



Perceptions of life and experiences of health care support among individuals one year after head and neck cancer treatment – An interview study

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ABSTRACT

Purpose: To examine how individuals treated for head and neck cancer perceive life one year after the end of treatment and how they experience supportive efforts from health care.

Methods: A semi-structured interview study of 21 patients was performed one year after the end of treatment. The patients gave their views concerning physical, psychological, and return-to-work issues, and their experiences concerning rehabilitative efforts from health care and particularly the contact nurse were captured. A thematic analysis was conducted.

Results: One year after treatment the patients were still suffering from side effects and from fear of recurrence, but they strived to live as they did before the cancer diagnosis, such as having returned to work and resuming leisure activities. Moreover, the rehabilitative efforts from health care had ended. Having access to a contact nurse, also known as a clinical nurse specialist, was positive, however, the participants lacked regular long-term follow-ups with the contact nurse regarding rehabilitation needs. Improvement possibilities were seen in clarifying the role of the contact nurse and that the contact nurse should show engagement and make the initial contact with the patients.

Conclusion: Despite the sequelae from treatment, the patients strived to live as before their diagnosis. By regular, engaged, and long-term follow-ups by the contact nurse, remaining needs may be uncovered, and appropriate individualized support and rehabilitation can be offered.

1. Introduction

Head and neck cancer (HNC) includes malignant tumours of the oral cavity, nasopharynx, oropharynx, hypopharynx, larynx, paranasal sinuses, and salivary glands (Mehanna et al., 2010). Both the tumour and treatment may, to different degrees, affect vital functions such as eating, speaking, and breathing. Surgical treatment may also alter physical appearance. In patients receiving radiotherapy or chemoradiation the acute treatment-related physical symptom burden such as swallowing difficulties, dry mouth, trismus, and pain, tends to be most pronounced at termination of treatment. Even if acute side effects decrease over the months after treatment some difficulties, such as taste changes and dry

mouth, are reported to last for years (Greedy, 2022). Further, patients may suffer from general consequences of cancer and cancer treatment such as fatigue (Bossi et al., 2019), fear of recurrence (Casswell et al., 2021), anxiety, and depression (Götze et al., 2020; van Beek et al., 2020). However, there is an interindividual susceptibility to treatment-induced effects and also patients' experiences of side effects differ. A number of studies have shown that the burden of side effects is negatively affecting the quality of life (QoL) (Abbas et al., 2019), returning to work (Chen et al., 2021), and socializing with others (Einarsson et al., 2019).

The complexity of HNC, its treatment, and its post-treatment difficulties stress the importance of health care system addressing supportive

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and rehabilitative issues during and after treatment in restoring QoL and resuming everyday life. Nowadays patients are generally cared for by multidisciplinary teams, including contact nurses (CNs). The CN is defined as a nurse with knowledge of the specific cancer diagnosis and its treatments and who plays a dedicated role in supporting and facilitating the patients during and beyond their cancer trajectory. The CN is also recognized as a clinical nurse specialist (Greedy, 2022). Frequent nurse-led follow-ups and supportive approaches such as targeted nurse-led pre- and post-surgical education programmes have been shown to improve QoL (Khantwal et al., 2021). Despite positive results as such, studies have shown that months and even years post-treatment, many patients treated for HNC still suffer from several unmet needs, and these mostly concern emotional issues such as dealing with physical changes, fatigue, and anxiety (Lee et al., 2016). Nowadays, the CN function is widely implemented (Fulton et al., 2016; Visser et al., 2015), having access to professional, engaged, and competent nurses is beneficial on several levels and helps the patient feel safe, secure, and included (Isaksson et al., 2014). With the aforementioned objectives in mind, Sweden introduced the National Cancer Strategy in 2009 (SOU, 2009). This strategy aimed to enhance the quality of cancer care, minimize disparities in cancer treatment across different national regions and population groups and ultimately improve the overall QoL for individuals affected by cancer. A key component of this strategy is the provision of a named CN to all patients suffering from cancer. However, a Swedish study conducted in 2018, which evaluated the effectiveness of the strategy, revealed that only 53% of patients with cancer reported being assigned a CN (Westman et al., 2018).

