



Providing care to a family member affected by head and neck cancer: a phenomenological study

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Abstract

Background Cancer is recognized as a family illness as many head and neck cancer (HNC) patients after treatment require assistance from a family caregiver throughout the rest of their life. The purpose of this study was to explore the lived experience of primary family caregivers of HNC patients dealing with laryngectomy regarding their complex supportive role.

Methods Phenomenological study based on individual interviews of twelve primary caregivers of HNC patients, recruited by purposeful sampling. Interview contents were analyzed in depth, in accordance with Colaizzi's descriptive analysis framework, to explore and identify significant themes and subthemes.

Results Analysis evidenced three main topics and subthemes embracing various aspects of the caregiver's lived experiences: (1) experiencing disease and the pathway of care, (2) handling changes to everyday life, and (3) support received by others.

Conclusion Given the essential role the caregiver has in the patient's post-treatment recovery, future planning of HNC patient care must consider the caregivers' needs. In order to guarantee an appropriate and effective health professional care, it is important to consider caregivers' issues and needs as part of HNC patient care planning from the diagnosis to the follow-up.

Keywords Caregiver · Survivorship · Head and neck cancer · Life experience · Oncology · Needs

Introduction

Head and neck cancer (HNC) represent a group of anatomically close tumors but with heterogeneous etiology, histology, diagnostic, and treatment [1]. The disease is mainly associated to risk factors such as smoking, alcohol abuse, and human papillomavirus' infection and is most frequently diagnosed

in men (four-fold higher risk of HNC in men compared to women, with 16.9 new cases every 100,000 vs 6.2 cases diagnosed between 2010 and 2014) [2, 3]. Treatment for HNC in most cases requires surgical resection, and in case of total laryngectomy results in substantial physical disfigurement and long-term functional impairment (e.g., food intake problem, breathing, swallowing, and speaking difficulties) [4–6],

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inevitably entailing the involvement of a caregiver for carrying out basic everyday activities [7, 8].

In family-based societies, care is most often provided by a close relative (spouse or child), who takes on the role of caregiver, in acceptance of their emotional tie to the patient/family member, even though they have no training or awareness on what this involves [9, 10]. A proficient caregiver may positively affect clinical outcomes for the patient; however, the caregiver may be affected by their change in roles, long-term care commitment, and responsibilities which cause the caregiver psychological distress, sense of inadequacy, guilt, and of being overwhelmed [11, 12]. Indeed, caregivers come to accompany the patient in every aspect of daily life to the extent they become, as some authors have identified it, a single unit with the patient, in a patient-caregiver “dyad” [13, 14]. The role and involvement of caregivers is not a new topic in medical literature. However, differently from other conditions, HNC and its invasive surgery may result in a quite peculiar setting: recovery after invasive surgery is particularly difficult and frustrating for the patient. Moreover, HNC comes with an unspoken corollary of patient behavioral issues (often the underlying cause leading to the cancer), which are not shared with other disease settings. Few studies have documented the quality of life of caregivers for HNC patients [15–18], as to needs in terms of literacy on laryngectomized patient assistance [7, 19], or their experience and psychological adaptations to their family members’ illness [19, 20].

The purpose of this study was to explore, through a phenomenological approach, the lived experience of primary family caregivers of HNC patients dealing with laryngectomy.

Methods

Study design

The study was carried out as a descriptive phenomenological study [21]. Compared with other approaches, this allows us to explore the essence of a specific phenomenon as lived subjectively by participants, and to investigate in depth what is essential and meaningful to them [22]. Participants were selected purposively for their aptitude to be self-reflective and express themselves verbally when interviewed [22]. The research question was “What is the lived experience and meaning of being a family caregiver to a HNC patient dealing with laryngectomy?”

Sampling and participant recruitment

The study was conducted between June and July 2017, thanks to the endorsement by the Friuli Venezia Giulia Laryngectomized Patient Associations who helped the researchers contact potential participants. Researchers reached

eligible participants by phone, explained the objective of the study, and asked their availability for an interview.

Caregivers were recruited according to the principle of purposive sampling [23]. Inclusion criteria were (1) being at least 18 years of age; (2) having assisted a family member with HNC who received radical surgery, from the diagnosis to the end of active treatments; (3) fluency in Italian language; and (4) with no documented cognitive impairment.

