

Understanding the challenges and need for support of informal caregivers to individuals with head and neck cancer - A basis for developing internet-based support

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ABSTRACT

Purpose: Being an informal caregiver of an individual with head and neck cancer can be demanding. Still, informal caregivers can provide valuable support to patients throughout the disease trajectory. The aim of this study was to explore informal caregivers' views on their challenges and needs in attaining high preparedness for caregiving.

Methods: Fifteen informal caregivers of individuals with head- and neck cancer participated in a focus group discussion or an individual interview. Thematic analysis utilizing an inductive approach was performed.

Results: The results describe the challenges that informal caregivers to individuals with head and neck cancer perceive and their needs for support in preparedness for caregiving. Three main themes were found: *Challenges of being an informal caregiver*, *Transformation in life* and *Informal caregiver's needs of support and sharing care*.

Conclusion: This study contributes to the understanding of the challenges for informal caregivers to individuals with head and neck cancer in increasing preparedness for caregiving. To improve preparedness for caregiving, informal caregivers need education, information and support regarding physical, psychological and social issues for individuals with head and neck cancer.

1. Introduction

Informal caregivers (ICs) are family members or friends identified by individuals with cancer as a primary source of informal care and support (Hudson and Paynem, 2008; Stenberg et al., 2010). Informal caregiving may entail positive aspects for the ICs, including a sense of purpose, emotional closeness and satisfaction in preserving the sick relatives' dignity (Anderson and White, 2018). However, ICs of individuals with cancer may experience a burden of responsibility and a variety of problems that arise from the demands of caregiving, including stress, loneliness, isolation, a heavy workload and shame and guilt (Girgis et al., 2013; Goren et al., 2014; Wang et al., 2021). ICs provide valuable

support to the patients throughout the disease trajectory (Balfe et al., 2018; Maguire et al., 2017) and are crucial in decreasing hospitalization and making it possible for patients to stay at home (Wang et al., 2018).

Individuals with head and neck cancer (HNC) often struggle with heavy symptom burdens due to the cancer disease and treatments. Depending on the location and stage of the tumour, HNC is associated with high morbidity (Begbie et al., 2019) and may affect swallowing, nutrition, hydration, speaking, communication, and breathing (Lokker et al., 2013). Sometimes, patients return home with a tracheostomy, nasogastric tube or endoscopic gastrostomy, and there are often both acute and late side effects from treatment, such as a dry mouth, altered facial appearance, pain, and fatigue (Alt-Epping et al., 2016), which can

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severely impact quality of life (Ehrsson et al., 2021). Thus, the dependence of the individual with HNC on their IC increases.

There are several studies measuring ICs' well-being regarding caregiver burden (e.g. Benyo et al., 2022; Wang et al., 2021; Castellanos et al., 2019; Thana et al., 2020). Caregiver burden can be described as a multidimensional biopsychosocial reaction resulting from an imbalance between care demands and a caregiver's care resources (Given et al., 2001). It has previously been described that ICs of individuals with HNC often report depression, fatigue and sleep disturbance due to the caregiver burden they experience (Benyo et al., 2022). A systematic review performed by Wang et al. (2021) identified unmet needs among ICs of individuals with HNC regarding information about the illness and its treatment. They also revealed the existence of a gap between clinical practice and caregivers. The ICs often perceived difficulties in caregiving tasks, e.g., dealing with nutrition, pain and dry mouth and managing a tracheostomy or a nasogastric tube (Castellanos et al., 2019). Consequently, informal caregiving can be physically and psychologically challenging and negatively affect ICs' quality of life (Thana et al., 2020). A study by Ringborg et al. (2022) performed on ICs to patients with oesophagus cancer showed that the ICs were mostly satisfied with the support from the healthcare before surgery, but after discharge from the hospital the ICs felt as though they were left alone and fully responsible for the patient's care. In addition, previous research has shown that the ICs' social and psychological needs for support peaks during the post-treatment period, and that ICs need support in adjusting to their new everyday life (Ringborg et al., 2022; Wang et al., 2021). Overall, ICs need support to be more prepared for caregiving.

Preparedness for caregiving can be defined as ICs' perceived capacity to provide physical, emotional or practical care and manage the stresses of caregiving (Mazanec, 2018; Schumacher et al., 1998). When cancer care shifts from the inpatient to the outpatient setting, ICs need to be prepared for the complexity of care and responsibilities they may be facing (Balfe et al., 2018; Kent and Dionne-Odom, 2019). Studies have reported that ICs who feel prepared have fewer worries (Bilgin and Ozdemir, 2022) and an increased capacity for caregiving (Mason and Hodgkin, 2019). More knowledge is needed about the specific support that ICs to individuals with HNC provide (North et al., 2021), the time they spend doing so and the burden they experience as a result thereof (Girgis et al., 2013; Weaver et al., 2022).

This study is part of a larger research project (Clinicaltrials.gov; Identifier: NCT05028452) focusing on developing online support for ICs to individuals with HNC. The published study protocol (Langegård et al., 2022) describes the development phase (I) and the feasibility phase (II). The project is a collaboration with an expert group of ICs to individuals with HNC to make sure that the intervention will be acceptable and relevant for the ICs to increase their preparedness for caregiving. Further, it is a collaboration with experts in medical, health and care sciences and human-computer interaction. Studies regarding the user interface are being conducted in parallel with this study (Ahmad et al., 2023). The current study will present the results of focus group discussions (FGDs) with ICs (phase I). The results will provide the basis for the development of the content of our planned intervention alongside clinical expertise and scientific evidence, including the Social cognitive theory (Schunk, 2012), the Unified theory of acceptance and the use of technology framework (Venkatesh et al., 2003).