Several studies have shown that many patients treated for HNC have long-lasting side effects that affect everyday life to different degrees. The present qualitative study will contribute to further insights by allowing patients to express their post-treatment experiences and their views on receiving supportive efforts from health care.

2. Aim

The aim was to examine how individuals treated for HNC perceive life one year after the end of treatment and how they experience supportive efforts from health care.

3. Materials and methods

3.1. Participants and procedures

The present study was part of a prospective interview project performed at two university hospitals in Sweden. From November 2018 to March 2019, patients diagnosed with HNC and about to finish curative treatment were invited to participate. Additional inclusion criteria were age over 18 years and performance status 0 to 2 according to the Eastern Cooperative Oncology Group Performance Status/World Health Organization Performance Status (WHO PS) (Oken et al., 1982). Exclusion criteria were severe alcohol/drug abuse, cognitive impairments, and inability to understand the Swedish language. The project was approved by The Uppsala Regional Ethical Review Board (No. 2016/244). All patients received oral and written information, and written consent was obtained. Forty-three patients were asked and a total of 25 patients agreed to participate in the project, which was considered as a sufficient number, and in the present study 21 patients were included in the final analysis.

3.2. Data collection

For the project, a thematically structured interview guide including questions about the participants' physical, psychological, social, and existential well-being was developed using concepts from the literature and clinical experiences. Each participant was interviewed on three occasions, including at the end of treatment ($n = 25$), 2–5 months later

($n = 24$, one drop-out), and approximately one year after the end of treatment ($n = 21$, one too ill, two deceased). All interviews were conducted in an undisturbed environment and were audio recorded. The interviews were performed face-to-face by the first author (BG) at one of the hospitals and by the third author (NW) at the other hospital. Twelve of the interviews were conducted by telephone due to the COVID-19 pandemic and the long distances to the hospitals. All participants were anonymised.

The focus of the present study has been on the last interview, one year after treatment termination, including 21 participants' perceptions of life and returning to work and how they experienced the role of health care and particularly the CN responsibilities. The questions asked are shown in Box 1. Data about marital status, living conditions, education, and working situation at the time of diagnosis were included in the interview guide and were answered by the participants. Medical data such as tumour site, cancer stage, and treatment were obtained from the patients' medical records. Characteristics of the participants are presented in Table 1.

3.3. Analysis

Due to the broad research questions and the fact that the participants were recapitulating the first year after treatment, the six phases of thematic analysis were used (Braun and Clarke, 2006). The first phases of the analysis were conducted by the first author (BG). (1) Initially, the recorded interviews were transcribed verbatim by the two interviewers. To become familiar with the interviews, the transcripts were read and re-read and searched for meanings and patterns, and a list of the contents was created. (2) To prevent missing narratives of significance, all of the data were initially coded and organised into groups. (3) Thereafter an initial thematic map was produced to enable an overview of the groups. Codes of interest for the study purpose were identified and sorted, and the first draft of potential themes and sub-themes was created. (4) This initial map was further developed into a thematic map by reviewing and refining the initial sub-themes and themes, and the data within the themes were re-examined to ensure that they were internally consistent and coherent, and suitable quotes were added. (5) Final reviewing, refining, and redefining of the themes was performed, and final naming was established in joint consensus by the first, second (JI), and last author (YTE). (6) A description of each theme was developed. The initial themes were ultimately refined into two themes and with two sub-themes for the first theme. The themes and sub-themes are presented in the result together with illustrating quotes.

3.4. Scientific rigour

The trustworthiness of this study was judged against the four criteria of Lincoln and Guba, namely credibility, dependability, transferability, and confirmability (Lincoln and Guba, 1986). Credibility rests on the two interviewers' (BG, NW) experiences of patients with HNC; however, a limitation of the study may be that the two interviewers may have had different interview approaches that may have affected the results. The participants were recruited at the end of treatment, and both interviewers had therefore met the participants earlier during the treatment period and thus were not strangers to them. Because the interviewers were not involved in the participants' overall treatment and care, these previous meetings hopefully contributed to the participants feeling safe and secure in the interview situation. The results are grounded in the narratives given by the participants; however, the participants chose what to share. The semi-structured interview guide was created by authors with experience from HNC and qualitative research (JI, GL, and YTE) and was created to be relevant for patients with HNC. The description of the analysis process and the inclusion of quotations may have further enhanced the study's credibility. The continuous discussions among the authors in reaching intersubjectivity strengthened both the credibility and dependability of the study.