Data collection

Information was collected by in-depth interviews conducted by two trained nurse researchers using a pre-planned guide for interviews that guaranteed the inter-rater consistency (Table 1). Caregivers were asked to describe and comment on their experience throughout the patient’s illness path. Special attention was devoted to the interviewees’ experience and perceptions, and when necessary, researchers posed probing questions in attempt to obtain detailed narratives [24]. Data collection ended after 12 interviews, when saturation was reached [25]; researchers recognized that no further significant information emerged and that all the themes had been confirmed by the sample. The interviewers did not know participants. The interviews, which lasted from 14 to 45 min, were recorded digitally and transcribed verbatim.

Data analyses

Interview contents were analyzed using Colaizzi’s descriptive analysis framework [21], divided into seven analytical steps: (1) reading of interviews by three researchers who listened to audio and read transcripts several times to get a sense of participants overall experiences; (2) identification of significant statements; (3) formulation and validation of meanings through team discussions; (4) organization of each significant statement into meaning units and subtheme into major themes; (5) checking of meaning units, subthemes, and themes by expert qualitative researcher; (6) meeting with participants for interviewers to return interview transcripts and discuss

Table 1 Interview guide

- | |
|---|
| 1. What feelings did you have when your beloved received the diagnosis? |
| 2. How did you feel about the treatments? |
| 3. What meant your beloved illness to you? |
| 4. Could you please tell me about your daily life? |
| 5. Could you tell me how you feel now? |
| 6. How do you see your future? |
| 7. What do you feel when you talk about this experience? |

emerging results; and (7) definition of overarching statements to summarize the participant's lived experience.

Analyses were done collaboratively and managed using purposely structured Microsoft Word tables.

Trustworthiness

To ensure trustworthiness and credibility throughout the study [26, 27], the researchers worked in team and systematically applied the agreed framework for the analysis. A panel of other three researchers who did not participate in the initial analysis reviewed, confirmed, or implemented findings gathered [28]. Finally, to guarantee that all analysis process could be traced back to interviews, an audit trail was maintained by an expert in qualitative studies researcher. Final findings were also submitted to participants to have them confirm/or not that these actually represented their experience.

Ethical considerations

The study protocol was approved by the Udine University Internal Review Board. Participation was voluntary and written informed consent was obtained from all individual participants involved in the study. All data handling were treated as confidential and anonymous; furthermore, participants could leave the interview at any time.

Results

Participant characteristics

Study participants included 12 caregivers (11 female) with mean age 63.8 years (range, 47–76), of which nine were spouses, two daughters, and one was a patient's son. In one case, a patient was assisted by two children, so both were interviewed as they had a significant role during the illness trajectory. Ten caregivers used to live in the same household with the patient. The demographic characteristics of participants are presented in Table 2.

As to the 11 patients (9 males), at the time of interviews, they had all undergone total laryngectomy and were followed up at a public outpatient Ear Nose & Throat Specialists Otolaryngology Head & Neck Service; none had been diagnosed a recurrent malignancy. Five had undergone surgical intervention alone, while the remaining also received radiotherapy after surgery.

At the end of analyses, researchers identified three main topics and subthemes: (1) experiencing disease and the pathway of care, (2) handling changes to everyday life, and (3) support received by others.

Table 2 The characteristics of the participants

	Number ^o	%
Caregivers	12	
Average age (years)	63.8	
Gender		
Male	1	8.3
Female	11	91.7
Relationship with the HNC patient		
Spouse/partner	9	75
Adult child	3	25
Education		
Middle school or primary school	9	85
High school	3	15
Occupational status		
Employed	4	33.3
Unemployed	1	8.3
Retired	7	58.4

Theme 1: Experiencing disease and the pathway of care

Receiving the diagnosis

As expected, diagnosis in most cases was received by the caregiver as a traumatic experience, even among two caregivers who were dealing with the recurrence in their beloved of a previous NHC. In most cases, the caregiver/family member considered the disease as emotionally impacting and associated the experience with negative feelings, such as disorientation and fear for the future and the struggle to deal with everyday challenges in assisting the patient or having to reestablish family management. Those who were not expecting a cancer diagnose experienced despair, discouragement, and disorientation.

