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Symptom experience and regaining normality in the first year following a diagnosis of head and neck cancer: A qualitative longitudinal study

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ABSTRACT

Introduction: Symptom experiences and their interference with life are not well-researched in head and neck cancer patients. The aim of the study was to explore and understand the experience of receiving treatment for head and neck cancer with particular focus on symptom experiences over a one year period from diagnosis.

Methods: A qualitative study design was used with a heterogeneous sample of 16 patients with head and neck cancer. Interviews, conducted at four time points over 12 months, provided a total of 50 interview datasets.

Results: Key themes derived include nutritional concerns, tiredness, and experiences related to the radiotherapy mask and regaining normality. These data highlight issues of importance in the first year of living with head and neck cancer: impact of nutritional changes on the lives of patients, including weight loss, dysphagia, xerostomia and taste changes; debilitation from ongoing fatigue; unpreparedness for and distress from the radiotherapy mask; and attempts to maintain a normal life amidst the interference of symptoms.

Conclusion: Multitude of symptoms impact the patients' life, particularly nutritional symptoms and fatigue, and interfere with the patients' survivorship and quality of life. The changing nature of symptoms over the first year from diagnosis in head and neck cancer patients and the identified issues in the attempt to normalize their lives need to be incorporated more fully into the supportive care of head and neck cancer patients in order to improve their experience and enhance their survivorship.

KEYWORDS: Dysphagia, Head and neck cancer, Nutritional concerns, Radiotherapy mask, Xerostomia

INTRODUCTION

Patients with a diagnosis of head and neck cancer experience significant concerns and challenges, particularly as head and neck are prominent parts of the body. Emotionally traumatic experiences have been described in head and neck cancer literature with significant changes reported in swallowing, speech and communication, sight, and hearing (Dropkin, 1998, 2001). There is limited qualitative work exploring such challenges in patients with head and neck cancers and little understanding of symptoms experienced during and after treatment. An interview study with 10 head and neck patients 6–12 months after completing treatments has shown that patients had complex changes and challenges to their lifestyles, including physical changes, concerns about cancer, work and day-to-day activities, difficulties with interpersonal relationships, and decreased social functioning (Semple et al., 2008). Furthermore, a qualitative study of 18 patients, using the International Classification of Functioning, identified areas of relevance were around body functions, daily activities, and contextual environmental factors

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(Tschiesner et al., 2009). Our recent work with nine patients who had laryngectomies for head and neck cancer has also highlighted the extreme difficulties this subgroup of patients experience in relation to altered airway, speech and communication, eating, and body image (Dooks et al., in press).

The majority of literature in this field is quantitative and focuses primarily on quality of life or specific aspects of disease and treatment trajectories such as dysphagia and malnutrition. A structured literature review on quality of life of head and neck cancer patients identified 165 studies and themes were about predictors of quality of life, functional outcomes, and questionnaire development (Rogers et al., 2007). Furthermore, studies have shown a significant link between malnutrition or dysphagia and quality of life (Jager-Wittenaar et al., 2011; Lovell et al., 2005).

There is a need for more qualitative work in this patient group in order to better understand the experience of living with and undergoing treatments for head and neck cancer. This type of work provides an opportunity for patients to voice their concerns and share their experiences using their own words, which are important elements of developing more patient-focused care provision and support. Hence, the aim of the present study was to explore experiences, over a one-year period, to enhance our understanding of issues and concerns described by patients with head and neck cancer.

METHODS

Design

The study design was qualitative conducting interviews prospectively over a period of one year. This study was part of a larger program of research looking at symptom experiences of eight cancer diagnostic groups, with head and neck cancer patients being one of the groups (see examples of programme output in Molassiotis et al., 2010a, 2010b, 2011; Johansson et al., 2010). Leventhal's self-regulation theory (Leventhal & Johnson, 1983) was used as the study's theoretical framework, enabling us to assess the meaning and significance of symptoms in this patient group over time, as it suggests that symptoms activate a cognitive search process, resulting in the construction or elaboration of illness representations. These representations then served as standards against which new information is matched and evaluated (Leventhal & Johnson, 1983).