Box 1

Interview topic guide

Key question summary – follow-up one year after treatment.

How are you doing physically?

How are you doing psychologically?

How are you doing socially?

Are you affected by side effects, and if so, how?

How has your rehabilitation been going?

Regarding your plans concerning return to work, how do you reflect on them now?

Have you had contact with professions within health care after treatment termination?

Have you had contact with the contact nurse, in which matters, and have you received the expected support?

Have your expectations concerning the contact nurse been fulfilled and functioned as you imagined?

Is there anything you are satisfied/unsatisfied with concerning the current function of the contact nurse?

Do you have suggestions on how the contact nurse function could be further developed in supporting the patients?

Table 1

Baseline sociodemographic and clinical characteristics of 21 patients with head and neck cancer. Numbers (n) are given.

Characteristics	Number (%)
Number	21
Age, median (min-max)	61 (36–75)
Sex	
Male	17 (81)
Female	4 (19)
Marital status	
Married/in a relationship	17 (81)
Single	4 (19)
Working situation at time of diagnosis	
Working	16 (76)
Retired	5 (24)
Working situation one year after treatment	
Working	14 (67)
Retired	7 (33)
Tumour site	
Oropharynx	12 (57)
Oral cavity	3 (14)
Larynx	3 (14)
Salivary gland	1 (5)
Unknown primary tumour	1 (5)
Nasal cavity	1 (5)
Cancer stage, UICC 8 ^a	
I	12 (57)
II	5 (24)
III	2 (9)
IV	2 (9)
Treatment	
Surgery	1 (5)
Surgery + radiotherapy	5 (24)
Radiotherapy	6 (28)
Radiotherapy + chemotherapy	8 (38)
Radiotherapy + chemotherapy + surgery	1 (5)

^a Union for International Cancer Control 8th edition.

Dependability was further strengthened by showing the questions asked in the interviews (Box 1) and by describing the steps in the research process, which gives the reader insights into the research process. Transferability was enhanced by describing the purpose of the study, the selection and characteristics of the participants, and the processes of data collection and analysis. Two factors that may have affected transferability and biased the results include sex - there were more male than female participants, although this was in line with the sex difference in HNC incidence in Sweden - and the fact that most participants were

diagnosed with oropharyngeal cancer and thus might not be fully comparable with other disease locations within the HNC area. Also, the facts that all participants were treated with a curative intent, that most had a tumour stage I-II, and that they were asked for participation at the end of treatment might indicate that patients with larger tumours and with the most severe side effects may have declined participation, and this may have biased the results. Confirmability was ensured through the audio-recording and verbatim transcription of the interviews, which allowed the participants' experiences to be captured. Reflexivity was strengthened by the interviewers' being aware of their prior knowledge of HNC.

4. Results

The results show how the participants perceived their lives one year after the end of HNC treatment. They were all striving to live life as normal as possible by engaging in leisure activities, working, etc., despite late and long-term side-effects and sequelae due to their treatment. Surviving a cancer disease may put one's life in a new perspective; however, once completing treatment and having left the period of intensive supportive care, it seemed to be difficult for the participants to seek and ask for support from the out-patient health care services. The most noteworthy finding was that the participants lacked regular follow-ups regarding rehabilitation and contact with their CN even one year post-treatment. Two themes were found to describe life one year post-treatment, namely **Adapting to a new life** with the two sub-themes *Finding a new everyday life despite disarray* and *Thoughts of cancer and fear of recurrence*, and **Health care support is available yet distant**.

