

# Symptom Experiences and Management of Patients with Head and Neck Cancer Receiving Radiation Therapy: Integrated Review

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## Abstract

There is a limited number of literature reviews of the symptom experience and self-management of head and neck cancer (HNC) patients who have undergone radiation therapy, in the period before, during, and after treatment. Moreover, a qualitative approach exploring these specific experiences and their management will benefit both health care providers and researchers to understand the factual experience. Knowledge of this kind is needed to help eliminate distress from treatment-related symptom toxicities and to develop novel and adequate interventions to support these patients' needs. A literature search was carried out in April 2017 using Cochrane, CINAHL, Ovid, Pubmed, PsycINFO, and ScienceDirect databases to review the literature on HNC patients, symptom experience and management during radiation or concurrent chemoradiotherapy. Symptoms experienced by HNC patients mainly relate to eating difficulties and uncertainty from the moment of being diagnosed with cancer until treatment completion. Symptom management is focused on self-management for out-patients by providing guidance, and disease education is delivered by knowledgeable healthcare providers with good interpersonal skills. Communication strategies with tailored information also provide vital data found in this synthesis. Early assessment and intervention with patients, and an effective family involvement, is important to facilitate access to quality oncology services. This is vital in helping overcome the uniquely complex treatment-related symptoms and to help patients and families to cope with the difficult time of getting through the treatment trajectory.

**Keywords :** symptom experiences, symptom management, head and neck cancer patient, radiation therapy, concurrent chemoradiotherapy, qualitative research

Head and neck cancer is the 6<sup>th</sup> most prevalent type of cancer with an annual incident rate of around 600,000 new cases worldwide.<sup>1</sup> Head and neck cancer (HNC) includes oral, laryngeal, oropharyngeal, salivary gland and other pharynx cancers.<sup>1</sup> Standard treatment of head and neck cancer involves radiation therapy at any time point of the treatment trajectory either for palliative or curative purposes.<sup>2</sup> To date, a multidisciplinary approach uses a combination of surgery, radiotherapy, and chemotherapy in order to treat HNC. The frequencies and severity of treatment-related symptoms occur depending on the dose of radiation but worsen when combined with the side effects of chemotherapy.<sup>3-5</sup>

A review of studies relating to radiation therapy suggested that altered fractionation radiotherapy was associated with an improvement in overall survival rates in patients with oral and oropharyngeal cancers (Hazard Ratio (HR) of mortality = 0.86, 95% CI = 0.76 to 0.98).<sup>6</sup> A review of chemotherapy treatment suggested that chemotherapy, in addition to radiotherapy and surgery, was associated with improved overall survival in patients with oral cavity and oropharyngeal cancers (HR of mortality = 0.84; 95% CI = 0.72 to 0.98,  $p = 0.03$ ).<sup>7</sup> However, neither review could find sufficient evidence as to which regimen was associated with better overall survival rates.

There are a number of common symptoms both local and systemic that are sometimes experienced by head and neck cancer patients receiving chemo-radiation treatment, such as fatigue, skin irritation, decreased appetite, sore throat/mouth, changes in saliva, dryness of mouth, alterations of taste, and difficulty swallowing. The severity and frequencies of these symptoms generally increase over the course of treatment and typically peak during the last few weeks of treatment.<sup>8</sup>

There is a limited number of literature reviews on symptom experience and self-management of head and neck cancer patients with radiation therapy, in the period before, during, and after treatment. Moreover, a qualitative approach to explore these specific experiences and management will benefit both healthcare providers and researchers to understand the experiences patients are faced with. Knowledge of this kind is needed to help eliminate distress from treatment-related symptom toxicities and to help the development of new adequate interventions to support these patients' needs.

### Aim

The purpose of this article was to conduct an integrative review to identify the symptoms experienced and to establish how to manage these symptoms for head and neck cancer patients undergoing radiation therapy with the findings of qualitative research.

### Method

#### *Search strategy*

A literature search was carried out in April 2017 using Cochrane, CINAHL, Ovid, Pubmed, PsycINFO, and Science-Direct databases to review the literature on HNC patient symptom experiences and their management during concurrent chemoradiotherapy. The search terms used were 'head and neck cancer' and 'symptom management', 'qualitative research' or 'qualitative study' or 'qualitative approach.'