Interviews were carried out by two experienced qualitative researchers who had received training in interviewing and supervision from a senior researcher. A narrative format was used and explored the experience of symptoms by asking patients to reflect on their experiences and eliciting their interpretations about significant experiences. Interviews were conducted prospectively over the first year: soon after diagnosis (T1), around 3 months (T2); 6 months (T3); and 12 months (T4). A common sequence of steps for the data collection, interpretation and analysis as described by Miles & Huberman (1994) were followed (such as noting the researcher's reflections, devising and affixing codes to field notes from interviews, conducting a more focused investigation in observed commonalities and differences in the next wave of data collection and so forth).

Sample

Recruitment took place in a tertiary specialist cancer center in the northwest of England. Thirty-six patients were approached for participation in the study using purposive sampling of maximum variation in the clinical characteristics of the patients. Twenty declined to participate primarily due to the longer-term commitment necessary for the study, being busy with other things or being stressed. Sixteen patients consented to participate (although one did not have an interview at T1 due to feeling unwell but remained in the study), leaving 15 participants contributing with interviews at T1. At T2, 13 participants provided follow-up interviews and three withdrew: one provided no reason and two could not be contacted. At T3, 12 participants provided follow-up interviews with one declining because he was having an operation and also did not want to continue talking about his illness. At T4, 10 participants provided follow-up interviews as one patient was too ill to participate and one died before the interview. In total 50 interviews were conducted. The sampling method was broad and included patients at any disease stage, and those receiving chemotherapy and/or radiotherapy after surgery in order to provide maximum variation in perspectives and views (patients may have received induction chemotherapy prior to their radiotherapy and some had had surgery as their initial treatment, and others radiotherapy with concomitant chemotherapy). Potential participants were identified during patients' routine outpatient follow-up visits. Patients were excluded if they had cognitive impairment at recruitment (as judged by clinicians), life expectancy of less than 6 months at recruitment, or were unable to carry out the interview.

Procedures

Ethical approval to conduct the study was provided by the hospital's Research & Ethics Committee and the Ethics Committee of the University of Manchester. Patients were recruited shortly after diagnosis/surgery when they arrived at the hospital to receive their first treatment. Patients were subsequently provided with information about the study and written consent was obtained. After recruitment, arrangements were made with patients to carry out the first interview, which for many was at or around the beginning of their treatment (T1). Follow-up interviews were held at three to five months post-diagnosis (T2), six to eight months (T3), and at 12–14 months (T4). The interviews were semi-structured and an interview topic guide was developed to aid in fluency of the interview and subsequent analysis. As reported previously (Molassiotis et al., 2010a, 2010b, 2011; Johansson et al., 2010), each interview started with the researcher asking the patient "How have you been feeling physically this past week?" Other questions included "How have you been feeling emotionally this past week?" "What were the most distressing symptoms you experienced and why? How did you attempt to manage your symptoms? What is it like living with the (reported) symptoms? How was the experience of receiving your treatment? What were the key issues of concern when you completed your treatment?" However, interviewers were not constrained to cover the items on the guide in any particular order and were encouraged to remain open to significant factors not identified in advance, following an iterative approach. New issues identified in the earlier interviews were incorporated into the interview guide for subsequent interviews. All interviews were tape-recorded (subject to respondents' consent) and subsequently transcribed verbatim professionally, with verification from the researchers and the field notes. While no formal member checking was carried out, each subsequent interview summarized the key issues discussed in the previous interview and provided the opportunity for patients to comment on them as part of the interview guide for the subsequent interviews. This, indirectly, provided some evidence of the accuracy of the data collected. Also, interviewers followed the same patients throughout the year and built rapport with them, which may have provided more honest and open responses. Regular meetings took place between the team members to discuss progress and any issues deriving from the study. As the final interviews at T4 did not provide any new information, it was deduced that data had reached saturation and recruitment stopped. The average interview duration was approximately 45–60 minutes. The interview location was at a convenient place for patients (often their home).

Information about socio-demographic characteristics including age, gender, education, and marital status as well as disease and treatment-related information (diagnosis, treatment received, and stage of cancer) were retrieved from the patients or the patients' records as appropriate.

