research. *Indian J Palliat Care* 2018;24:78-81.

### Access this article online

#### Quick Response Code:



**Website:**  
www.jpalliativecare.com

**DOI:**  
10.4103/IJPC.IJPC\_140\_17

self-acceptance, and adequacy than women. External events are less likely to be internalized by men and are less sensitive to rejection, promoting greater self-esteem and an elevated appraisal of self-worth. Men also perceive themselves as better equipped with intrapersonal strength to cope with stress.<sup>[6]</sup> Hence, this research aimed at developing the framework based on the experiences of women suffering from HNC.

Concurrently, the burden of HNC has a negative impact on QOL. Literature review suggests that psychosocial well-being and factors affecting that are an important aspect to be studied in patients with HNC. In qualitative research, the concepts are derived during the analysis phase based on the individual experiences and what they value. In quantitative research, the conceptual models guide the researcher in the process and the result of qualitative research is the emergence of conceptual models. Therefore, these tools can be considered for providing quality care on oncology nursing.

## METHODOLOGY

### Participants

This conceptual model developed as part of the study on self-image and QOL of HNC patients. This was a qualitative study conducted using phenomenological approach. Participants recruited in the study were seven women receiving radiation therapy as treatment modality during the 4<sup>th</sup> week of radiation from tertiary care hospitals. They ranged between 40 and 65 years in age and were predominantly living with family. The educational qualification was less than primary education for all of them. Participants represented three different states of South India. The represented religious affiliations were Hindu, Catholic, and Protestantism. Participants were recruited for the study using “purposive sampling,”<sup>[7]</sup> i.e., selecting the cases that benefit the most for the study since they are rich in information as they have experienced the phenomenon and were able to articulate that experience. The guiding principle used in deciding the sample size (sampling) was data saturation, i.e., sampling to the point where there was no new information obtained.<sup>[7]</sup> Sampling was ended when saturation was achieved.

### Data collection and analysis procedure

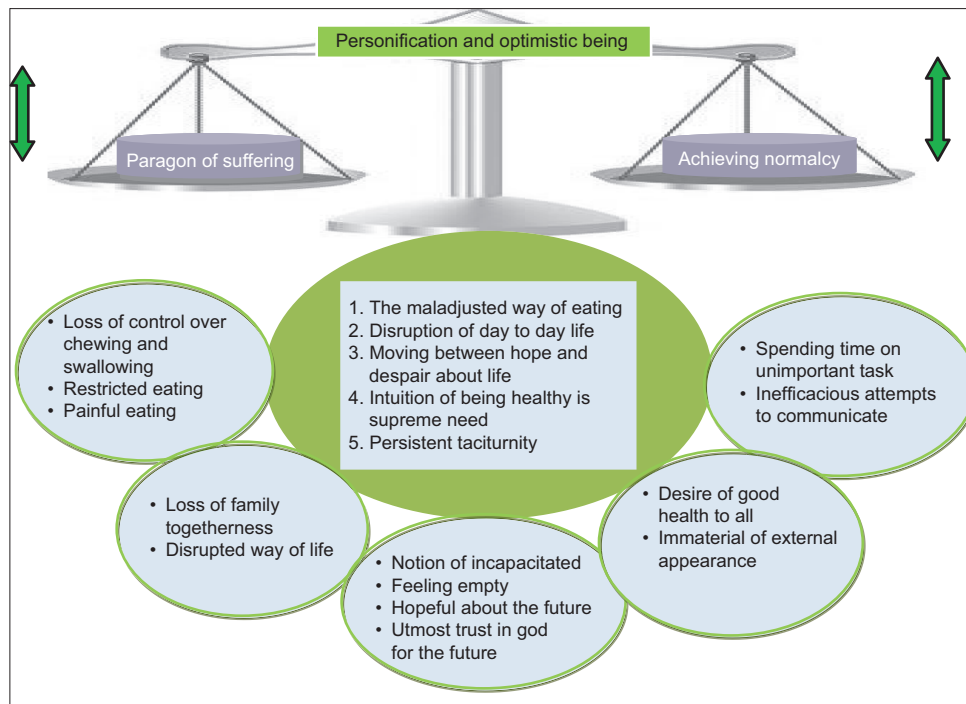
Data were collected by face-to-face interview with the participants. In-depth, open-ended interviews were conducted to elicit and explore their perception on QOL and experiences of living with HNC using a preprepared interview guide. For encouraging and eliciting broad responses and communicating their own experiences, understandings, and perspectives of living with HNC, an open-ended broad question was posed. A set of subsequent questions were posed based on the responses to the broad question to obtain in-depth information. Interviews lasted between 35 and 60 min and were audiotaped. The nonverbal behavior was documented in the diary. Data collection and analysis was done simultaneously. Each participant was approached twice, the first one was for data collection and the second one was for member checking,<sup>[7]</sup> obtaining participants’ reaction by providing feedback of

emerging interpretation for establishing the credibility of qualitative data. The researcher bracketed<sup>[7]</sup> herself to gain insight into the common features of lived experience by identifying and holding in abeyance preconceived opinions and beliefs about the phenomenon under the study. The amount of data saturation was decided based on the consensus between two researchers. The patterns of subthemes and themes emerged out of analysis using Husserl’s descriptive phenomenology. Thus, the conceptual framework is developed and designed based on the themes derived from the experiences of participants suffering from HNC.