The search yielded 13,763 publications but only 90 articles met the criteria for abstract screening. Only 12 publications were identified to be related to radiation. After narrowing down to HNC alone, a total of 9 publications were included in this study. To ensure that up-to-date data was gathered on interventions in the management of symptoms experienced by head and neck cancer patients receiving radiation therapy, the literature searched was from 2006-2017.

#### *Inclusion and exclusion criteria*

##### **Inclusion**

- Head and neck cancer patient receiving radiation therapy
- Symptoms experienced and related management
- Qualitative study
- English language
- Peer-reviewed

##### **Exclusion**

- Quantitative study or mix-method studies were excluded
- Articles that did not study symptom experience and management were excluded

A total of nine articles were included in the review.

#### *Quality Assessment*

The quality of the nine papers reviewed met the inclusion criteria using a Critical Appraisal Skills Programme (CASP) in line with the Qualitative Research Checklist.<sup>9</sup>

### Findings

The nine studies conducted their research on different numbers of participants from eight up to twenty. Eight of them used semi-structure interviews for collecting data from head and neck cancer patients (and their caregivers) who had experienced radiation therapy. The clinical settings for these studies were outpatient settings in both Europe and the US. They explored the experiences of patients diagnosed with head and neck cancer to understand their holistic and real-world experiences by using interpretive epistemological assessments. The data illustrated that the results of treatment-related symptoms occurred with the same cancer treatment and radiation therapy. The treatment toxicity significantly affects the intensity of physical, psychological, and emotional function side effects.<sup>10</sup> From the central questions: what does it mean to live with the experience of head and neck cancer patients undergoing radiation? how were these experiences managed? the main concepts from the research were identified and synthesized to answer these questions. These fell into three major themes: symptom experience, self-management strategies, and communication with tailored information.

#### *Symptom experience*

The symptom experience in head and neck cancer patients was identified by examining the findings of previous research in terms of psychological experience of living with head and neck cancer. Six key concepts emerged as follows: uncertainty and waiting; disruption to daily life; the diminished self; making sense of the experience; sharing the burden; and finding a path.<sup>11,12</sup> All of the qualitative research examined head and neck cancer patients experiencing active treatment. The research helped not only to explain what had happened and how they chose to deal with the cancer and its side effects, but also to comprehend the reasons and process for their choices. There are three aspects of symptom experience faced by head and neck cancer patients influenced by treatment-related symptoms: changes in eating habits; feeling uncertainty; and communication with tailored information.

#### *Eating difficulties*

HNC is a unique condition often characterized by disfigurement and impaired access to social functions as a

consequence. The symptom experience includes the physical aspect, local side effects of radiation treatment, and the cancer itself. All the nine papers showed that difficulty eating as the major cause in terms of functional and social disability, though there were differences in the view of coping and management strategies to deal with symptoms including dysphagia, xerostomia, change in eating habits, pain, and physical changes. These are the main foci of the studies. The symptoms mentioned can be categorized into two types: localized symptoms of treatment and adjacent areas and organs such as mucositis, pain, dysphagia, xerostomia, skin change, change in eating and; systemic symptoms such as fatigue, nausea, constipation, and dizziness as also observed in all other cancers.<sup>13-18</sup> The physical side effects, specifically from radiation-induced eating problems, were clearly reflected in patients' perceived quality of life.<sup>16</sup>

### Uncertainty

Uncertainty was experienced from the point of first being diagnosed with head and neck cancer and coping and understanding the proposed treatment course leading to overwhelm and in some cases complicated situations that emerged along the cancer trajectory.<sup>19</sup> HNC patients and caregivers have to deal with a change in lifestyle and having to be well-prepared for advanced combination treatments with complex psychological and emotional side effects.<sup>13</sup>

The psychological aspects identified by a number of studies included concerns around the side effects from treatments, such as loss of social function, body image, sense of control, and change in relationships.<sup>14,15,19,20</sup> The psychological aspects could not be isolated from physical symptoms as they concurrently impacted each other in social functioning.<sup>20</sup> Change in body image and eating habits influenced their psychological suffering, change in relationships, and impairment of social functions such as eating, drinking, and speaking.<sup>14,15,19</sup>