Data Analysis

Data analysis was carried out by three researchers: the senior investigator; an academic researcher with experience in qualitative research and supportive care; and an experienced head and neck cancer nurse clinician. All transcripts were read and then analyzed using manifest content analysis, following analytical procedures described by Graneheim and Lundman (2004). The unit of analysis was the whole interview of a participant over time. Initially, this was done independently by identifying words, lines, and sentences (meaning units) that were grouped together as they related to the same central meaning (coding units). These categories were then brought together under higher order headings (themes). Themes were compared and contrasted between the three researchers. Data was analyzed both cross-sectionally and longitudinally to allow for themes important at a given time or over time respectively to surface. Cross-checking, refinement of themes and using Leventhal's model as a broad framework supported the rigor and trustworthiness of the data. The clinical value of the findings was also discussed within the analysis team. A final framework of themes was then identified and agreed upon, after assessing these themes both over time and within the same time in all patients. Two of the researchers returned to the transcripts to ensure that all instances of the themes were identified and to confirm the range and extent of the patterns developed. The project team held regular meetings to discuss data collection, data quality, and analysis. Regular second party checks were made at each stage of the framework construction and inductive derivation, to ensure accuracy was maintained at every stage of the analysis.

RESULTS

Patient Characteristics

The mean age of the 16 participants was 61 years (SD = 13.7, range = 34–80). Fourteen were male and two female and the majority were either married ($n = 9$) or separated/divorced ($n = 5$). Seven patients had secondary/high school education, two primary education only, and five college education or higher. Most were retired ($n = 7$), while six were employed, and three unable to work due to their illness. All were of white Caucasian ethnic background and most ($n = 13$) reported being Christian. The majority had oral or oropharyngeal cancer, while one had laryngeal cancer and one a squamous cell cancer in the vocal cords. Half of the sample received treatment with curative intent and the remaining patients with palliative intent. Eight participants were treated with radiotherapy only while four were treated with chemotherapy plus radiotherapy, and four had surgery only (as an initial treatment). Stage of cancer was early in seven participants, while six had advanced disease, and stage of disease was unknown in three.

Themes

Four themes emerged from the interview data. The most prominent issue reported by 13 patients related to nutritional concerns. Tiredness or lack of energy was the foremost symptom apparent in our data and issues related to this form the second theme. The mask used in delivering radiotherapy comprises the third theme. The final theme revealed through our analysis relates to re-gaining 'normality' in head and neck cancer patients' lives.

Nutritional Concerns

This theme is defined as all aspects of eating, nutrition, food intake (including nutritional supplements), and weight-related concerns that were experienced by patients. At T1, all patients reported symptoms that affected their nutritional intake and described their impact on everyday life. Most patients reported struggling with appetite loss, taste changes, and xerostomia. Xerostomia was particularly a problem on arising (e.g., "... it's a job to start swallowing at first ..." HNP24, T1).

Dysphagia was also commonly reported and variously expressed:

> "... I got a bag of crisps the other day, I had one, swallowed it, oh that were it-like swallowing a bag of nails..." (HNP24, T1).
>
> "... He (the surgeon) put them holes in it, at the roof of me mouth, and me drinking, it goes down my nose if you are not careful with it" (HNP26, T1).

Sore throat was reported in patients receiving radiotherapy, although most patients were able to manage it with recommended treatments:

> "Not very sore [throat]. Its not something that fetches tears to your eyes but ... you know something's happening or something's changing" (HNP34, T1).

Taste changes were described as important, impacting on their appetite and weight. Sensations of early satiety were also communicated. While nutritional supplements may have been given to patients by their clinicians, patients expressed inability to tolerate them, describing them as hard to swallow and unpalatable:

> "You don't get the full flavour ... for some reason it [nutritional supplement] has a reaction with me tongue ... it's not going to do me good if it makes me sick"(HNP27, T1).
>
> "... energy drinks ... better off in the cat" (HNP29, T1).

Finally, several patients were edentulous, which added to their problems with nutritional concerns as they could not chew well. Some reported worry over inadequate nourishment and so liquidized their food to ensure adequate nutritional intake.

By mid-treatment (T2), patients reported a worsening of all symptoms as well as continued weight loss. Some patients reported xerostomia severe enough to almost prevent all eating or drinking and food had lost its pleasure.

