

Patients perceive tonsil cancer as a strike at psycho-socially “vital organs”

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ABSTRACT

INTRODUCTION: Tonsil cancer (TC) is a type of head and neck cancer (HNC) that is predominantly associated with infection with human papilloma virus (HPV). In Denmark, the incidence of HPV-related HNC has increased fivefold over the past three decades. HNC more often affects men than women, and HPV-related HNC tends to affect younger age groups than other HNCs. The present study examined the long-term health-related quality of life (QoL) in patients with TC.

MATERIAL AND METHODS: A medical anthropological approach was applied using individual qualitative interviews with seven former TC patients. The participants included men and women who had undergone various treatments, i.e. radiation therapy, chemo-therapy and operation. Data were analyzed using a narrative methodology.

RESULTS: Treatment sequelae peaked within the first three months and included severe pain in the radiated area, nausea and fatigue. Within this period, patients were unable to eat solid food and often had difficulty speaking. Half of the participants lost some of their hearing due to radiation. Even two years after treatment, most participants had persisting sequelae, mainly xerostomia, porous teeth and reduced mobility of the tongue and jaw. Fatigue and difficulties eating and communicating, in particular, had a very negative effect on the participants' psycho-social QoL.

CONCLUSION: This study allowed for a deeper understanding of the negative effects of HNC on patients' QoL. These QoL effects ought to be included in future considerations of HPV vaccination of boys as well as girls.

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Approximately three out of four head-and-neck cancer (HNC) patients are men [1]. Tobacco use and alcohol consumption have long been predominant risk factors, but recent data show that persisting infection with human papilloma virus (HPV), especially type 16, plays an increasing role in certain types of HNC. Hence, while smoking is declining in the Western world, the overall incidence of HNC is rising [2, 3]. In Denmark, the incidence of HNC has increased more than fivefold since the 1970s and the rate of HPV 16-positive tumours rose from 37% to 72% from the early 1990s to 2009 [4, 5].

The tonsillar region and the base of tongue are the predilection sites for HPV-related HNC [6]. Patients with HPV-positive cancers have a mean age of 59 years; thus, HPV-positive cancers are seen in an age group approximately ten years younger than those affected by HPV-negative cancers, and often in patients with no history of alcohol and tobacco use [7].

The patient often presents with a lump in the neck as the initial symptom. The primary tumour is often small and does not in itself give rise to symptoms. HPV-positive tumours exhibit a separate biologic behaviour that includes improved response to (chemo-)radiation and better survival than HPV-negative HNC [1]. In a recent Danish study, the disease-specific survival rate was 72% in the HPV16-positive group compared with 34% in the HPV16-negative group [4].

Radiotherapy is the primary treatment of HNC, but it is often supplemented by chemotherapy and/or operation. Radiotherapy, in particular, damages the oral mucosa, salivary glands, bone and dentition, and tends to cause mucositis with pain, hypo-salivation and taste loss, radiation caries, and, more rarely, osteo-radio-necrosis. The mucositis and taste loss may subside within the first months after irradiation, while hypo-salivation is usually life-long. Osteo-radionecrosis and dental problems may develop several years later [8].

Any life-threatening disease entails worries about dying, impairment and pain [9]. Quantitative studies examining the quality of life (QoL) of HNC patients have showed that the sequelae of HNC affect key areas such as the patient's ability to speak, eat and drink, in particular, but also hearing and mobility in the HN area are affected [10]. Some studies indicate that depression is particularly pronounced in HNC patients, even compared with other cancer patients [9].

To understand how these sequelae are interrelated and how they affect patients' everyday lives, qualitative research methods are most suitable. A few such studies provide valuable insights into QoL in HNC patients [11, 12]. As a first of its kind, the present qualitative study aimed to focus specifically on 1) the QoL effects of cancer in the tonsillar region (TC) and 2), at a time when the immediate sequelae after treatment had receded and the long-term effects had largely settled. The purpose of focussing on TC was to concentrate on the

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 TABLE 1

Participant characteristics.

