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"Women's experiences of head and neck cancer: an interpretative phenomenological analysis"

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Abstract

Purpose Head and neck cancers (HNCs) are predominantly studied in men. This study aimed to explore women's experiences of HNC.

Methods The study was based on the secondary analysis of interviews conducted by using the life story methodology with patients who underwent surgery for HNC. We selected seven particularly rich interviews regarding the experience of cancer and first conducted a thematic analysis to identify key patterns in the data. We then applied interpretative phenomenological analysis (IPA) to explore in depth how participants made sense of their experiences.

Results Key themes were identified across different phases of the illness journey, including diagnosis, treatment, post-treatment, recurrence, and future projection. A major challenge was *diagnostic wandering*, as many women did not fit the typical head and neck cancer (HNC) profile—typically a man who consumes alcohol and tobacco. Identity loss was a central issue, with themes of reclaiming one's body post-surgery and the loss of feminine symbolism (infertility, hair loss, self-recognition). Coping strategies varied: some sought social support and aimed to return to work, while others viewed surgery as essential for recovery.

Conclusion These findings highlight the need for personalized support tailored to women's specific needs and challenges.

Implications for cancer survivors This study emphasize the importance of providing personalized support that closely aligns with the needs of female head and neck cancer survivors. It is crucial to consider their subjectivity, recognizing that each experience is unique, to better assist them in overcoming adversity. Tailoring care to their individual realities will more effectively address their emotional and physical difficulties.

Keywords Head and neck cancer, Women, Gender study, Interpretative phenomenological analysis, Lived experience

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Introduction

Head and neck cancer (HNC) is the seventh most common cancer worldwide, with 325,000 deaths annually and 660,000 new cases reported each year [1, 2]. Men are most affected by this type of cancer; however, the gender gap has been narrowing in recent years [3]. Unlike breast or prostate cancers, HNCs remain understudied in the humanities and social sciences. Yet, the physical and psychological repercussions of treatments such as surgery, chemotherapy, and radiotherapy are numerous. Physically, patients experience functional deficits such as voice and speech disorders, along with a high prevalence of pain and burns [4–7]. In addition, individuals with HNC may encounter difficulties in eating and may experience malnutrition [8]. In some cases, a gastrostomy is necessary to prevent severe malnutrition [9].

On a psychological level, depressive and anxious symptoms often persist and even increase after the end of radiotherapy [10, 11] and surgery [12]. Anxiety and depressive disorders are twice as prevalent in individuals with head and neck cancer compared to those with other types of cancer [13]. Furthermore, treatments such as surgery can sometimes lead to disfigurement and, consequently, a disruption in body image [14]. In fact, 75% of individuals who have had HNC express concerns about their body image [15]. As a result, the identity of those with HNC may be affected by these multiple treatment consequences.

To explore identity, one can rely on autobiographical memory, which encompasses all of an individual's personal memories [16]. It consists of semantic and episodic memories unique to each person and is a major component in maintaining identity [16]. Autobiographical memory allows people to maintain a sense of continuity and make sense of their experiences [16]. This memory is often significantly affected during aversive events such as cancer [17]. Moreover, there is a social dimension to autobiographical memory. It enables people to present themselves and share their stories with others, contributing to the maintenance and development of social bonds [18, 19]. It is easy to imagine that autobiographical memory, disrupted by a tragic event such as HNC, could lead to difficulties in an individual's relationships with others.

This situation is especially challenging for those with HNC: on the one hand, they face physical alterations and a significant identity upheaval, leading to difficulties in connecting with others. On the other hand, treatment-related difficulties can lead to stigmatization and social isolation [20–24]. Stigmatization is a multifactorial phenomenon that is also associated with the etiology of HNCs, which includes alcohol and tobacco use, as well as sexual practices [25, 26]. Individuals who have had HNC report a loss of identity [27, 28] and a sense of discontinuity, meaning that they no longer feel like the same person

over time [29] and report negative overall body image [30] and dissatisfaction with body image following head and neck cancer treatments [24, 30–32]. Consequently, these patients are likely to experience profound psychological trauma [33–35]), making it essential to offer them appropriate support for their difficulties. In addition, rehabilitative or even preventive care (speech and physical therapy) related to functional deficits is often necessary [36–40].

Studies show that gender affects disfigurement, with women experiencing more social pressure related to voice changes and alterations in appearance following total laryngectomy [41]. Furthermore, HNCs, whose etiologies are primarily associated with alcohol, tobacco, and papillomavirus infection, are still diagnosed late and represent a public health challenge [3, 42, 43].

Currently, only two qualitative studies have explored the experiences of individuals treated for HNC [44, 45], but these studies included only one or two women. However, because women tend to express their experiences differently and seem to face more social pressures than men, it is relevant to explore their experiences and personal narratives of the illness and its treatments.

The objective of this study was to deeply explore the experiences of women who have undergone treatment for HNC, in particular to understand how they make sense of the "head and neck cancer" event through their life stories.