“I remember perfectly! An awful feeling! I couldn't speak... I was totally paralyzed. It's a feeling one can't describe, because in that moment you see your life flashing before your eyes. You don't know how to react (...)” (CG 7)

Several caregivers considered the time interval between reaching a diagnosis and treatment of the malignancy unacceptably long making them feel as if they had been stuck in time. Furthermore, a few participants lamented they did not appreciate the way diagnosis was communicated (either too abruptly or with hesitation on behalf of the physician).

This doctor was a bit embarrassed... at least that's how I perceived it... that she couldn't find a way to tell us it was bad. But one also has to put herself in the shoes of the person in front of them waiting!” (CG 6)

Dealing with the referral to surgical procedure

Upon being informed that their loved one had to undergo a surgical procedure, most caregivers felt extremely worried, being concerned about their relative's health conditions and survival to the operation.

“As we stepped outside today told me: “he’s got a tumor, one of the most aggressive types.” I felt my whole world turn upside down! “shoot! He told me it would take just 15 minutes for biopsy and then we could go home! But he never did return!” (CG 8)

Experiencing the illness of their loved one

Another dominant feeling was the burden arising from the worries and the care to be provided to their loved one; most experienced high level of distraught during the treatments, given the poor prognosis or uncertainty of outcome. Furthermore, the majority of them declared to be overwhelmed by responsibilities in their role of family provider; thus, they had little time to metabolize the illness and attribute meaning. The physical duties involved with the care for their loved ones were considered a true burden and calvary.

Little meaning and lot of the anger! You try not to break the rules, never to go overboard, but then you get sick anyways... and big time! This is what I felt: anger!” (CG 5)

Uncertainty on the future

Participants expressed much concern for the future evolution of the disease in terms of response to treatment and possible recurrence of cancer. Some of them declared to live day by day without planning long-term activities.

“I live one day at a time, without making any plans. When I’ve something that needs to be done, I get up in the morning and do it, without saying ‘tomorrow we’ve got to ...’” (CG8)

Theme 2: Handling changes to everyday life

Facing changes in daily life

During the hospital stay, the caregiver had to adapt to and become acquainted with the unknown hospital environment. The occurrence of the disease forced the caregiver to drastic changes to their family routines and time allocation, as well as

to adjusting their home to accommodate the patient's needs and limitations. The caring activity severely decreased the caregiver's time for caring for their own health, family time, and social engagements. The situation also affected the rest of the family activities and habits as well. In some cases, they were so dedicated that they established an almost symbiotic relationship with the patient.

“When you're caring for a person, that's all you think about...that person comes first without thinking about yourself” (CG7)

The responsibility in providing care

All the caregivers declared they felt accountable for the well-being and care of their loved one, making the illness and its related aspects a priority over everything else. Most felt they were inadequate and unprepared, compared to the professionals in the hospital setting, to provide the care they imagined the patient would have needed. At the moment of discharge, two caregivers felt a true sense of abandonment:

“when he was in the hospital, one could call out at any time. At home instead I was always afraid.” (CG8)

Strongly impacting aspects of disease: physical deformity and loss of voice

For many participants, the physical changes were a shocking experience.

“when I saw him I was shocked because of how swollen he was, and all those drainage pipes. I had to hold myself to the bed” (CG3)

Furthermore, all the interviewees reported communication difficulties because their beloved loose the voice after surgery. However, later in the course of the disease recovery, the factor of the physical deformity of voice was associated to a more positive feeling, as the patients gradually began accepting their exterior aspect and limitations in vocalizing, or slowly regained vocal function. This also opened the way to a more positive attitude, and a more serene relationship between caregiver and patient. This, however, did not occur in all cases, as some patients did not accept the loss of their voice; therefore, the feeling of being *different* remained and made them feel uncomfortable.

“He was nervous, especially during the first months because he couldn't speak. Having to write made him upset and the more I was struggling to understand him, the more upset he'd become” (CG7)

Theme 3: Support received by others

External relationships: support and abandonment

Most participants claimed they received lots of support, especially from other family members and hospital staff with whom they even established a close relationship over the extended hospitalization period. Particularly, they felt staff was very supportive, present, and available throughout the hospital stay and recovery and a caregiver compared the staff as a family. Only in few cases the caregivers did not have time to engage in any relationship with the staff or did not feel comfortable asking additional support. Another strong element was the support received by other patients with same disease experience.