Gender	Occupation prior to tonsil cancer diagnosis	Age at the time of diagnosis, years	Age at time of interview, years	Treatment ^a
Male	Self-employed mechanic	52	54	Radiotherapy (+ upper spine), chemotherapy, operation (tumour area and one tonsil)
Male	Self-employed translator	57	65	Radiotherapy, operation (both tonsils and base of tongue)
Male	Engineer	60	65	Radiotherapy, chemotherapy, operation (both tonsils and lymph nodes)
Female (pilot)	Medical assistant (general practitioner)	54	62	Radiotherapy and later neck dissection (no previous tonsillectomy)
Female	Children's dentist	55	62	Radiotherapy, operation (one tonsil and part of the oral cavity)
Female	Reflexologist, employed at an institution for disabled youth	58	65	Radiotherapy, operation (both tonsils)
Female	Public servant (state)	60	64	Radiotherapy, chemotherapy (discontinued due to unacceptable side-effects), operation (tonsillar tissue, tonsils had been removed in childhood)

a) All participants received 33 radiation therapies à 66 Grey. Radiotherapy was always accompanied by medical treatment and intensive pain management.

primary HPV-related HNC type, which is also the largest subgroup of all HNC cancers, and to gain a clearer understanding of the QoL effects of HNC minimally affected by confounders such as smoking and alcohol abuse.

MATERIAL AND METHODS

An initial literature study was carried out to identify relevant topics for a semi-structured interview guide aiming at obtaining in-depth knowledge about patients' narratives of their experiences with TC [13-15]. The interviews were transcribed verbatim and analysed using a narrative approach focusing on the ways patients frame their disease experiences and relate significant elements – such as physical, emotional and social disease impact – to each other [14].

Including a pilot interview, individual interviews were carried out with seven former TC patients (four women and three men) in their homes (Table 1). The participants were recruited via the Danish Network of Head and Neck Cancer Patients. In order to focus on long-term QoL effects, patients were eligible if they had completed treatment for TC a minimum of two years earlier. To focus on patients at working age (as their everyday lives could be otherwise affected than those

of pensioners), participants should be no older than 65 years of age. Their mean age at the time of diagnosis was 56.6 years; at the time of the interviews, it was 62.4 years. No participants knew their HPV status; and because their disease perceptions were central to the study, such data were not subsequently collected. Patients of both sexes were included with a view to capturing any gender differences.

Reportedly, none of the participants had excessive alcohol consumption prior to falling ill. Three never smoked and one had quit many years back. No participants smoked at the time of the interviews. Self-reporting may underestimate such habits, but as far as this could be observed during the interviews, the patients' reports in this regard appeared still to hold true. No personal information about the participants was passed on to the authors and the participants' anonymity was safeguarded throughout the study. All participants gave informed consent and the study did not require ethics committee approval.

Trial registration: not relevant.

RESULTS

The participants' perceptions of their course of disease were highly influenced by their communication with health-care providers throughout the disease trajectory. The extent to which they had been informed about potential side-effects and treatment sequelae varied considerably as did the empathy encountered. As is common in HNC patients, the side effects of radiation therapy set in after approximately two weeks. The skin and oro-pharyngeal cavity was gradually burned, and intense pain, fatigue, nausea and faintness peaked within the first three months after the completion of therapy. The two participants completing chemotherapy suffered temporary hair loss, fatigue and reduced immune defence; one suffered persistently damaged nerve ends. The participant who had neck dissection had severe chronic pain and muscular defects in the entire HN area; she had become permanently unable to eat solid food and had pronunciation problems.

In all participants, radiation caused damage to the salivary glands and was followed by a high sensitivity of the oro-pharyngeal cavity and a disrupted sense of taste. Radiation also caused a propensity to infections and varying degrees of difficulty eating and drinking, which in two persons was linked with porous teeth and gingiva and osteonecrosis.

In combination with a decreased mobility of the tongue and jaw, this meant that some patients had minor speech difficulties.

Most of these sequelae improved within the first 1-2 years after treatment at which point a certain level

of functioning had been regained and advances were small and slow. By then, most were able to consume most foods and drink, though not all and not necessarily easily, and the oral cavity would still be sensitive. Most patients had learned some “tips and tricks” as to when, how and what to consume. Teeth problems, however, would endure or even commence subsequently.