After the end of treatments (T3), these symptoms still persisted but some improvement was expressed by half of the sample. Eating and taste had improved and patients reported eating a broader range of foods, which appears to have contributed to some improvement in the patients' weight. However, reports of xerostomia and the lack of saliva persisted by three patients. Patients' focus at this time was commonly around gaining weight. Some patients, particularly at T1–T2, provided lengthy descriptions about the importance of nourishment so their immune system did not become "*depressed*" and importantly, treatments did not need to be postponed. At the one year landmark (T4), participants spoke of improvements in most symptoms although taste changes continued to be a problem for some:

> "My taste is a bit rotten ..." (HNP37, T4).
>
> "My taste ... is not bad but things are not like they were though. It's one of the worst features of this cancer" (HNP26, T4).

A patient who had a laryngectomy described his fear of choking when swallowing:

> "The only frightening bit is, you know, you can choke ... I'm always choking inside" (HNP37, T4).

The management of these symptoms was ad hoc with little concrete information from health professionals. Pharmacological interventions were offered for some symptoms (i.e., morphine for sore throat; moisturizing lotion or aloe vera cream for irritated skin during radiotherapy/skin rashes or sleeping tablets for difficulty sleeping); however, most symptoms were self-managed. Such approaches included drinking water/fluids for dry mouth, liquidizing food, eating soups, eggs and soggy bread or having boiled sweets, sucking on toffees, and other such dietary adjustments. Patients also gargled and used artificial saliva or chewed gum to increase their saliva. Only one patient, a Buddhist, used complementary therapies (yoga) and positive thoughts to manage symptoms. Dietary changes were particularly common as some medicines had unwanted side effects and their effect was short-lived. Patients were balancing the use of the medications with the impact on their lives, for example, opioid antitussives for cough versus waking at night or use of opioids for pain/sore throat versus feeling drowsy.

Tiredness

Tiredness highlights all codes related to being tired and lacking energy including the physical, emotional, and social manifestations of this symptom/side effect. This crucial symptom identified in most patients' accounts of their experiences was tiredness:

> "I am drained completely ..." (HNP6, T2).

Patients variously described this experience as being "lethargic" or having "weak muscles" and claimed it was not relieved by sleep:

> "...it's not that kind of tiredness. It's a tiredness where you find it very difficult to sleep" (HNP27, T1).

This tiredness appeared to cause considerable frustration as patients found they were not able to do the things they used to do, resulting in restrictions on their social life and errands as well as day to day activities at home:

> "... [I feel] tiredness on exertion, lots" (HNP37, T3).

While some patients found their tiredness to be continuous, others described it as intermittent:

> "The tiredness has just crept over me and I just want to lie down and go to sleep ..." (HNP29, T1).

Tiredness was also observed to be exacerbated by having to go to hospital for treatment and the hospital transport itself depleted others of their energy.

Tiredness continued to be detailed at T2 and T3, although some improvement was communicated at T3. Tiredness appeared to be unrelenting at T4, which for some was even more problematic as they were returning to work. They found the tiredness made their return to work a stressful experience. However, for others, changes in energy levels were attributed to "old age."

Radiotherapy Mask

While we have not specifically asked about the radiotherapy mask, half of the patients interviewed talked about their radiotherapy mask and hence this theme describes the emotional impact on patients from the use of the radiotherapy mask. Patients described it with vivid comments:

> "The only thing I hate is having me head locked like, with that mask on..." (HNP29, T1).
>
> "I used to dread it. I felt like Frankenstein putting the damn thing on" (HNP6, T2).
>
> "I call myself Zorro, you know ... That stuff frightens me, that one does" (HNP25, T1).

It was a very distressing experience often leading to panic, as patients could not see nor speak while they had the mask on. Generally, they were unprepared for this experience and found it difficult to cope with it. Potent memories of the mask were communicated even at the 12-month assessment point.

One patient had kept the mask and used it for Halloween as he views it as a horror story. He also uses it to compare the size of his head before (when he had lost a lot of weight) and now, as an indirect measure of weight improvement.

