



Living an everyday life with head and neck cancer 2–2.5 years post-diagnosis – A qualitative prospective study of 56 patients



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ABSTRACT

Rationale: There are many studies available describing how patients are affected by head and neck cancer (HNC) and its treatment. Usually these studies are quantitative and focus on assessing patients' quality of life or distress post-treatment. These studies are important, but they are of limited value if we are interested in understanding more about HNC in an everyday life context.

Objective: The purpose was to determine how life was lived and valued during and after treatment for HNC and to detect different transitions in returning to everyday life.

Methods: During 2009–2012, 56 patients with HNC were consecutively included, and interviewed at 6, 12, and 24 months post-treatment about how they lived their lives. All patients received primary treatment at a tertiary referral university hospital in Sweden.

Results: Four different trajectories and transitions emerged. The first group ($n = 15$) evaluated their illness experience as a past parenthesis in their life suggesting that they had psychologically left the illness behind. In the second group ($n = 9$), the impact of the disease seemed to be diluted by other strains in their life, and although these patients to some extent were still hampered by side effects, they regarded them as 'no big deal'. The cancer really made a difference in the third group ($n = 12$) in both positive and negative ways and seemed to reflect a balance between such effects. In the fourth group ($n = 20$), the physical and/or psychological problems predominated and the patients' lives had changed for the worse.

Conclusion: The narratives showed that being afflicted by HNC has different impacts depending on how the patients live their lives – it is a matter of individual transition in an everyday life context. This idiosyncrasy challenges the meaningfulness of screening efforts to identify vulnerable groups for psychosocial intervention.

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1. Introduction

Head and neck cancer (HNC) includes cancers of the upper aerodigestive tract and represents one of the ten most common cancers worldwide (Mehanna et al., 2010). Due to the location of the tumour and the toxic side effects of treatment, HNC often has a significant impact on the life of those afflicted and is often associated with decreased quality of life and increased psychological distress (Devins et al., 2013; Ronis et al., 2008). Hence, both the

treatment and the illness itself might affect the patient's ability to resume an everyday life after treatment.

There are a great number of studies describing different aspects of how the illness and its treatment affect patients with HNC both physically and psychosocially. Common physical problems include dry mouth and throat, swallowing problems, speech problems, and pain, while the psychosocial problems include psychological distress and damage to the body image and self-esteem (Myers et al., 1999). Most studies that have focused on how patients are doing after treatment assess cohorts of patients with structured pre-defined questionnaires that measure dimensions of quality of life or distress (Chaukar et al., 2009; Rogers et al., 2007).

These kinds of studies are undoubtedly important and are a prerequisite for sound outcome evaluations in clinical trials. We have also learned from them that patients with HNC at a group level seem to return to a pre-treatment quality of life status after

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approximately one year (Humphris and Ozakinci, 2006; Ronis et al., 2008). However, if we are interested in the processes that occur over time with the patient in his/her everyday life context, these studies do not necessarily provide us with sufficient information – the outcomes are remote and impersonal because the variables are decontextualized. Even though a growing number of longitudinal studies have also been conducted (Myers et al., 1999), there is still a lack of studies that examine the patients' own words when they share their concerns and experiences and evaluate the changes in their life situation after being diagnosed with HNC.

We have become rather accustomed to stories of cancer, which are often presented in a 'heroic' form and have become part of literature and media in western culture. In social science qualitative studies, evaluating the impact of chronic illnesses on patients' lives is often connected to a narrative research tradition in medical sociology. This conceptualizes a change in terms of identity, self-concept, or 'biographical disruption', i.e. being sick disrupts patients' views of themselves in the world, which leads them to evaluate their lives differently (Bury, 1982; Charmaz, 1983; Hubbard et al., 2010). However, others have shown that chronic illness is not always disruptive, but might instead be conceptualized as 'biographical continuity' (Williams, 2000) or even 'biographical flow' (Faircloth et al., 2004) – people might 'bracket off' the impact of the illness and thus maintain a sense of a coherent pre- and post-disease self. The illness thus becomes just another part of an ongoing life story. Both Frank (2003) and Sinding and Wiernikowski (2008) further challenge the common simplified templates in society about how life will turn out after chronic illness, and they, in different ways, call attention to the importance of the everyday life context for the understanding of how patients construct their illness experience.