The psycho-social impact of eating difficulties

Clearly, being able to eat and drink is associated with the patient’s ability to uphold life and health. Also, when the participants lost their appetite, the capacity to eat and taste, or they could only consume a special diet in peculiar ways, this had a noticeable impact on their social life. Food often had to be cut into tiny bites and taken with large quantities of water; it had to be chewed for a long time (and in some cases noisily) to be swallowed. Hence meeting over coffee, having dinner with friends or a professional lunch became linked to embarrassment and self-consciousness.

Meals are a significant way of communicating who you are, so identity is affected when you do not eat or if you eat and drink in odd ways. Our participants had felt socially marginalised due to their eating impairments and had missed enjoying meals, talking about food or getting a drink with others. Many had avoided eating and drinking in professional contexts from fear of seeming incompetent.

The quality of life impacts of reduced communication skills and changed appearances

The participants’ speech was variously restricted by xerostomia and/or surgical removal of parts of the oral cavity or tongue. They explained that the capacity to speak clearly is linked to communicating who you are and enter into meaningful conversations with others. As such, this ability was central to their social role and self-esteem.

For some, speech impairment had played an important role in their work capacity. For instance, a nurse had been worried that she might accidentally spit on patients, that they would not understand her or take her seriously. Others felt they had lost their professional authority because others might not find them knowledgeable anymore. At the time of the interviews, all but one was pensioners.

Three participants had hearing impairment following radiation. This would add to their sense of social isolation and further limit their communication and their ability to enjoy the sounds of nature, music, etc. Finally, some participants felt self-conscious about changed appearances. One had visible scars in the head and neck, another had had facial lymphoedema, and many had poor teeth which they felt was stigmatising.

Consequences on psychological quality of life

All participants mentioned fatigue and loss of former strength as sequelae of TC that significantly affected their QoL. Many stated they had often felt too feeble to uphold their usual commitments and to enjoy activities giving their life pleasure and meaning such as travelling, going out and doing sports. Most felt they had never entirely regained their former strength.

All in all, the challenges with respect to communicating, enjoying meals, socialising and engaging in other pleasurable activities caused a much reduced level of psychological well-being. Several participants stated that they had not been as afraid of losing their life as they had been of losing the things giving it pleasure and meaning. Most participants had been unprepared for things not getting back to normal after a year or so and all but one had suffered from depression. Three participants had contemplated suicide at some point in the course of disease.

One participant had turned to alcohol for a while and two got divorced. In another participant, the TC treatment triggered a severe psychosis; and in one it triggered bipolar disease for which he was receiving life-long treatment. All participants had received psychological counselling with varying success.



TEXT BOX 1

“For a couple of years, I didn’t think I had any quality of life, at all ... I was condemned to eating soups or the like. If we went out, I had to be able to get something different from what the others ate. The food really affected my self-esteem. I didn’t feel like being with others if we were to eat. I felt like you’re not worth anything if you can’t even eat. It’s better now because I can eat again, but the two things are really connected”.



TEXT BOX 2

“I thought I’d be fit for fight by then. So it was a shock that late summer to realise that I was absolutely not fit for fight and that it absolutely did not pass. I had all these sequelae. My life wasn’t like it used to be and I would never get it back. I didn’t think life was any fun at all. I had lost all the things that made me happy”.