In order to develop the upcoming intervention to increase ICs' preparedness for caregiving, it is important to understand which aspects of the caregiving experience that are challenging and important for ICs. Therefore, this qualitative study aimed to explore ICs' opinions regarding their challenges and needs in attaining a high preparedness for caregiving.

2. Method

2.1. Design

The study had a qualitative design using thematic analysis to interpret data from FGDs and individual interviews (Braun and Clarke, 2006).

2.2. Participants and setting

2.2.1. Informal caregivers

The ICs were selected to provide experiences of a wide range of challenges and the needs for support among ICs to individuals treated for HNC. The inclusion criteria were adult ICs (>18 years) to individuals with various stages and sites of HNC, about to start treatment, on treatment or who had completed treatment within three months before the study. The demographics of the individuals with HNC and their ICs are shown in Table 1. The exclusion criteria for both the individuals with HNC and the ICs were cognitive impairments and not understanding, speaking or reading Swedish. Twenty-four ICs were invited and fifteen agreed to participate. Their mean age was 58 years (range 34–75 years); ten ICs were women.

Table 1

Demographics of the individuals with head and neck cancer and their informal caregivers.

Individuals with head and neck cancer		Informal Caregivers	
Sex		Sex	
Female	6	Female	11
Male	9	Male	5
Age (years)		Age (years)	
55–65	6	30–40	2
66–75	6	41–50	1
76–85	2	51–60	5
86–95	1	61–70	5
		71–80	2
Tumour site		Relationship to patient	
Oral cavity	6	Partner, living together	1
Hypopharynx	1	Married	9
Salivary gland	1	Child	4
Oropharynx	6	Friend	1
Larynx	1		
Surgery		Education	
Yes	3	University >3 years	7
No	12	University <3 years	3
		Secondary school	5
Radiotherapy		Financial situation: range 0–10 ^a	
Yes	13	0–5	1
No	2	6	2
		7	3
		8	7
		9	0
		10	2
Informal caregiver's participation in focus group/interview		Computer use	
Before treatment	5	Highly skilled	7
During or within 3 months of treatment	1	Quite skilled	7
After treatment	9	Quite unskilled	1
		Support from someone	
		No	1
		Yes	14
		Someone to share feelings with	
		No	3
		Yes	12

^a Financial situation: The assessment was made by informal caregivers, with 0 = the worst possible financial situation and 10 = the best possible financial situation.

2.3. Procedure and data collection

Individuals with HNC who had an IC who could potentially be approached for inclusion were identified by a contact person at the ear, nose and throat clinics or the oncology/radiotherapy clinics at three university hospitals in Sweden. Subsequently, a researcher contacted each identified individual with HNC, and if the individual consented, the researcher contacted their IC and informed them about the study (Langegård et al., 2022) and inquired about participation in the study. Thereafter written information about the study was sent home to the IC. An interview guide, based on clinical expertise and literature, with open-ended questions regarding ICs' challenges and needs for preparedness for caregiving and support guided the FGDs.

- What has been the major challenge for you as an IC to an individual with HNC?
- What kind of support did you need in the role as an IC to an individual with HNC?
- What support did you get that met your needs?
- What support did you lack in the role as an IC?

The FGDs, as described by Krueger (2014), and the two individual interviews, were conducted by the last author (YTE) and moderated by the first author (UL), who took notes and asked supplementary questions. All the FGDs and individual interviews were conducted online.

Three FGDs, each including four or five ICs, and two individual interviews with ICs were conducted. The FGDs lasted 70 min, and all participants participated equally in the discussions. The two individual interviews lasted 45 and 60 min.

During the FGDs and individual interviews, all participants used webcams. All sessions were audio-recorded. The data were collected between May and November 2021.

2.3.1. Data analysis

All FGDs and interviews were transcribed verbatim. Thematic analysis, as described by Braun and Clarke, was conducted (Braun and Clarke, 2006; Clarke and Braun, 2017). An inductive approach was used to explore the challenges and needs for support of ICs to individuals with HNC. The six-step analysis process was a collaboration where all research team members participated (Braun and Clarke, 2006; Clarke and Braun, 2017) (Table 2).

Table 2
The thematic analysis of the focus group discussion and individual interviews based on the six steps suggested by Braun and Clarke (2006; Clarke and Braun, 2017).

Step 1	The authors (UL, YTE) read and re-read the interviews to become familiar with the entire dataset, while searching for patterns and meanings. Immediately after each interview, the first author (UL) wrote narrative accounts of the participant's story, providing an initial list of ideas and points of interest.
Step 2	Initial codes were generated iteratively by transferring items of interest, questions, connections between data items, and other preliminary ideas reported by the participants to a more conceptual level.
Step 3	The coded and collated data extracts were examined for potential themes of broader significance. Themes were developed from the initial codes. Eventually, themes were retained or rejected based on consensus. Quotes were linked to the codes.
Step 4	A hierarchical map, including main themes and subthemes, was created. Only themes assessed to have adequate commonality were used and coherence was tested for accuracy.
Step 5	The mapped themes underwent further review, defining, and refining. Narrative description was performed of each theme, including why it was relevant to the broader study question.
Step 6	The themes and the underlying story were described in the results, including how the researchers interpreted the data, and supplemented with illustrative quotes.