4.1. Adapting to a new life

4.1.1. Finding a new everyday life despite disarray

Even though the side effects from treatment had improved over time and the participants were more or less performing activities similarly to before their diagnosis, several remaining side effects were described. The participants could still suffer from treatment-related side effects such as dry mouth, taste changes, difficulty swallowing, mucus, voice issues, and lump-like sensations in the throat. Also, post-surgical sequelae such as a stiff neck and weak arm strength after neck dissection, a dysfunctional mouth, swallowing issues, troublesome and exhausting speech, and facial disfigurement were experienced. Further, fatigue and disturbed sleep were mentioned. Despite this, the

participants had a positive attitude towards their difficulties and strived to live life as before their cancer diagnosis by engaging in activities, socializing, and working.

"Physically I feel good [...] however, strength is a problem [...] there are small side effects that don't really affect anything." (Participant 16)

"Over this part of the face, there is pressure, it stings, it beats [...] it's still very stiff and bumpy there, all the scars and all, [...] so, that's what bothers me [...] I try to do ordinary things too, go downtown. I think people take this... so, you see that people look at you when you come but it isn't, I think it goes relatively well. People are tolerant, I think [...] The lip hangs down [...] if you eat a sandwich, you must ask for a knife and fork, it's just that." (Participant 24)

Of 16 participants who were working before the diagnosis, 14 were working one year post-treatment, and of these 9 had returned to work at 1–5 months post-treatment. Two had not taken a single day off during or after treatment. The return-to-work process differed among the participants, and 7 participants returned full time 1–5 months post-treatment, 5 adopted a softer way back to work by returning part time and then successively increasing their working time, and 2 participants had not yet reached full time at one year post-treatment. Most participants had had contact with their workplace during their sick leave, and they knew they were welcomed back when they could make it. Further, to facilitate returning to work they were offered to work part time with slowly increased hours, facilitated work tasks, or temporary reassignment to other duties. The participants had different reasons for choosing full or part time, for example, due to the surgery one participant had an arm that was not fully mobile and had less strength, but although the work required two strong arms, thanks to a supportive workplace the participant was released from the heaviest tasks. Also, one participant started part time to spare the voice, while another could, due to other task assignments, work full time.

"I could start coming back half time and be on the administrative part, and my substitute, she took the lesson part. So that I could come back at a pretty good pace." (Participant 11)

To be working was seen as overall positive and stimulating and that it prevented staying at home thinking about the illness, but it was also important due to financial issues. The participants experienced themselves as managing their workdays well, but fatigue was reported. Evenings and weekends were for resting and gaining strength, and in hindsight some said that they might have returned to work too early after treatment. Hearing loss, tinnitus, and numbness in the feet due to cisplatin-based chemotherapy were further factors negatively affecting the workday.

"... so it is, you're tired in the evening, but you have not been before, not in that way." (Participant 1)

Concerning the participants who were retired, most of them experienced having more or less regained their strength and could manage daily chores such as working on the farm, fishing, going to the gym, dancing, renovating the house, and participating in associations.

4.1.2. Thoughts of cancer and fear of recurrence

Even if most participants were feeling psychologically well, psychological ups and downs were expressed. Although most participants had reached a point where the cancer was not occupying their minds on a daily basis, thoughts about the cancer were never far away and they were always aware of the risk for recurrence. New sensations such as pain, a changed voice or swallowing pattern, or peculiar feelings in the neck immediately awoke fear and anxiety.

"But that's how it is, thoughts come at different times. Sometimes you are in an upward curve, and then everything is fine and sometimes you go downhill when you think it's hard, and think about what's hard [...] I'm maybe up and down pretty fast." (Participant 23)

Before the regular medical follow-ups, thoughts and fears of recurrence arose to different degrees. The participants strived not to worry in advance, although as the date of the appointment approached worries and anxiety began to grow.

"The days before you have to go to a check-up appointment, then you start to feel like, yes feel, yes but isn't it a little tender, a little tender here maybe, ehhh yes like that." (Participant 4)

In sum, striving to resume their everyday life as before the diagnosis by taking up activities and returning to work showed the positive attitude these patients had. This was despite struggling with both physical side effects from treatment and the fear of recurrence.