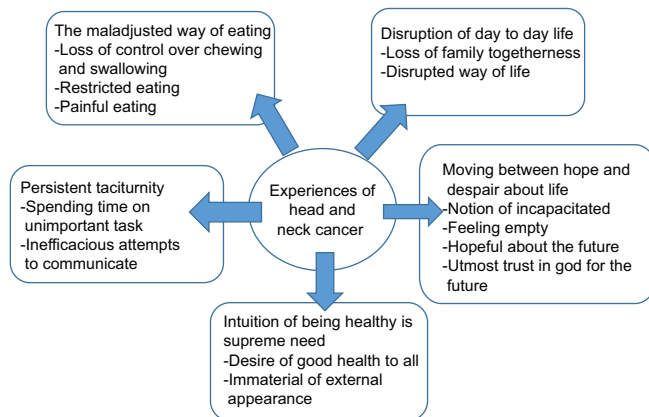
Husserl’s descriptive phenomenological approach was used to reach the true meanings through engaging in-depth into reality, by emphasizing the descriptions of human experiences such as seeing, hearing, believing, feeling deciding, remembering, evaluating and acting.<sup>[7]</sup> Open Code software 4.0 (OPC 4.0) version (Sweden) was used to analyze the data. The Colaizzi process for phenomenological approach was followed to analyze the data.<sup>[8]</sup> In view of obtaining the general sense of the whole content, each transcript was read and re-read following which a significant statement appropriate to the phenomenon under the study was extracted. Coding was done after formulating a significant meaning from each statement. Similar patterns of codes were sorted into subthemes and themes and integrated into an exhaustive description of the phenomenon under the study [Figure 1]. The phenomenon was also described to the research participants to validate whether the phenomenon described by the researcher is the same as that of the experience of the participants.

## RESULTS

The data analysis, in this study, generated over 200 codes, 13 subthemes, and 5 themes. The key categories of subthemes and themes are represented in Figure 2. The phenomenon that emerged from the data analysis represents the experience of “Personified as paragon of suffering, optimistic being of achieving normalcy” [Figure 1]. During the 4<sup>th</sup> week of radiation therapy, patients with HNC experience many physical symptoms such as difficulty in eating, swallowing, difficulty in verbal communication, tiredness, pain, and changes in the salivary secretion in addition to psychological symptoms and social problems. Subthemes related to these symptoms are depicted in the outer small circles in the model. The main themes evolved were represented in the inner bigger circle. The subthemes were linked to each other, and all subthemes were linked to the main themes by intersecting the outer line of the inner circle, considering the HNC participant as a whole system. This model has balance as the main symbol because these attributes represent themselves or personify as the model or paragon of suffering. Concurrently, the will, desire, and optimism of being cured and leading a healthy life in the future were certain in them. Thus, participants continue to experience both positive and negative feeling and there was a balance between the suffering at present and optimism toward achieving normalcy in the future. Nevertheless, the



**Figure 1:** Conceptual model of the phenomenon of lived experiences of head-and-neck cancer patient.



**Figure 2:** Themes and subthemes based on the experiences of head-and-neck cancer women.

balance between these two constructs may fluctuate based on the context of suffering, which was represented by the arrows on either side of the model [Figure 1].

**Theme 1: The maladjusted way of eating**

This theme describes the physical symptoms experienced by the participants. The focused experience was pain, difficulty in eating and swallowing due to pain, limited choice of food, impaired oral mucus membrane integrity, impaired salivary secretion, and changes in the quantity and consistency of saliva. Perception of loss of control over chewing and swallowing, restricted eating, and painful eating or eating were regarded as painful experiences under this category.

**Theme 2: Disruption of day-to-day life**

Interruptions in the regular day-to-day activities are described under this theme. The ordinary everyday routine was disturbed due to the long-term stay in the hospital. Being away from home and family, feeling like going home, disruption of everyday activities due to physical symptoms, inability to perform daily activities due to physical symptoms and side effects and fatigue, inability to sleep or sleeping for longer duration due to fatigue, and difficulty in spending the time during the stay in the hospital were the experiences described under this category.

**Theme 3: Moving between hope and despair about life**

The experiences of HNC patients based on the perception of their present life and future expectations were described under this theme. The experience of living with HNC engendered them to feel desperate and conversely had an expectation of being cured and leading a normal life in the days ahead. The notion of incapacitation, i.e., the conception of deprivation or debilitation, was described by the participants such as inability to help oneself and decreased strength and power. Feeling empty describes the lack of meaning in the life or giving up the hope and conversely they also remained hopeful about future and had an inspiration of optimism about the future life by having faith in God of being cured and getting well soon.