2.3.2. The research team and expert group

The research team included expertise in nursing and medical aspects of HNC, ICs in the HNC context, internet-based interventions, human-computer interaction and user-centred design. An expert group consisting of ICs was associated with the research team to provide their views on the project.

2.4. Ethical considerations

All procedures performed in this study involving human participants followed the ethical standards of the institutional research committee and the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Swedish Ethical Review Authority (Dnr: 2020-04650). Verbal and written information about the study was given, and written informed consent was obtained before the enrolment of individuals with HNC and their suggested ICs.

The FGDs and individual interviews were conducted online using end-to-end encrypted Zoom software, ensuring that no unauthorized persons could enter the meetings, in accordance with the EU General Data Protection Regulation (Lobe et al., 2020).

The authors had no professional relationships with the ICs. Some ICs interviewed about their experiences may find this to be either an emotional burden or therapeutic (Gysels et al., 2008). The moderator immediately addressed any strong emotions that arose during the FGDs. If deemed necessary, the moderator initiated contact for a follow-up dialogue. This occurred once, when one of the ICs cried during an entire FGD.

3. Results

The results describe the challenges and needs of support for preparedness for caregiving among ICs to individuals with HNC. The ICs stated that they felt poorly prepared for caregiving tasks and in some cases, that the responsibility was too much. They expressed a need for more information and support from health care. Three main themes were constructed: *Challenges of being an IC*, *Transformation in life* and *ICs' need of support and sharing care* (Fig. 1).

In the results, the term 'IC' is used for ICs to individuals with HNC, and the term 'relative' for individuals with HNC, to facilitate reading.

In main theme 1, *Challenges of being an IC*, three subthemes were identified: *feeling excluded*, *impact on daily life* and *carrying the uncertainty*. Being an IC entailed a wide range of responsibilities, adaptations and worries. The majority of ICs described that they wanted to be involved and take responsibility for the caregiving of their relative, even at the expense of their own well-being.

The subtheme *feeling excluded* comprised ICs' experiences of a lack of information from health care about their relative's health status, resulting in a feeling of not being involved in care. This affected the ICs' preparedness for caregiving. The optimal situation would have been to receive information from the time of diagnosis and then continuously during and after treatment. Increased participation in the relatives' care was requested by the ICs. However, some ICs had relatives with high levels of personal integrity, who did not want the ICs to be included in care.

He doesn't want much help, he wants his integrity. But he also talks very openly about how he feels or if he has any problems and so on. But, I test the waters and approach him carefully. But just being there is sometimes enough. (Participant 1)

Some relatives were treated far from home and their ICs were not able to attend the clinic. Those ICs clearly stated that they felt excluded from health care.

I wished that the health care staff had contacted me by telephone. That they could've thought about that my husband lives far from the

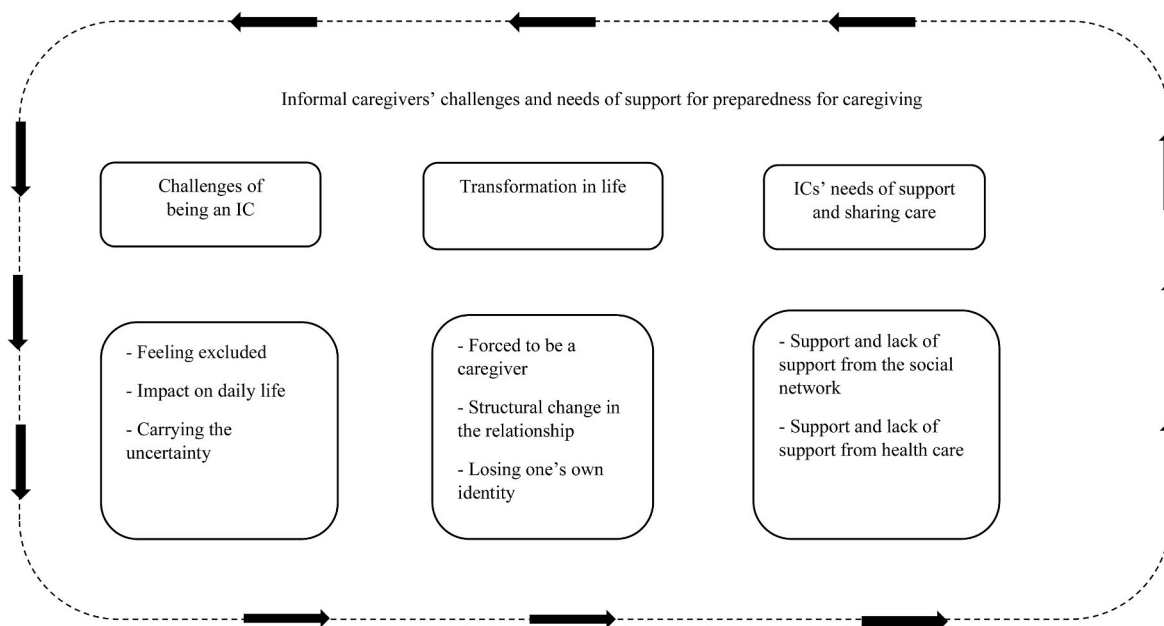


Fig. 1. Main themes and subthemes of informal caregivers' (ICs') views on challenges and needs of support to increase preparedness for caregiving to individuals with head and neck cancer. The arrows illustrate that ICs to individuals with head and neck cancer struggle with many challenges and need support. The themes are both interrelated and independent of each other.

hospital and also how he lives when he's there, he's actually there all alone during those weeks. (Participant 5)

Impact on daily life: The cancer affected the whole family regarding work, leisure activities and social life. It meant that the ICs and the rest of the family adapted their daily lives completely based on the relative's needs. The change also entailed moments of feeling isolated and forced to stay at home because the ICs had to be available to their relatives.