4.2. Health care support is available yet distant

Taking into consideration the number of physical and psychological issues arising from the participants' illnesses and treatments, and which were still present in daily life one year post-treatment, the second theme captured how the participants experienced supportive efforts from health care during the first year after treatment. After undergoing treatment, the focus was on regaining strength, being able to eat, and improving their voice and speech, and they longed to resume their activities from before their diagnosis. During the first post-treatment period of about 3 months, most participants had follow-ups with, for example, a speech therapist, dietician, and dentist and/or performed specific exercises with the help of programs and schedules they had received from health care. However, after 3 months these contacts ceased. One year after treatment one participant had resumed contact with a speech therapist due to difficulties in managing voice rehabilitation without support, and another was considering resuming contact with the speech therapist. One participant had a known almoner and felt safe with the possibility to resume contact if the need should arise. Returning to leisure activities as before the diagnosis was also seen as a rehabilitative action in regaining life. None of the participants had received an individual rehabilitation plan, but the benefit of a rehabilitation plan was mentioned.

"It's important that when you go home you get clear instruction on what to do in the form of a plan or good tips and advice and so on [...] physical exercises you can do, and foods you can eat, and yes, all that such stuff ..." (Participant 15)

At the time of diagnosis, all participants had a dedicated CN and had received their contact information, but one year post-treatment only a few reported that they still had contact with the CN. Having a name and number and the possibility to make contact if needed was well appreciated and gave feelings of security. The CN was experienced as a safety net and a channel into the health care system and as a professional, and it was appreciated when the CN made contact.

"I have spoken with the CN several times, and the CN has called a few times, so I think that is positive." (Participant 17)

Less appreciated was when health care failed in its commitment, such as when the CN function was experienced as vague, invisible, or lacked engagement, and when the post-treatment transition between clinics was unclear.

"You kind of thought maybe that they would contact you in the future as well, but no, it has not been that way, but I haven't called them either, no more than when I would have called and booked an appointment." (Participant 2)

Such flaws could result in a lack of confidence towards the CN and feelings of rejection, and when having questions some patients looked for answers elsewhere within the health care system, on the Internet, or through national health care support.

"There is no one asking, how are you? So they ask everything, but it isn't supportive in that way, how is the rehabilitation, do you need help? I haven't experienced that commitment." (Participant 19)

Regardless of the experiences the participants had with the CN, possibilities for improvement of the CN role and function were expressed. The transition between CNs and clinics should be more clarified, and the CN should not be based upon one specific person, but as a service that would not be absent, for example, during vacation periods. The role of the CN would benefit from being more structured and clarified, and the CN should take the initiative in contacting the patients. Further, it is important that the CN is open on a personal level and shows interest and engagement in the individual patient.

"If you are a CN, you must also show that you have that role, so you have a special role towards me as a patient, and I don't really feel that [...] it feels like, eh, you [the CN] should be a little more open to the patient and show that you have that role, otherwise I don't really understand it." (Participant 13)

In sum, although support was available after leaving health care, rehabilitative efforts had ended after one year post-treatment. Having the name and number to a known CN was undoubtedly positive, but the function would benefit from being more clarified and by the CN showing more engagement.

5. Discussion

The purpose of this study was to examine how individuals treated for HNC perceived life one year post-treatment and their experiences concerning supportive efforts from health care. At one year after treatment, the participants had returned to work and had resumed leisure activities in spite of remaining physical or psychological side effects. An important finding was that rehabilitative efforts from health care had one year post-treatment ended although needs of rehabilitation remained at a considerable level. Having access to a CN was seen as positive, but the participants lacked regular and long-term follow-ups by the CN. Further, the participants saw improvement possibilities concerning supportive efforts from health care, mainly structured and safe transitions between hospitals and clinics and making the CN function more structured and engaged.

Even if the side effects had improved one year after treatment, there was a wide spectrum of remaining physical and psychological side effects among the participants that affected them to different degrees. The strive to regain and live life as before the diagnosis refusing to withdraw from returning to work or joining social contexts with others was visible in this study. The desire to take charge of life and not letting cancer take control may be referred to as perceived self-efficacy (Hoffman, 2013). This belief in one's capability to realize behaviours in reaching a desired result is reported to be essential in reaching positive goals, such as increased QoL (White et al., 2019), and in self-management (Barlow et al., 2002). In the present study, the participants were seen to use strategies such as having a positive attitude towards their situation, incorporating physical side effects as part of their new daily situation, returning to work and/or resuming other activities from before the diagnosis, striving not to worry, and continuing to socialize with others, this is in line with previous research (Dunne et al., 2017).