“Being supported by someone like you helps you go on”
(CG8)

The need for information

Lastly, another aspect mentioned was the amount of information they received. Most declared the hospital provided extensive information, which satisfied their request for information. Only one caregiver stated that she wished healthcare professionals had been more present and had supported her with more info. One thing she would have wanted was to be made more aware about the future and the options available for voice rehab.

“If they had told us before what we were in for, maybe we would have faced the disease in a different way”
(CG8)

Discussion

Despite the challenging nature of HNC caregiving, this topic remains quite understudied; thus, the present study specifically addressed the issues of being a family caregiver of a patient affected by HNC. Differently from other oncological settings, HNC is most often linked to a patient’s behavioral issues and environmental influence, such as excessive smoking, drinking, or risky sexual conduct [29]. In presence of these issues, family dynamics are heavily tarnished by these behaviors and affect relationships and tolerance/coping strategies within the family. The spouse or the offspring of a person with these addictions or unhealthy behaviors may perhaps have tolerated these for years and managed to keep the family balance. The diagnosis of HNC may represent a breaking point or not. Caregivers

are called to carry forth a number of tasks from emotional support to symptom management, while taking on new responsibilities in the patient’s care and re-assigning roles inside the household [30]. As broadly acknowledged, cancer is recognized as a family illness [31]. Indeed, participants to our study acted out of obligation towards the family member, accepting their role unconditionally. However, most were caught unprepared by the situation and felt an increasing sense of uncertainty from the very moment of the diagnosis (shocking or dramatic) throughout recovery (deemed as a true calvary) or disease progression. During interviews, we observed that each participant attributed a personal meaning to the trajectory of care of their loved one, and aged caregivers seemed to handle illness with a more positive attitude compared to younger caregivers. Demographic variables such as younger age and lower socioeconomic status are often identified as risk factors for distress [32]; however, these findings should be also explained within context of a strong family-oriented culture of our participants who were female spouses or daughters with an average age of 63 years. Further studies aimed at exploring the experience of male caregivers of HNC patients, younger generations of caregivers and offspring may reveal other dynamics. Another interesting topic that emerged was the pathway leading to diagnosis and treatment of the disease. In our study, these moments as reported by caregivers were deemed as unbearable. Similar findings have been previously reported only by Röing et al. [23], who had discussed alterations in the perception of time during treatment, which can appear as slower or faster compared to normal pace. For some caregivers, events occurring after the diagnosis happened too fast making it difficult for them to understand what was going on. For others, time required for treatments appeared too slow and reported their disappointment regarding the time passing between the first diagnosis and surgical intervention. Disappointment was also manifested in reference to the little information received about the illness, the treatment options, their side effects, and the progression of care, which certainly fed to their anxiety. Speaking of a more practical responsibility, caregivers must become familiar with technical procedures and complex tasks, such as managing tube feeding and tracheostomy care [33]. In the present study, most caregivers had undertaken their role acting out of obligation towards the family member, without realizing the many responsibilities it entailed. All participants described assistance to their loved one as going beyond attending the patient’s daily needs (grooming and feeding) or addressing physical discomfort.

Unlike caregivers of other cancer patients, the majority of participants declared a radical and permanent change in role within the family household, in personal lifestyle and degree of responsibility taken on. This condition was linked to the

patient's irreversible physical conditions like loss of voice, impairments in speech, visible disfigurement and a radical change in body image, refusal to eating in public, and the fear of stigma. Assisting a loved one in some cases was experienced as an imposed limit to the caregivers' own life-space, demanding the caregivers to put aside their own needs, relationships, and social life. However, if on one hand this led to an initial sense of frustration of the caregivers, on the other, this also led them to develop a sense of duty for caring for their beloved and even blame for not having enough time to dedicate to their care. Through this dual condition characterized by feelings of blame and guilt, and a strong obligation, many caregivers cope with this situation, strengthening their relationship with the patient and creating a sort of "symbiosis."