Emotional distress, psychological distress, fear, and anxiety have all been investigated in multiple studies. All the dimensions, such as physical, psychological, and emotional, are inter-related in head and neck cancer throughout the cancer treatment trajectory. Almost fifty percent of oropharyngeal cancer patients developed depression disorder.<sup>13</sup> Change in life routine and disrupted expectations may cause distress in head and neck cancer patients from diagnosis to receiving active treatment.<sup>20</sup> The radiation treatment process influenced the emotional state of patients and caused anxiety and distress such as the use of an immobilization mask used during the irradiation process.<sup>21</sup>

### Self-management strategies

Symptom management strategies need to be concerned with a wide range of social, physical, and emotional difficulties and these need to be handled by providing adequate support for patients during a challenging process. Communication and

collaboration between patients, family, and healthcare teams were also perceived to be important.

### A competent and knowledgeable healthcare provider

A competent and knowledgeable healthcare provider supports patients both with verbal and written tailored information. Appropriate management should include specialists such as a psychologist and nutritionist in the multi-disciplinary team.<sup>18,21</sup> Symptoms experience leads the patients to seek information and guidance from doctors and nurses, therefore, the information given along with an effective response to patients' needs is crucial to improve symptom status outcome and well-being, both physically and psychologically.<sup>14,21</sup>

### Interpersonal relationship

Interpersonal relationships were predominantly facilitated by the social resourcefulness of close family and friends, using the experiences of others who had undergone similar treatments at the same time to positively reappraise their own situations. Family is very important for patients including sharing family meals, travel plans, spending time with family members, and emphasizing positive thinking. Some patients relied on family support networks to attend appointments.<sup>15,20,21</sup> Strategies to help individuals such as social support and openness with friends were used, as well as approaches to getting air.<sup>19</sup> Drawing on experiences of others was helpful as well as meeting the experts at the same time to positively reappraise their own situations and to gain more information and practical advice to move forward.<sup>14,19,21</sup> The nurse-patient relationship can help patients to select the appropriate approach to provide comfort from pain; the importance of good manners and understanding with appropriate support can instill confidence which subsequently encouraged the patients to engage with the treatment plan.<sup>18</sup>

### Self-management

Individual patients coped with symptoms in many positive ways such as active planning, trial and error, positive focus, regular exercise, meditation, religious beliefs, and distraction strategies.<sup>14,15,17</sup> The patients essentially become their own primary caregivers and manage their symptoms themselves on a day to day basis.<sup>17</sup> The key element that links patient, family, and the health care team is communication around occurring symptoms, managing side effects, and monitoring the symptoms.<sup>18</sup> The outcomes of symptom management strategies are to ease the severity of physical symptoms and also to reduce the emotional side effects that occur before, during, and after treatment.

### Communication strategies with tailored information

Information was received from experts and professional healthcare providers.<sup>19</sup> The information needs for patients are particularly of importance during the acute phase, when patients have to plan for active treatment, and during long-term

or late phases once they have finished treatment and have to take care of themselves at home.<sup>21</sup> Communication is the means to convey appropriate information after having conducted an information needs assessment.<sup>17,18</sup> The right information delivered to the right patients by the right person is the key to ensure that patients receive the information they need. Appropriate and effective education can help to eliminate uncertainty and symptom distress (both physical and emotional) and as a consequence improve their health status outcome.<sup>19</sup>

### Discussion

This qualitative evidence synthesis can provide a context to develop insights from the nine primary research studies. Data extracted from a cross studies comparison with an existing nursing model which is often referred to in cancer patients was based on the Symptom Management Theory (SMT) from UCSF School of Nursing. The three essential concepts of SMT include symptom experience, symptom management strategies, and symptom status outcomes. Symptom experience is a simultaneous perception, evaluation, and response to the change in how an individual is feeling, either in frequency or severity. Symptom management strategies are efforts to eliminate the symptom experience in several ways to reduce the frequency, minimize the severity, and relieve the distress of symptoms. Symptom status outcomes are clear and measurable outcomes to assess after symptom management strategies have been implemented.<sup>22,23</sup> As a theoretical framework guideline was applied to consider the trustworthiness of information found in the nine research articles, it was found that symptom management in head and neck cancer patients (HNC) receiving radiation or chemoradiotherapy does not occur in isolation. Symptom experience of patients lead them to seek management strategies through self-management, health care providers, family and friends to reduce severity and to relieve symptom distress. There is an urgent need to help the patient to manage symptoms as well as getting through this difficult time. Recently, more knowledge is emerging about the symptom cluster effect occurring in these fields, especially in cancer-related symptoms.<sup>24</sup> We have to focus on multiple symptoms occurring in an individual, and not only consider a single symptom.<sup>25,26</sup> HNC patients receiving a combination of both radiation therapy (RT) and combined modality treatment (CMT) have impacted both quality of life (QOL) and outcome status.<sup>3,4,27</sup> The effectiveness of interventions to manage symptoms still needs best practice for individual patients who live with uncertainty, disruption of daily life and needed support for their physical and psychological well-being.<sup>6,7,10,17,21,28</sup>