Maintaining Normality

This theme is the constellation of all aspects communicated about returning to normal life, finding meaning in the cancer journey, quality of life concerns, social adjustment, and survivorship/living with cancer. While patients' reports at T1 were mostly centered on treatment effects, at T2 patients described efforts to normalize their life and return to pre-illness lifestyles. Some patients stated thinking "*what now*?" and questioned what the future may bring for them. This was the time patients appeared to be making sense of the positive and negative experiences of having cancer. Financial worries were also communicated as well as worries about the cancer coming back. Some new symptoms had developed over the past few months and patients became hyper-vigilant of these symptoms, particularly those that were linked with their initial diagnosis, such as hoarseness of voice. These symptoms were a source of substantial stress.

At T3, patients described feeling anxious about returning to work and at times felt frustrated because of symptoms they continued to experience. These thoughts were described as "*painful to think*" However, patients equated returning to work with returning to normal, which provided an opportunity to regain some control over their lives.

At T4, most patients of working age had returned to work, although they still found it to be stressful. Patients continued to express feelings of anxiety about their futures and restricted mobility secondary to fatigue. They felt these problems interfered with the quality of their survivorship.

Issues around continuity of care initially expressed at T3 were more prominent at T4 particularly as much of their care now moved from the specialist center to their local hospital and general practitioner. Some patients at T4 continued to express feeling socially inhibited as they did not drink alcohol and did not feel like going out. One patient mentioned that if he talks it gets his throat "*going*" and everyone then looks at him. Hence, he preferred to stay home. Most common ways of coping with the cancer and treatment side effects were positive thinking and comparing their situation to others.

> "... Other patients are bedridden, I got off lightly so far" (HNP6, T1).
>
> "Lots of people are worse off than me" (HNP20, T4).

DISCUSSION

Our findings highlight the "chronicity" of some symptoms and the impact they have on the lives of patients with head and neck cancer. Furthermore, patients' struggles to balance treatments, side effects and everyday life, and the emotionally intense period of maintaining normality and returning to work toward the one year time point were extant. These did not take place in isolation. Patients also reported their impact on significant others, creating even greater complexities.

Key concerns expressed include nutritional issues, such as weight loss, malnutrition, dysphagia, xerostomia, and taste changes. These were present and substantially affected life during the first six months with some improvement over time. However, taste changes were still evident at 12 months. Particularly, the impact of dysphagia on head and neck cancer patients' quality of life has been highlighted in quantitative work with 51–85% of patients reporting swallowing difficulties, some as long as 28 months post surgery or longer (Lovell et al., 2005; Garcia-Peris et al., 2007; Tong et al., 2011), with malnutrition being present in 16–20% of patients (Jager-Wittenaar et al., 2011; Garcia-Peris et al., 2007). Malnutrition has also significant associations with quality of life (Jager-Wittenaar et al., 2011; Capuano et al., 2010). Our data not only confirm these problems but also shows how patients learn to self manage their existence. Xerostomia has been frequently reported in our sample, leading to altered taste and concerns of malnutrition, an area on which the literature has not yet focused adequately. The complex and interconnected experience of nutritional symptoms has been identified in a phenomenological study of eight patients (Larsson et al., 2003) and the altered meaning of food is described in detail in another study of 17 patients (McQuestion et al., 2011). Future research would need to focus on the clustering of these related symptoms and suggest more strongly cause and effect relationships. This may lead to development of preventative or corrective interventions. Eating problems can remain for one year or more after treatments (Larsson et al., 2005) and our study confirms this, particularly in relation to taste changes and weight loss. Weight loss, moreover, is related in patients' minds with worsening of their cancer while weight gain was found to be a major focus in our study after treatments ended. This was connected with returning to "normal" and moving forward with life. Continuous nutritional problems can lead not only to impaired quality of life but also the need for supplements or tube feeding, increasing health care costs. Nutritional supplements are commonly offered to head and neck cancer patients, although most find them unpalatable or unacceptable due to their thickness and taste, and so do not benefit from them. This is vital area of care in need of improvement. Early and ongoing nutritional interventions with regular patient review should also include psychosocial nutritional rehabilitation. This should acknowledge the significance of food, manage related patient anxieties and explore the meaning of food for patients.