There's been some absence from work. Partly because ... my dad always wants me to go with him to the hospital. So I've become ... a parent to my own parent. In my case, that's what it's been like. (Participant 7)

The nutritional problems that arose due to the cancer disease and its treatment caused changes in meals and diets also for ICs. The entire family adapted their eating habits to what the relative could eat, even if it meant a sacrifice on their part.

I've changed my eating habits. If my husband doesn't eat meat, neither do I. The diet is changed. It's not the same food now as it was six months ago. Not at all. I adapt my food to what he can eat. (Participant 6)

In the last subtheme, *carrying the uncertainty*, ICs expressed uncomfortable feelings of uncertainty, for example when they were waiting for a diagnosis or seeing the effects of the treatment. The ICs were aware that their future together with their relatives might be curtailed and they felt fear at the prospect of losing a loved one.

When the first operation was done, the doctor said that the tumour is gone and it's all over. After two weeks, the doctor said that they had to perform one more surgery. And again, after a few weeks, the doctor said that they also have to treat him with radiotherapy too. And it felt uncomfortable, I hope they've got it right this time. (Participant 10)

In main theme 2, *Transformation in life*, three subthemes were identified: *forced to be a caregiver*, *structural change in the relationship* and *losing one's own identity*.

The relationship between the IC and their relative could be supportive or tense, and the relationship was changed during the illness

trajectory, e.g., from being a partner or child to being a full-time caregiver at home. This transition and new role could create a strain on the relationship.

The subtheme *forced to be a caregiver* illuminated the feelings that arose when the relative was at home. The ICs were expected to perform caregiving tasks and that responsibility led to feelings of vulnerability or abandonment. The ICs felt that they lacked the resources and knowledge required to perform the caring tasks that they were forced to deal with.

I was the one who had to take care of dressing my mother's wounds after she was discharged from hospital. She'd been promised home care, but they couldn't offer home care on the weekends. Of course, it would've been easier if I'd gotten some kind of information beforehand. (Participant 14)

After the surgery, I lived with my father. He was feeling very poorly. He probably didn't think he would feel so bad after the surgery. I supported him, so he got enough to eat and took the medication at the right time. So I woke him up when it was time to take medicine so he wouldn't get these peaks of pain. (Participant 7)

The subtheme *structural change in the relationship* is about how the relationship changes regarding responsibilities, as ICs took on an increased burden of practical responsibilities, for example being the only one responsible for household chores.

You are used to being two adults and discussing everything, how to handle different things. And now, ... I have to take care of everything on my own because she doesn't have the strength. And yes, sometimes it is hard, but you have more stamina than you think. (Participant 2)

The subtheme *losing one's own identity* concerned how the ICs could lose their own identity by becoming completely absorbed in the sick relative's world. If you lose yourself, it becomes difficult to provide support to someone else. Losing one's own identity could also relate to the relatives' changed personalities as a result of pain or difficulties sleeping, which led to irritability and aggression, characteristics that ICs did not recognise.

She's been very annoyed, I didn't recognise my mother or her personality. From being very kind and humble and never saying anything that could hurt you. Now she can say things that don't feel good. But at the same time, I understand, it's not her personality, it's her disease that's saying those things. (Participant 14)

Absence of intimacy and sexuality affected the relationship. This could be due to problems in the treatment area, such as pain or a foul-smelling mouth. Changed appearance due to the tumour, treatment and side effects could lead to unwanted feelings, such as being ashamed of their relative's appearance. This could lead to distancing.

Regarding intimacy and sexuality, it has changed. It's on hold, or we're just waiting for everything to be over. So it can be as usual again. (Participant 15)

Main theme 3, *ICs' needs of support and sharing care*, comprised two subthemes: *support and lack of support from the social network* and *support and lack of support from health care*.

Support and lack of support from the social network: It was important that ICs felt they were not alone and that someone in their social network cared about them too. This underlined the importance of practical and emotional support and appreciation from family and friends, including their relatives and employer.

My employer said 'when you need to help your wife, you can leave when you need to do'. It's made it a lot easier. I've driven her to radiotherapy when she couldn't drive herself. And that was every day. (Participant 3)

Some ICs lacked support from their social network. They felt loneliness and a significant burden of responsibility. ICs found it hard to ask for help and support and in some cases found it hard to define what kind of help or support they needed. Instrumental support, e.g., practical help at home, could sometimes be more important than emotional support such as supportive conversation.

Asking for help is not always easy. It can be difficult to specify what that help should consist of. It is easy for a relative or a friend to offer their support. 'Let us know if there is anything we can do.' But exactly what that help would consist of is not so easy to define. It's probably easier to get more mental support, to call someone and talk when the need arises. (Participant 2)

The subtheme *support and lack of support from health care* comprised experiences of receiving informational support, but also experiencing a lack of informational support regarding the cancer disease, the side effects of treatment, symptom management and life after treatment.

I would also say that we lack a lot of written information on how to take care of him. Because he has both a feeding tube and he has a lot of antibiotics and various medicines. He has a tracheostomy that needs to be taken care of ... so there are a lot of things that need to be taken care of and it can be difficult to keep track of everything. Health care focuses on the treatment but ... hasn't always planned for what may happen after the treatment. I would've liked more support. Perhaps more regular visits and so on. (Participant 4)

Support from a multi-professional team during and after treatment was desired. Several participants felt that they needed emotional support from an almoner or a therapist, either in a group or individually.