In interpreting such findings, it is worth to recall that in many cases, the caregiver has often been dealing with problematic family issues long before the diagnosis of cancer, HNC often being linked to the patient's long-term problematic behaviors such as tobacco and alcohol addiction (which eventually contributed to development of cancer). Interestingly, despite some family situations being apparent to clinicians, caregivers very rarely mention these aspects with the clinicians or nurses assisting their family member, nor volunteer any information on family matters. Indeed, in our study, these aspects never emerged, suggesting a possible reluctance on behalf of the caregiver to speak out about these issues and the perception of social stigma.

Another aspect that emerged was the frustrations linked to permanent limitations to social activities outside the house, such as, for example, going out to the restaurant or travel for long journey. In literature, social and relational problems of HNC patients are well acknowledged [6, 23, 34–39]. In the present study, findings evidence how all this inevitably affects caregivers, who reported feeling as isolation and abandonment in dealing with the situation and the difficulties throughout their loved one's illness. Whereas, when interviewees were part of a support group or being able to share one's experience and feelings with others, these situations contributed to creating a sense of belonging and understanding, reinforcing previous studies findings further on [40].

Practical implications

Findings from present study highlight the relevant role of family caregivers, suggesting the need for a better recognition of this role throughout the patient's path of care. Caregivers in many situations are an extension of patients' needs and expectations [30], so recognizing their role during clinic visits may offer opportunities to increase their relevance and empowerment as well as create the conditions to ask questions or offer support.

In such perspective, healthcare professionals should consider assessing the caregivers' knowledge and readiness to provide care of laryngectomized patients for the entire trajectory of care, periodically, perhaps by planning short literacy programs. Tailored teaching and training programs on HNC and on long-term patient care of family members could help caregivers adjust to their relative's diagnosis [41], reduce their task burden, and improve their coping abilities and resources. Further steps could be following caregivers over time to detect excessive burden from patient assistance in advance, and supporting them in finding ways to manage it. By offering caregiver psychosocial interventions, adopting a dyad framework, and suggesting coping strategies, health professionals can help the caregiver achieve a sense of control, coping, and self-care. Also, in consideration of the tendency to isolation and frustrations linked to limitations to social activities outside the house described in literature, health professionals should address the issue of public outings of the caregiver and patient and encourage their interaction with the surrounding community [42]. In fact, several authors suggest (e.g., Langenberg et al. [13]; Gage [43, 44]; Given et al. [45]) these situations be avoided. Putting the caregivers in the proper conditions to care for their loved one in a proactive way and engage in maintaining social relationships can in fact protect them from psychosocial fatigue, burden, and distress. Not least, the creation of support groups or events for caregivers could support their coping needs for sharing experiences with other family members and health professionals. In alternative, the hospital could engage with patient networks to find dedicated meeting spaces within the hospital environment and organize brief training sessions for caregivers and patients as well. These interventions should be offered after a few weeks of active treatment because caregivers have time to adjust to their relatives' diagnosis [41].

Limitations

Since this study followed a phenomenological approach, the number of participants is small. Nonetheless, we managed to reach saturation and tried to deepen the recursive meanings given by participants and pictured the essential features of their experience. Moreover, considering our participants limited demographic variability, further investigation should be conducted to better explore caregivers' generational differences, and support healthcare professional plan specific educational programs for caregivers. Regarding rigor, each methodological step was done with at least two researchers and the supervision of an external qualitative methodologist. Despite this study being conducted in one country, and the findings may be reflective of its culture, it offers a useful reference point for other research among caregivers of laryngectomized patients in other cultures and settings.

Conclusion

The present study highlights the meanings caregivers give to their experience in order to support and live with a laryngectomized patient. It seems likely that caregivers' feelings mirror the patients' experience; nonetheless, they show different needs and prerogatives. It is not new that caring for the caregivers is demanding but still compelling for healthcare providers; thus, phenomenological approach offered an engaging way for interviewees to describe their lived experiences and contributed to the gap in the literature by providing a better understanding of their role during treatments and transition period. Therefore, several recommendations and suggestions for professionals and for future research emerged as well as the necessity to consider also caregivers' issues as part of laryngectomized patient care planning from the diagnosis to the follow-up.

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Compliance with ethical standards

The study was exempt from formal ethical approval by the Internal Review Board composed by Academic Hospital and University members.

Conflict of interest The authors declare that they have no conflict of interest.

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