Resuming everyday activities as before the diagnosis and returning to work were powerful driving forces. Despite side effects and regardless of type of HNC, 14 of the 16 participants who were working at diagnosis were still working one year after termination of treatment, and 2 had retired. Notwithstanding the relatively small number of participants in the present study, this was a positive and important result because patients with HNC, in comparison with other cancer diagnoses, are reported to be a vulnerable group in returning to work (Cooper et al., 2013; Ross et al., 2012). As described in the results, returning to work was meaningful in different respects, such as being stimulating, giving

structure and purpose to everyday life, and providing financial security, which is in line with other studies (Isaksson et al., 2016; Wells et al., 2013), but may also be driven by factors such as a sense of duty and morality. According to Swedish legislation, the employer is responsible for rehabilitation measures at the workplace (Socialförsäkringsbalk, 2010:110), and most participants experienced a supportive workplace/employer offering the possibility to return when feeling ready, to work part-time, and to have adjusted work tasks. However, work required strength, and it was leisure time that paid for this. These mixed experiences of being positive about returning to work, but also being exhausted from working, have been previously described (Isaksson et al., 2016). The strategies used in this study suggest that to see life in a positive way seems to be a conscious choice and, one year post-treatment, even if the side effects had improved there was a wide spectrum of remaining physical and psychological difficulties involving such as fatigue and fear of recurrence. This multi-dimensional world the participants were living in is important for the CN to acknowledge and address in a longer-term perspective. In the present study the CN was positively described as being professional, and the participants felt safe and secure in having this easy access to health care. However, one year post-treatment rehabilitative efforts from health care had ended and the participants lacked regular follow-ups with the CN. Most rehabilitative efforts had ended as early as 3 months post treatment, a time when the participants were entering a new era when acute side effects have faded and they must face and accommodate to long-lasting and often irreversible sequels (Nilsen et al., 2020). This risk of lack of organized support from 6 to 12 months post treatment is recognized in previous research (Moore et al., 2014). In the present study the participants saw possibilities for improvement. A CN making contact, showing engagement in care and well-being, and showing openness was appreciated and wished for. Having such an open approach towards the patients may facilitate the healing process and increase the possibility for a good nurse-patient relationship to be established (Rchaidia et al., 2009). An individual rehabilitation plan may be beneficial in recognizing and approaching remaining needs and may also decrease the risk for patients becoming lost in transition within the health care system. Although the CN function is not new, our results may be an indication that the function may not have reached its full potential in terms of structures and routines.

6. Conclusion

There are several layers in the present study. The participants pointed out that the transition of care within the health care system is critical for a safe and trustful shift of CN nurses and need to be developed. One year after treatment for HNC, the participants strived to live life as before the diagnosis and showed a great deal of self-efficacy and self-management. However, vulnerability was found in the remaining sequelae, fear of recurrence, and fatigue. Self-managing seems to be an active choice and requires hard work, and the participants saw possibilities for improvement of the CN function in addressing and supporting the needs they still had. This study indicates that supportive and engaged nurse-patient follow-ups may be beneficial in both the short and long term in regaining everyday life after treatment. Further research is needed, both concerning the numbers of patients having access to supportive efforts from health care and CNs, but also qualitative studies investigating the perceived benefits from such meetings.

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CRedit authorship contribution statement

Brith Granström: Formal analysis, Data curation, Writing - original draft, Writing - review & editing. **Joakim Isaksson:** Conceptualization, Writing - original draft. **Nilla Westöo:** Data curation, Writing - original draft. **Thorbjörn Holmlund:** Writing - original draft. **Krister Tano:** Writing - original draft. **Göran Laurell:** Conceptualization, Writing - original draft. **Ylva Tiblom Ehrsson:** Conceptualization, Writing - original draft, Supervision.

Declaration of competing interest

None of the authors have any conflict of interest.

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