I have to fight back the tears. I don't know how to explain it, but the tears are there and waiting, but don't come out all the time. And we haven't been offered any psychological support, but on the other hand, I've made sure that my husband receives psychological support. But it's going well. We'll get through this. We also have good friends who support us. (Participant 10)

In addition to emotional support, the ICs wanted more informational support and education about practical aspects such as speech, feeding

tubes, trismus, oral hygiene, tracheostomies, body weight and suggestions on food that would be easy to eat and nutritious.

4. Discussion

The results described ICs' views of challenges and their needs for increasing their preparedness for caregiving of their relatives with HNC. Many ICs stated that they would have needed support in the challenges of being an IC to an individual with HNC. ICs often changed their priorities so that they could take a role as a caregiver to their relative. For some, being an IC required a gradual adaptation, while others experienced it as an immediate change in daily life. ICs often changed their daily routines, work and obligations at home and some even neglected their health needs to ensure their relative was taken care of. Many ICs needed support in the transformation in life and emotional and practical support from their surrounding network and health care. The results of this study will provide a basis for developing the online intervention Carer eSupport.

The relationship between the IC and their relative was often transformed. One reason was the heavy burden regarding increased responsibility in the relative's home. As a direct effect of the cancer, or as a consequence of the treatment, the relative's ability to participate in daily chores and activities was often reduced. Some inabilities appear immediately and persist, while others may develop as late effects. The relationship was affected by the caregiving tasks, which encroached on the ability of ICs to choose how to live their lives and the balance between wanting to taking care of the relative or taking care of oneself. It also included the ICs needing to negotiate the tensions that arose in the relationship when the relative's demeanour and behaviour changed. This is confirmed by a recently published study by [Weaver et al. \(2022\)](#) investigating the perspectives of caregivers to an individual with HNC and how ICs needed to navigate a new and different relationship and recognised a newfound uncertainty regarding how to interact with the relative. [Girgis et al. \(2013\)](#) discussed the changed relationship between ICs and their relatives and concluded that there was little support available specifically for caregivers. They considered it reasonable to recommend that interventions should support caregivers with their essential needs. Other studies have similarly found that ICs often experience disruptions in their own lives and set aside their own needs ([Dodd et al., 2019](#); [Halkett et al., 2020](#); [Tranberg et al., 2021](#)). This implies that during the treatment period, ICs must be allowed to adapt to being caregivers. After the end of treatment, it is recommended that ICs and relatives receive support to find their way to a new daily life. Examples could be finding a balance in their family roles, finding a feasible way to share household chores, and seeing if ICs can work as before or resume their leisure interests. This would be relevant whether the IC is a partner, a child or has another type of relationship to the person with cancer ([Ringash et al., 2018](#)).

The ICs often lacked information about the disease, its treatment and its consequences. This raised feelings of uncertainty regarding what the disease entailed, which were reinforced when healthcare professionals did not include ICs in care. In addition, the ICs sought emotional support, although their focus was on their relatives. [Andershed and Ternstedt \(2001\)](#) theory of relative involvement in care describes ICs' participation in care as occurring in light or in dark. When ICs experience participation and are well-informed about care, it occurs in the light. The opposite is at hand in care in the dark. [Wang et al. \(2021\)](#) presented similar results which indicated that ICs' experiences of uncertainty or unmet needs negatively impact their well-being. On the other hand, if ICs feel secure and receive satisfactory support, i.e., receive the information they need and are included in care, this can affect their well-being in a positive direction.

The ICs in the present study who had supporting social networks thought it was important to receive confirmation and not feel alone in the situation. If they needed help, they knew it was within reach. There was also a group of ICs who were alone with the responsibility of caring

for their relatives. That responsibility became a burden that impacted their well-being negatively. These results are comparable to those of Lambert et al. (2012), who discussed that unmet needs contributed to caregivers' burdens and increased the risk of patient distress, anxiety and depression.

The results of this study show that ICs to individuals with HNC need support. Based on the need we will develop an internet-based support, Carer eSupport. Carer eSupport is planned to be developed based on the contents of the three themes presented in this study, as well as clinical expertise and other scientific evidence, and will be presented on a website. This will be done in collaboration with the expert group of ICs who have their own experience of being ICs to an individual with HNC. Carer eSupports' relevance, acceptability, and user experience will be tested in a feasibility study (phase II) (Langegård et al., 2022). Thereafter the intervention will be evaluated in a randomized controlled trial. Gathering information and letting ICs share the information in an online intervention is an opportunity to help them achieve preparedness for caregiving. The intervention Carer eSupport is intended to be a source of knowledge and support for the ICs. The support may be delivered through live electronic education for ICs and a library with written and audio-visual material. It may be possible to use discussion forums and digital rooms to meet other ICs for interaction and exchanging experiences. The activity in this digital rooms may reduce their feeling of loneliness. It may also be possible to meet healthcare professionals in digital rooms. The goal is to promote a safe transition from hospital care to caregiving at home by facilitating for the ICs, which also benefits the patients. Carer eSupport could be a complement to health care in addressing the identified gaps by providing ICs with information and practical support on health care tasks, which has been requested by ICs to simplify daily life. The intervention is also intended to reduce the ICs' feelings of vulnerability. Carer eSupport will strengthen the ICs and hopefully increase their courage to make demands regarding involvement in care and getting the information required to be more prepared for care. The potential for this is confirmed by D'souza et al. (2017), who evaluated the impact of a tailored multimedia information tool on the psychosocial outcomes among ICs of individuals with HNC. They showed that the ICs receiving the intervention had higher levels of satisfaction with information provision than the control group without any intervention.