The present study is a contribution to the few qualitative studies that have focused on patients' experiences of living with HNC. In a recent and comprehensive meta-synthesis of qualitative studies of HNC, Lang et al. (2013) stressed that patients with HNC experience significant disruption to normal daily activities both physically and emotionally and that the resumption of everyday life is affected by whether the patients see their life as diminished, merely changed, or even enhanced by the experience of cancer. However, most of the reviewed qualitative studies were based on few participants and did not follow the patients throughout the disease trajectory. As a result, we seldom get to know more than the patients' physical and psychosocial well being at single points in time following treatment. Although a couple of studies have used more prospective designs showing *transitions* (Molassiotis and Rogers, 2012), these studies are mostly based on relatively small sample sizes. Therefore, there is a need for prospective contributions about these transitions based on a larger sample of participants.

The present study followed a consecutive sample of patients with HNC from the beginning of radiotherapy treatment to a point 2–2.5 years later by means of repeated interviews, which were based on the patients' own descriptions of how they lived and valued their everyday life. From an explorative perspective, the purpose was to determine how life was lived and valued during and after treatment for HNC compared to pre-cancer life and to detect different transitions in returning to everyday life.

2. Method

2.1. Participants and procedure

From 2009 to 2012, 145 patients diagnosed with HNC were consecutively included (87% of those asked to participate) in a project that investigated how they experienced health care and different aspects of how they accustomed themselves to a new form of

everyday life. Patients were eligible for inclusion if they had a histologically confirmed diagnosis of HNC and received primary treatment at a tertiary referral university hospital in Sweden. The patients received radiotherapy either as single modality treatment or combined modality treatment. Exclusion criteria were mental/cognitive impairment, drug addiction, palliative treatment, a prior history of another form of cancer, or recurrence of HNC or other forms of cancer. The project was approved by the Ethical Review Board at Umeå University.

All patients participated in a face-to-face interview with a specialist nurse at the beginning and at the end of radiotherapy treatment. These interviews were thematically structured and were intended to gain knowledge about how the patients looked upon the disease process; their well being and appraisal of their situation; their relations to work, family, and leisure time; and if and how their everyday life had changed when comparing their life with their pre-cancer life. The face-to-face interviews were complemented with repeated follow-up interviews that investigated the same themes at 6, 12, and 24 months post-treatment. Most of these interviews were conducted at follow-up visits at the hospital, and when this was not possible they were carried out by telephone. Each of the follow-up interviews was deliberately connected to the previous interview and examined the patient's view on their present life in order to enable a process perspective on the transitions in their everyday life.

The present study is based on the first 58 patients with loco-regional control who participated in the 24-month follow-up interview. Two patients were excluded from the study due to new cancer diagnoses other than HNC. In all, 56 of the 58 included patients were prospectively interviewed five times, at the beginning and end of radiotherapy treatment and three times up to 2.5 years post diagnosis. In total, 280 interviews were conducted.

2.2. Analysis

All interviews were conducted by a specialist nurse involved with the project. Notes were written down during the interviews. The notes consisted of the patients' own statements and descriptions of how they lived and valued their lives. A few appealing statements were also written down word by word. The analysis then comprised the following steps.

The notes for each patient were read through by the first or second author. They then, in temporal order, cut out sections of text into a new document reflecting the essentials of how each patient told about their HNC and its impact on their everyday life (Riessman, 2007). The authors then edited each document into a condensed case narrative (1–3 pages) reflecting a process over time from diagnosis to 2–2.5 years post treatment. The rationale behind this construction of the patients' narratives was the huge amount of data that had to be processed.

The first and second author then independently categorised the 56 case narratives by means of the similarities/differences methodology, i.e. characterising codes were assigned to each narrative that facilitated their grouping based on similarities and differences into categories representing different trajectories (Strauss, 1987).

The first and second author then together scrutinized their respective groupings until they reached dialogic intersubjectivity (Kvale, 1996), i.e. they discussed disagreements until they found consensus and the preliminary categories were constructed accordingly.

Finally, because each narrative was constructed from several interviews and reflected a process containing descriptions as well as valuations, i.e. it was a complex construction, we tested the reliability of the categorization. The third author was given the preliminary categories (groups) constructed by the first two

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