The three main themes identified in this research synthesis have been meaningful in focusing on symptom experience and management of head and neck cancer patients receiving active treatments. A range of experiences across the treatment trajectory from start, during, and after treatment have been explored. Management strategies used by patients, family, and health care professionals to support and manage the side effects have a multi-dimensional approach. The role of information

in terms of collaboration and participation can increase the interpersonal relationship to build trust and gain new knowledge.<sup>29,30</sup>

### *Efforts to improve intervention*

Symptom self-management strategies are an effort to delay or minimize symptoms experienced. These strategies can be effective in reducing the frequency, minimizing the severity, and relieving the distress of symptoms. Cancer treatment tends to be given to the patient as an out-patient, so increasing attention is being given to self-management strategies used by patients. Early assessment to detect the symptom severity or interference can reduce or delay onset by developing a tailored intervention to a single or a cluster of symptoms. An attempt to improve symptom management and psychosocial care in head and neck cancer patients used a psychosocial program following a mix-methods design. This was used to test the feasibility of a tailored telephone-based stress management intervention, and it was found that the intervention helped to buffer the negative emotional and physical impacts and higher satisfaction was reported by participants in the control group.<sup>31</sup> The most significant dose-limiting acute toxicity during radiation or chemoradiotherapy is radiation-induced mucositis and is associated with functional consequences in the short and long term. There are currently no approved strategies or interventions to prevent this symptom. The current recommendation followed by NCCN guidelines suggested excellent oral hygiene with rinsing with saline, sodium bicarbonate, and water.<sup>32</sup> Weekly symptom monitoring by skilled and trained professional nurses has been found to reduce hospitalization rates and to increase adherence of head and neck cancer patients during radiation therapy.<sup>30</sup> Information provided online to help patients increase knowledge and improve patient compliance in prostate cancer prior to radiation therapy was found to be highly satisfactory in terms of education strategies.<sup>33</sup>

### Conclusion

The diagnosis of head and neck cancer, particularly when treated with a combination of complex treatments, can cause complications in symptoms which are toxic to both patients and their families. Symptom experience in patients with head and neck cancer receiving radiation or chemoradiotherapy treatment were both physical and emotional, with suffering before, during, and after active treatments. Symptom management strategies should be concerned with the multi-dimensions of everyday living. An effective management with patients participating in the decision-making process of their own treatment plan can encourage patient learning to perform self-management and to contribute towards a better experience during the treatment period. An effective intervention in terms of patient preference and physical and emotional comfort will be most valuable in term of expected outcomes. Healthcare providers should create strategies to manage symptoms with a holistic approach.

### Implications for nursing practice and health policy

Early assessment of any symptom cluster before, during, and after treatment is mandatory for clinical oncology nursing, especially in head and neck cancer patients. To understand patients' experiences with treatment-related symptoms, qualitative research helps to explore subjective feelings from individual feedback. Symptom management strategies consist of a multi-dimensional approach to deal with symptoms that have occurred, drawing from knowledge and understanding of the phenomenon in question. It is important to highlight the importance of holistic care, to encompass not only the

physical but also the psychological and emotional aspects of symptom experience. Competent and knowledgeable nurses should be concerned with and be trained to gain new knowledge and the nursing curriculum should include management strategies. Further research in the field of managing symptom clusters should be conducted, especially in complex and advanced treatment scenarios. Furthermore, technology should accompany the latest developments to improve the effectiveness of a multidisciplinary approach and improve sustainability by increasing self-management strategies to aim for optimal health status and treatment outcomes.