4.1. Discussion on the research methodology

In accordance with the suggestions of Braun and Clarke (2021), the thematic analysis was conducted in a structured and traceable way, in collaboration between all members of the research team. Field notes were taken during and immediately after each FGD and individual interview, to ensure reflexivity. To confirm the analysis quality and that the analysis was rigorous, the primary researcher (UL) documented and wrote extensive and detailed notes on analytical and theoretical insights (Braun and Clarke, 2019). Notes were taken on how codes developed from observations and ideas. The primary researcher (UL) used member checking and group debriefing to support the trustworthiness of their interpretations and analysis (Lincoln and Guba, 1986; Nowell et al., 2017). In addition, the expert group of ICs gave feedback on the results. Variation in the responses was captured and saturated, as described by Braun and Clarke (2021). We are aware that the participants only shared what they wanted to relate.

4.2. Strengths and limitations

The major strength of this study is the use of FGDs and interviews with ICs to individuals with HNC, which gave us knowledge on what is required to increase their preparedness for caregiving. Another strength was the collaboration with the expert group consisting of ICs to individuals with HNC, who actively take part in the development of the contents in the online portal and provided feedback. One limitation is

that the study was conducted during the COVID-19 pandemic, which may have affected the results, as the ICs had not been able to visit the hospital to the same extent as they would under normal circumstances. It also meant that several ICs had been working from home and were more available to their relatives during the disease and treatment period than would usually be the case.

The use of technology to perform interviews online has both benefits and drawbacks. Saarijärvi and Bratt (2021) concluded that qualitative interviews performed online are valid and trustworthy alternatives to traditional face-to-face interviews. Moreover, such interview methods might change the notion that face-to-face interviews are the gold standard, as interviews performed at a distance serve their purpose more cost-effectively, while promoting inclusion in research. However, we lost those people who rejected participation in the study due to a lack of technical knowledge.

5. Conclusion

This study contributes to the understanding of the challenges for ICs to individuals with HNC in increasing preparedness for caregiving. To increase their preparedness for caregiving, most ICs need education, information and support regarding physical, psychological and social issues. The results of this study will be used to build an intervention online to improve ICs' preparedness for caregiving at home, to mitigate future issues and challenges.

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Clinical trial registration

The project is registered at [Clinicaltrials.gov](https://clinicaltrials.gov) (Identifier: NCT05028452).

Date of registration: 2021 08 31.

CRedit authorship contribution statement

Ulrica Langegård: Conceptualization, Methodology, Software, Validation, Formal analysis, Resources, Data curation, Writing – original draft, Visualization, Project administration. **Åsa Cajander:** Methodology, Writing – review & editing. **Awais Ahmad:** Methodology, Writing – review & editing. **Maria Carlsson:** Methodology, Writing – review & editing. **Emma Ohlsson Nevo:** Methodology, Writing – review & editing. **Birgitta Johansson:** Conceptualization, Methodology, Writing – review & editing, Supervision, Funding acquisition. **Ylva Tiblom Ehrsson:** Conceptualization, Methodology, Software, Validation, Formal analysis, Resources, Data curation, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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References