**Theme 4: Intuition of being healthy is supreme need**

The participants of the study opined that being in the state of good health to self and others was the supreme need. Looking attractive externally was insignificant and looking good externally was immaterial. Desire of being in the state of good health for self and others was expressed by the participants

with the feel of no one else suffering from such illness of head and neck cancer. Less attention was focused toward external appearance and mention of looking good externally was not worthy; rather being in the state of good health is significant.

#### Theme 5: Persistent taciturnity

Remaining detached for a longer duration due to inability to communicate properly was described under this theme. The patients feel that their verbal communication was inefficacious due to loss of voice and tone. Moreover, communication was difficult owing to changes in the oral mucus membrane and pathology. Participants remain detached or involve in unimportant activities to spend their time. Excessive secretion of the mucus, changes in the integrity of oral mucus membrane, presence of oral ulcers, changes in the tone, and inability to move the tongue were few of the major causes for difficult communication. The participants remained detached from others since the communication was difficult. Since the effort on communication was nugatory, the participants also verbalized that they do not communicate with others.

## DISCUSSION

The conceptual model of QOL of women presented in Figure 2 is drawn from the words and understandings of a diverse group of women suffering from HNC. QOL is a multidimensional concept. In the present study, pain was the most excruciating symptom experienced by the participants and was the root cause for other experiences such as inability to eat and chew, disrupted way of life, and notion of incapacitation; however, the symptom was sufficient to affect other domains of QOL.

The four major dimensions of QOL – physical symptoms and well-being, social well-being, psychological well-being, and spiritual well-being – for cancer patients is best described by the conceptual model developed by Ferrel *et al.* The model demonstrated that the experiences of pain and fatigue are the variables that influence all the dimensions of QOL.<sup>[1]</sup>

The subthemes and themes evolved from the study were linked to each other by considering that one experience can affect the other directly or indirectly. The patient with HNC was considered as holistic in the current research. The most influential definition of health which is also internationally well known by World Health Organization is “a state of complete physical, mental and social well-being, and not merely absence

of disease or infirmity.” Health is considered as a holistic view which includes all aspects of physical, mental, and social domains. Health has been considered as an ancient concept. QOL is coined in the 20<sup>th</sup> century to measure the health status since the disease-specific data and the traditional medical survival were not sufficient to measure health.<sup>[9]</sup>

## CONCLUSION

The concept of QOL is relevant to nursing discipline. Cancer and cancer-related treatments greatly impact the QOL among cancer patients. Continuous evaluation of impact of cancer and cancer treatments, adopting strategies to decrease the adverse effects, and improving the QOL are very much essential for oncology nurses and caretakers of oncology patients. This conceptual model will contribute to develop strategies to improve physical, psychological, and social care to improve the QOL of women suffering from HNC.

#### Financial support and sponsorship

Nil.

#### Conflicts of interest

There are no conflicts of interest.

## REFERENCES

1. Lavdaniti M, Tsitsis N. Definitions and conceptual models of quality of life in cancer patients. *Health Sci J* 2015;9:1-4.
2. Pruyt JF, de Jong PC, van Poppel JW, van den Borne HW, Ryckman RM, de Meij K. Psychosocial aspects of head and neck cancer – A review of literature. *Clin Otolaryngol* 2009;11:467-74.
3. Nayak SG, Pai MS, George LS. Self concept of head and neck cancer patients – A systematic review of qualitative studies. *Int J Sci Res* 2015;4:123-5.
4. Nayak SG, Pai MS, George LS. Self-image of the patients with head and neck cancer: A Mixed method research. *Indian J Palliat Care* 2016;22:331-4.
5. World Cancer Day; 2015. Available from: [http://www.worldcancerday.org/sites/wcd/files/atoms/files/WCD2015\\_FactSheet\\_4\\_QualityOfLife\\_EN\\_Screen.pdf](http://www.worldcancerday.org/sites/wcd/files/atoms/files/WCD2015_FactSheet_4_QualityOfLife_EN_Screen.pdf). [Last retrieved on 2015 Oct 31].
6. Roothman B, Kirsten DK, Wissing MP. Gender differences in aspects of psychosocial well-being. *S Afr J Psychol* 2013;33:212-8.
7. Polit DF, Beck CT. *Nursing Research*. New Delhi: Wolters Kluwer (India) Pvt. Ltd., New Delhi. 2012.
8. Shosha GA. Employment Of Colaizzi’s strategy in descriptive phenomenology: A reflection of a researcher. *Eur Sci J* 2012;8:31-43.
9. Nilsson E. Aspects of Health-Related; 2012. Available from: <https://www.diva-portal.org/smash/get/diva2:492046/FULLTEXT01.pdf>. [Last accessed on 2017 Jun 10].