**Table 1:** Symptom Experiences and Management of Patients with Head and Neck Cancer Receiving Radiation Therapy

Year	First Author	Sample	Data collection	Data analysis	Symptom Experience	Management
2007	Larsson M <sup>29</sup>	9 HNC	Semi-structured interviews.	Interpretative phenomenology. Analysis of data Colaizzi.	Symptom distress and eating problems are a profound of disruption in daily life from cancer and treatment. During treatment insufficient information and lack of time to ask questions. After completed treatment patients felt left alone with their problem and were worried for the future.	There are negative self-care strategies such as avoiding participating with friends and family, poor oral hygiene. Positive self-management strategies such as being accepted and supported by family to help and empower to get through hard times. Seeking information from skilled health care providers who can support and guide patients during the trajectory of care.
2008	Semple CJ <sup>14</sup>	10 HNC	Semi-structured interviews.	Thematic analysis.	Change and challenges in HNC patients' lifestyle from following treatment were not one aspect alone but a complex set of needs and difficulty coping.	Majority of patients seemed to accept what happened and to adapt over time. The most commonly used strategies were active planning, disguising and trial and error. A range of factors helped them to cope, including religious belief, positive focus, and professional support.
2011	McQuestion M <sup>20</sup>	17 HNC	In-depth interviews.	Thematic analysis.	The meaning and impact of eating changed when patients received radiation treatment.	HNC patient suffered losses in physical, emotional, and social aspects. A better understanding of eating problems is needed to preserve the symbolic meaning of food, body image, and social support. Therapeutic education and empowerment is needed to help patients to be well prepared to implement self-management.
2014	Charalambous A <sup>16</sup>	15 HNC	Individual narratives.	A hermeneutic phenomenological structural analysis.	Xerostomia can cause suffering in the body, mind and the patients' wider world. Feeling helpless and alone.	The emphasis and provision of adequate information on xerostomia in preparing steps before and during radiation, including dietary supplements, were for the most part implemented. Some conditions were ignored and a lack of well-accepted practice in healthcare providers to respond to subjective complaints of dry mouth was observed.

Year	First Author	Sample	Data collection	Data analysis	Symptom Experience	Management
2015	Schaller A <sup>15</sup>	26 HNC	Interviews and an interview guide.	Content analysis.	HNC patients experience pain and how it influences those who are receiving radiotherapy.	For pain management, nearly all patients used pain medication regularly but were concerned with side effects. Overwhelming fatigue; resting did not help. Positive thinking about outcome of treatment and family and friends' support significantly helped alter mood, lessened preoccupied minds and strengthened relationships.
2015	Brockbank S <sup>13</sup>	24 HNC	Focus group and semi-structured interviews.	Thematic analysis.	Swallowing difficulties or dysphagia can cause malnutrition and impacts quality of life of HNC patients. Patient's perspective of pre-treatment preparation about changes to eating, drinking, and swallowing after CCRT.	Half of all participants experience moderate to severe dysphagia and they require information on the impact and prognosis of their ability to swallow. They preferred in-depth knowledge given verbally by a professional about dysphagia. Differing views on information delivery was dependent on patients' emotional state. Providing information that is individually tailored to patients' need and preferences should be the most important concern.
2016	Pattison N <sup>18</sup>	8 HNC	Face-to-face, in-depth interviews.	Thematic analysis.	Patients' views of the experience of pain related to radiotherapy.	Self-management strategies need good communication between pain specialist and patients to help learn how to live with, and manage, the pain.
2016	McQuestion M <sup>17</sup>	17 HNC	Semi-structured interviews.	Thematic analysis.	Radiation-related symptoms that occurred and coping mechanisms from the diagnosis stage to treatment.	Listening to advice from professionals, staying focused on the present, being attentive to tomorrow, and looking towards a positive outcome of treatment. Being positive, maintaining a routine, being distracted by engaging activities, using humor, and seeking support from others.
2016	Taylor A <sup>19</sup>	20 HNC and 17 caregivers.	Semi-structured interviews.	Framework analysis.	Physical and psychological difficulties over time with an experience of uncertainty.	Types and sources of information and caregivers used along treatment trajectory. These were informative, experiential and professional from various sources such as: ex-patients; family members; and health professionals. These were useful particularly when uncertainty occurred.

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