- Ahmad, A., Premanandan, S., Langegård, U., Cajander, Å., Johansson, B., Carlsson, M., Tiblom, Ehrsson., 2023. Positive Design Framework for Carer-eSupport: A Qualitative Study to Support Informal Caregivers of Patients with Head and Neck Cancer in Sweden. *JMIR Cancer* 9, e45748. <https://doi.org/10.2196/preprints.45748>.
- Alt-Epping, B., Seidel, W., Vogt, J., Mehnert, A., Thomas, M., van Oorschot, B., Wolff, H., Schliephake, H., Canis, M., Dröge, L.H., 2016. Symptoms and needs of head and neck cancer patients at diagnosis of incurability-prevalences, clinical implications, and feasibility of a prospective longitudinal multicenter cohort study. *Oncol. Res. Treat.* 39, 186–191. <https://doi.org/10.1159/000445307>.
- Andershed, B., Ternestedt, B.M., 2001. Development of a theoretical framework describing relatives' involvement in palliative care. *J. Adv. Nurs.* 34, 554–562. <https://doi.org/10.1046/j.1365-2648.2001.01785.x>.
- Anderson, E.W., White, K.M., 2018. It has changed my life": an exploration of caregiver experiences in serious illness. *Am. J. Hosp. Palliat. Med.* 35, 266–274. <https://doi.org/10.1177/1049909117701895>.
- Balfe, M., O'Brien, K., Timmons, A., Butow, P., O'Sullivan, E., Gooberman-Hill, R., Sharp, L., 2018. Informal caregiving in head and neck cancer: caregiving activities and psychological well-being. *Eur. J. Cancer Care* 27, e12520. <https://doi.org/10.1111/ccc.12520>.
- Begbie, F.D., Douglas, C.M., Finlay, F., Montgomery, J., 2019. Palliative intent treatment for head and neck cancer: an analysis of practice and outcomes. *J. Laryngol. Otol.* 133, 313–317. <https://doi.org/10.1017/S0022215119000574>.
- Benyo, S., Phan, C., Goyal, N., 2022. Health and well-being needs among head and neck cancer caregivers—A systematic review. *Ann. Otol. Rhinol. Laryngol.* 132 (4), 449–459. <https://doi.org/10.1093/otolaryng/otab063>.
- Bilgin, F.D., Ozdemir, L., 2022. Interventions to improve the preparedness to care for family caregivers of cancer patients: a systematic review and meta-analysis. *Cancer Nurs.* 45 (3), E689–E705. <https://doi.org/10.1097/NCC.0000000000001014>.
- Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. *Qual. Res. Psychol.* 3, 77–101. <https://doi.org/10.1191/1478088706qp0630a>.
- Braun, V., Clarke, V., 2019. Reflecting on reflexive thematic analysis. *Qual. Res. Sport Exerc. Health* 11, 589–597. <https://doi.org/10.1080/2159676X.2019.1628806>.
- Braun, V., Clarke, V., 2021. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual. Res. Sport Exerc. Health* 13, 201–216. <https://doi.org/10.1080/2159676X.2019.1704846>.
- Castellanos, E.H., Dietrich, M.S., Bond, S.M., Wells, N., Schumacher, K., Ganti, A.K., Murphy, B.A., 2019. Impact of patient symptoms and caregiving tasks on psychological distress in caregivers for head and neck cancer (HNC). *Psycho Oncol.* 28, 511–517. <https://doi.org/10.1002/pon.4968>.
- Clarke, V., Braun, V., 2017. Thematic analysis. *J. Posit. Psychol.* 12, 297–298. <https://doi.org/10.1080/17439760.2016.1262613>.
- D'souza, V., Blouin, E., Zeitouni, A., Muller, K., Allison, P., 2017. Multimedia information intervention and its benefits in partners of the head and neck cancer patients. *Eur. J. Cancer Care* 26, e12440. <https://doi.org/10.1111/ccc.12440>.
- Dodd, R.H., Forster, A.S., Marlow, L.A., Waller, J., 2019. Psychosocial impact of human papillomavirus-related head and neck cancer on patients and their partners: a qualitative interview study. *Eur. J. Cancer Care* 28, e12999. <https://doi.org/10.1111/ccc.12999>.
- Ehrsson, Y.T., Fransson, P., Einarsson, S., 2021. Mapping health-related quality of life, anxiety, and depression in patients with head and neck cancer diagnosed with malnutrition defined by GLIM. *Nutrients* 13, 1167. <https://doi.org/10.3390/nu13041167>.
- Girgis, A., Lambert, S., Johnson, C., Waller, A., Currow, D., 2013. Physical, psychosocial, relationship, and economic burden of caring for people with cancer: a review. *J. Oncol. Pract.* 9, 197–202. <https://doi.org/10.1200/JOP.2012.000690>.
- Given, B., Kozachik, S., Collins, C., DeVoss, D., Given, C., 2001. *Caregiver Role Strain. Nursing Care of Older Adults Diagnosis: Outcomes and Interventions*. Mosby, St. Louis, MO, pp. 679–695.
- Goren, A., Gilloteau, I., Lees, M., daCosta DiBonaventura, M., 2014. Quantifying the burden of informal caregiving for patients with cancer in Europe. *Support. Care Cancer* 22, 1637–1646. <https://doi.org/10.1007/s00520-014-2122-6>.
- Gysels, M., Shipman, C., Higginson, L.J., 2008. I will do it if it will help others": motivations among patients taking part in qualitative studies in palliative care. *J. Pain Symptom Manag.* 35, 347–355. <https://doi.org/10.1016/j.jpainsymman.2007.05.012>.
- Halkett, G.K., Golding, R.M., Langbecker, D., White, R., Jackson, M., Kernutt, E., O'Connor, M., 2020. From the carer's mouth: a phenomenological exploration of carer experiences with head and neck cancer patients. *Psycho Oncol.* 29, 1695–1703. <https://doi.org/10.1002/pon.5511>.
- Hudson, P., Payne, S., 2008. Chapter 15. The future of family caregiving: research, social policy and clinical practice. In: Hudson, P., Payne, S. (Eds.), *Family Carers in Palliative Care: A guide for health and social care professionals*. Oxford Academic, pp. 277–304.
- Kent, E.E., Dionne-Odom, J.N., 2019. Population-based profile of mental health and support service need among family caregivers of adults with cancer. *J. Oncol. Pract.* 15, e222–e231. <https://doi.org/10.1200/JOP.18.00522>.