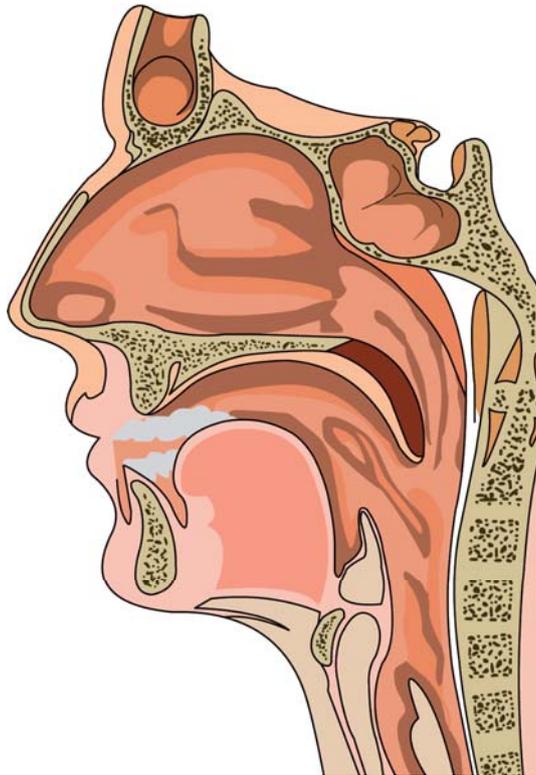
“I felt brutally reduced in all these aspects; I felt I had lost so much of my quality of life. I didn’t know if I would ever get a life that I would find worth living. I didn’t have the fortitude to see the people I wanted to be with. I didn’t think that I was worth being with either. So there was a great loss, a kind of sorrow and the timeline was indefinite. I didn’t know how much I’d be able to fight my way back. The turning point came when I went skiing again – and I could do it”.



TEXT BOX 3

“One becomes more attentive towards the entire body, but on the head and neck area, in particular, because it’s the vital organs you’ve got up here. It’s your hearing, your speech, your appearances – well it’s your whole social life that rests in that area!”.

Anatomy of the nose and throat.



Years after diagnosis, all but one participant had heard that TC can be related to HPV infection, but none knew of their own HPV status. Still, this information caused relief because the relation to smoking and drinking was perceived as stigmatizing HNC as a “life-style disease” that you could only blame yourself for getting. In contrast, HPV infection was not seen as self-inflicted.

To most participants, concerns about relapse gradually receded over time. Still, a particular attention towards potential symptoms would always remain.

DISCUSSION

This study confirms that HNC patients may suffer very negative effects on their psychological as well as physical well-being even in the long term. A quantitative study carried out among Danish HNC patients showed that 67% had more than 20 sequelae [16]. We used qualitative research methods to further understand how TC patients’ everyday lives were affected by the interplay between the disease and its sequelae. Qualitative interviews with a limited number of participants allow us to understand a phenomenon in depth, and the results may be generalised analytically, but not statistically. This is a strength as well as a limitation.

Including patients via the patient network may involve some negative selection bias, since they might represent patients with more severe sequelae. The opposite may, however, also hold true as some partici-

pants said they came forward on behalf of those who were too feeble.

The ability to socially communicate who you are through dialogue and behaviour, such as table manners, is central to upholding a positive notion of self-worth. Eating impairments alone often carry an emotional as well as a social loss as food is a medium of socio-cultural interaction as well as a way of giving and receiving consolation, love and care. You show your persona and social status through food, and food and weight is connected to a sense of normality and health [17].

The present study showed that the severe psychological sequelae of TC could be caused by HNC treatment so seriously affecting a part of the body that is of vital importance to aspects of life carrying joy, pleasure and meaning – what one patient called the “vital organs”. The affected functions are also associated with personal characteristics, such as intelligence, etiquette and professionalism. Most patients in this study had become unable to uphold their jobs. This is noticeable since TC often affects people at working age. Men and women appeared to be equally affected by the disease.

It is very important for patients that health-care professionals understand the QoL effects related to HNC and inform patients about the common physical and psycho-social effects of the treatment of HNC as well as the health-care system’s offers of support by psychologists, patient groups, physio- and occupational therapists, specialised dentists, etc.

Today, it is considered likely that HPV vaccination will protect against HPV-related HNC, but this is difficult to show in clinical trials. Recent trials show a very high efficacy of quadrivalent vaccination, not only on cervical cancer, but also on other HPV-related ano-genital cancers in men and women [18, 19]. This perspective is very promising and the expected prevention of many cases of HNC is one of the reasons why some countries now recommend HPV vaccination of boys as well as girls [20]. While we cannot know how many of the patients in this study could have avoided TC through vaccination, it appears likely that not only lives but also immense suffering may be spared though future HPV vaccination of both sexes.

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