Fatigue, although a common and debilitating symptom in most cancer patients, has not been investigated thoroughly in head and neck cancer. We show that it is an ongoing symptom throughout the first year after diagnosis and remains at a high level at all assessment points. Their fatigue was not relieved with sleep, led to significant frustration, interfered with return to work, and restricted daily activities. Fatigue also has been linked with malnutrition (Jager-Wittenaar et al., 2011), creating an even more urgent situation. The literature on cancer-related fatigue highlights the impact of this symptom on everyday life, shows the need for regular assessment and provides some evidence of effectiveness with a number of interventions, including prioritizing activities/energy conservation; exercise; psychosocial interventions; and complementary therapies (Goedendorp et al., 2009; Cramp et al., 2008;

Molassiotis et al., 2007; Sood et al., 2007). All these approaches are applicable to head and neck cancer patients, too, who should be assessed regularly and offered appropriate therapeutic options. Management of fatigue is particularly important when patients are entering longer term survival and fatigue is interfering with returning back to work and living a normal life.

The distress, fear, and panic described in relation to wearing the radiotherapy mask is something that has not, to our knowledge, been identified previously. Patients have vivid memories of this and communicated them to us even at one-year follow-up assessment. Their use of metaphors is informative as they provide understanding of the cognitive and affective underpinnings of patients' illness experiences. They can help patients to shape their experiences in ways that promote adaptation and positive self-regard (Reisfield & Wilson, 2004). Importantly, patients felt unprepared for this experience and this, in itself was distressing. This area of care deserves more attention and patients should be prepared for the experience. Those that find it difficult or anxiety-producing should be offered appropriate interventions to manage their distress. For example, in our hospital, we use progressive muscle relaxation training to calm patients during the radiotherapy session while they are wearing masks. Distraction techniques or listening to music may also be useful interventions.

Maintaining normality was the final key theme identified from our participants, mostly evident in the one-year assessment point. Patients were preoccupied up to the third assessment primarily with their treatment and managing side effects. When treatments were completed, issues about returning to work and to as normal a life as possible within their new limitations became the main focus in patients' lives. Returning to work was viewed both as a positive sign of "*moving on*" with life and as an anxiety generating situation as restricted mobility, eating problems, and fatigue made this transition challenging. These limitations prevented patients from fully reintegrating into the community and maintaining "*normality*." The concept of normality is important in the lives of cancer patients and many strive to avoid cancer having detrimental effects on daily living, often by intentionally "being positive" (O'Baugh et al., 2003). Issues of continuity of care were expressed by several patients at T4, suggesting that they may have felt less secure in relation to their care moving from their specialist cancer center to generalist primary care. Similar feelings have been expressed in past research, suggesting the need for greater consistency in and continuity of care (Larsson et al., 2007a). Patients reported little in the way of coping mechanisms in this study. Thus, enhancing patients' coping skills may improve the transition to survivorship and the illness experience. This area merits further investigation.

While this is one of few qualitative studies of symptom experiences of head and neck cancer patients, its findings need to be interpreted in light of its limitations. The sample consisted of primarily males, and females may respond differently to symptoms and to cancer itself (Dooks et al., 2012). Also, while the longitudinal design of the study allows for some observations to be made over time, comparing and contrasting is less straightforward. The maximal variation sampling method used can be both a strength and a limitation of research, as it focuses on broad issues applicable to head and neck cancer patients irrespective of their specific treatment effects and prognosis. Patient treatment details were not collected over time, and some issues raised in subsequent interviews may be linked with new treatments received or change in the clinical status of patients. Finally, as this study was part of a larger one, interview questions used were generic to fit with the needs of the wider study. This may be a limitation in this current analysis.

Head and neck cancer patients experience a complex treatment and post-treatment process, significant symptoms and difficulties in their transition to survivorship. All these impact on quality of life. With deeper understanding of the significance of these issues and concerns in patients' lives, it is imperative that more effort is directed to consistent and careful patient follow-up both during treatment and in the survivorship period to address these unmet needs for care and support. Development of supportive care nursing clinics may be an important contribution to patients' health and well being, and patients already have positively evaluated such a clinic (Larsson et al., 2007b). The complexity of challenges experienced by head and neck cancer patients requires a rethinking of how supportive care is provided in order to meet patients' physical, emotional and social needs more fully.

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