- Krueger, R.A., 2014. *Focus Groups: A Practical Guide for Applied Research*. Sage publications.
- Lambert, S.D., Harrison, J.D., Smith, E., Bonevski, B., Carey, M., Laws, C., Paul, C., Girgis, A., 2012. The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. *BMJ Support. Palliat. Care* 2, 224–230.
- Langegård, U., Cajander, Å., Carlsson, M., von Essen, L., Ahmad, A., Laurell, G., Ehrsson, Y.T., Johansson, B., 2022. Internet-based support for informal caregivers to individuals with head and neck cancer (Carer eSupport): a study protocol for the development and feasibility testing of a complex online intervention. *BMJ Open* 12, e057442. <https://doi.org/10.1136/bmjopen-2021-057442>.
- Lincoln, Y.S., Guba, E.G., 1986. But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *N. Dir. Progr. Eval.* 1986, 73–84. <https://doi.org/10.1002/ev.1427>.
- Lobe, B., Morgan, D., Hoffman, K.A., 2020. Qualitative data collection in an era of social distancing. *Int. J. Qual. Methods* 19. <https://doi.org/10.1177/160940620937875>.
- Lokker, M.E., Offerman, M.P., van der Velden, L.A., de Boer, M.F., Pruyn, J.F., Teunissen, S.C., 2013. Symptoms of patients with incurable head and neck cancer: prevalence and impact on daily functioning. *Head Neck* 35, 868–876. <https://doi.org/10.1002/hed.23053>.
- Maguire, R., Hanly, P., Balfe, M., Timmons, A., Hyland, P., O'Sullivan, E., Butow, P., Sharp, L., 2017. Worry in head and neck cancer caregivers: the role of survivor factors, care-related stressors, and loneliness in predicting fear of recurrence. *Nurs. Res.* 66 (4), 295–303. <https://doi.org/10.1097/NNR.0000000000000223>.
- Mason, N., Hodgkin, S., 2019. Preparedness for caregiving: a phenomenological study of the experiences of rural Australian family palliative carers. *Health Soc. Care Community* 27, 926–935. <https://doi.org/10.1111/hsc.12710>.
- Mazanec, S.R., 2018. Perceived Needs, Preparedness, and Emotional Distress of Male Caregivers of Postsurgical Women With Gynecologic Cancer. *Oncol. Nurs. Forum* 45 (2), 197–205. <https://doi.org/10.1188/18.ONF.197-205>.
- North, A.S., Carson, L., Sharp, L., Patterson, J., Hamilton, D.W., 2021. The unmet needs of patients with advanced incurable head and neck cancer and their carers: a systematic review and meta-ethnography of qualitative data. *Eur. J. Cancer Care* 30, e13474. <https://doi.org/10.1111/ccc.13474>.
- Nowell, L.S., Norris, J.M., White, D.E., Moules, N.J., 2017. Thematic analysis: striving to meet the trustworthiness criteria. *Int. J. Qual. Methods* 16. <https://doi.org/10.1177/1609406917733847>.
- Ringborg, C.H., Schandl, A., Wengström, Y., Lagergren, P., 2022. Experiences of being a family caregiver to a patient treated for oesophageal cancer-1 year after surgery. *Support. Care Cancer* 30 (1), 915–921. <https://doi.org/10.1007/s00520-021-06501-5>.
- Ringash, J., Bernstein, L.J., Devins, G., Dunphy, C., Giuliani, M., Martino, R., McEwen, S., 2018. Head and neck cancer survivorship: learning the needs, meeting the needs. *Semin. Radiat. Oncol.* 28, 64–74. <https://doi.org/10.1016/j.semradi.2017.08.008>.
- Saarijärvi, M., Bratt, E.-L., 2021. When face-to-face interviews are not possible: tips and tricks for video, telephone, online chat, and email interviews in qualitative research. *Eur. J. Cardiovasc. Nurs.* 20, 392–396. <https://doi.org/10.1093/eurjcn/zvab038>.
- Schumacher, K.L., Stewart, B.J., Archbold, P.G., 1998. Conceptualization and measurement of doing family caregiving well. *Image - J. Nurs. Scholarsh.* 30, 63–69. <https://doi.org/10.1111/j.1547-5069.1998.tb01238.x>.
- Schunk, D.H., 2012. Social cognitive theory. In: Harris, K.R., Graham, S., Urdan, T., McCormick, C.B., Sinatra, G.M., Sweller, J. (Eds.), *APA Educational Psychology Handbook, Theories, Constructs, and Critical Issues*, 1. Am Psychol Assoc, Washington, DC, pp. 101–123. <https://psycnet.apa.org/doi/10.1037/13273-000>.
- Stenberg, U., Ruland, C.M., Miaskowski, C., 2010. Review of the literature on the effects of caring for a patient with cancer. *Psycho Oncol.* 19, 1013–1025. <https://doi.org/10.1002/pon.1670>.
- Thana, K., Lehto, R., Sikorskii, A., Wyatt, G., 2020. Informal caregiver burden for solid tumour cancer patients: a review and future directions. *Psychol. Health* 1–23. <https://doi.org/10.1080/08870446.2020.1867136>.
- Tranberg, M., Andersson, M., Nilbert, M., Rasmussen, B.H., 2021. Co-afflicted but invisible: a qualitative study of perceptions among informal caregivers in cancer care. *J. Health Psychol.* 26, 1850–1859. <https://doi.org/10.1177/1359105319890407>.
- Venkatesh, V., Morris, M.G., Davis, G.B., Davis, F.D., 2003. User acceptance of information technology: toward a unified view. *MIS Q.* 425–478. <https://doi.org/10.2307/30036540>.
- Wang, T., Mazanec, S.R., Voss, J.G., 2021. Needs of Informal Caregivers of Patients with Head and Neck Cancer: A Systematic Review. *Oncol. Nurs. Forum* 48 (1), 11–29. <https://doi.org/10.1188/21.ONF.11-29>.
- Wang, T., Molassiotis, A., Chung, B.P.M., Tan, J.-Y., 2018. Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. *BMC Palliat. Care* 17, 96. <https://doi.org/10.1186/s12904-018-0346-9>.
- Weaver, R., O'Connor, M., Golding, R.M., Gibson, C., White, R., Jackson, M., Langbecker, D., Bosco, A.M., Tan, M., Halkett, G.K., 2022. My life's not my own": a qualitative study into the expectations of head and neck cancer carers. *Support. Care Cancer* 30 (5), 4073–4080. <https://doi.org/10.1007/s00520-021-06761-1>.