Methods

The princeps study

The data analyzed for this study were derived from research on the autobiographical memory of individuals who have undergone surgery related to HNC. The primary objective of the source study was to explore the narrative identities of these individuals, whose treatments often lead to functional deficits, possible disfigurement, and psychological distress. To address this objective, we first conducted interviews by following the life story methodology developed by Habermas [46, 47]. This method involves, in the first step, asking participants to write down seven events that they consider significant in their life history on cards. In the second step, participants are asked to narrate their life story from birth to the present day, including the seven events previously noted on the seven cards in their narrative. Participants completed a questionnaire in which they were asked about their age, gender, family situation, type and stage of cancer, date of surgery, type of surgery, level of education, and socio-professional category. Please find attached the questionnaire translated into English that the participants completed.

Table 1 Participant characteristics¹

Partipant	Age	Study level	Time since surgery in years	Origin	Type of cancer	Treatment
Aurélie	31	Master's degree	3	Association ²	Orphan cancer ³	Several surgeries Chemotherapy Radiotherapy
Mathilda	46	Bachelor's degree	2	Association	Squamous cell carcinoma of the tongue	Surgery, free flap reconstruction
Hélène	41	Master's degree	1	Association	Squamous cell carcinoma of the tongue	Surgery, graft, radiotherapy, chemotherapy, immunotherapy
Stéphanie	48	Bachelor's degree	11	Association	Parotid cancer	Surgery, unknown for the rest of the treatment, recurrence in palliative care ⁴
Manon	26	Master's degree	0	Association	Submandibular gland carcinoma	Chemotherapy, surgery, radiotherapy
Jaqueline	53	Vocational training	6	Hospital⁵	Gingival cancer	Surgery radiotherapy
Madeleine	53	Vocational training	7	Association	Squamous cell carcinoma of the oral cavity	Neck tumor removal twice with flap, fibula flap, multiple surgery, chemotherapy and radiotherapy ⁶

¹The names appearing in the table are pseudonyms. ²Individuals who were recruited from a specialized association for head and neck cancers. ³One participant has an orphan cancer, leading to prolonged diagnostic wandering. Several diagnoses were successively proposed and later revised, leaving persistent uncertainty about the exact nature of her disease. ⁴The patient has undergone multiple treatments and several surgeries, experiencing numerous side effects. Due to treatment fatigue and exhaustion, she has decided not to continue treatment for now. ⁵Individuals who were recruited from hospital. ⁶The patient has undergone multiple surgeries, including flap reconstruction, which was unsuccessful. She has had a very painful journey and was hospitalized for several months due to post-surgical and radiotherapy complications

The selected interviews

To meet the objectives of the current study, we selected seven interviews with women from the 25 interviews conducted with female participants. We selected the interviews that were the most insightful regarding the participants' lived experiences and their cancer. Accordingly, we chose seven interviews (Table 1), with durations ranging from 15 to 40 min.

The choice of the method of analysis

Relevance of IPA for studying the lived experiences of women with head and neck cancer

IPA (Interpretative Phenomenological Analysis) goes beyond thematic analysis by providing a deeper understanding of individual lived experiences in their uniqueness. Rather than merely identifying common patterns, it focuses on how each person perceives and interprets their own reality. This approach is particularly relevant for exploring adverse life experiences, such as those of women undergoing treatment for head and neck cancer (HNC), where subjective interpretations play a crucial role.

The choice of IPA was reinforced by our discussions with healthcare professionals, including maxillofacial surgeons and a psychiatrist, who regularly treat patients undergoing extensive procedures such as reconstructive surgery. Our colleagues highlighted the significant variability in how patients experience and cope with treatment-related consequences: while some patients adapted well despite severe physical disfigurement, others with milder visible effects experienced profound psychological distress. This divergence suggested that beyond physical factors, individual perceptions shape each patient's lived experience.

These insights confirmed the relevance of IPA in capturing the complexity and subjectivity of these experiences. By emphasizing the richness of qualitative data over sample size, IPA is well-suited for an in-depth exploration of cognitive and emotional processes. This method typically involves a smaller number of participants (6 to 10), allowing for a detailed, interpretative approach to analyzing personal narratives [48–50].

Through this framework, we aim to explore the nuanced, deeply personal experiences of women navigating cancer treatment, shedding light on how they make sense of their journey and adapt to their evolving realities.

The analytic steps

The analysis began with conducting interviews, applying the principles of phenomenological reduction and intersubjectivity to ensure a deep understanding of the participants' experiences. Once the interviews were completed, I carefully listened to each one, paying close attention to the details and nuances in the participants' voices. Following this, the interviews were transcribed verbatim to ensure that no information was lost during the process. After transcription, I reread the interviews multiple times to immerse myself fully in the discourse, allowing for a comprehensive understanding of the content. The next phase involved coding the data by identifying meaningful units. Importantly, no predefined codes or themes were applied; the coding process was open, with themes with themes being identified through the analysis of the data itself. Once the initial coding was complete, I organized the codes into broader themes and subthemes. This process was repeated for each interview, with new subthemes and themes being identified as necessary based on the evolving data. After coding and organizing the themes, I entered them into a summary table (see appendix 1) to facilitate comparison and review. A crucial step was conducting a cross-reading of the various themes and subthemes, connecting them to uncover relationships between them. Through this cross-analysis, the researcher identified potential lines of interpretation, leading to a deeper understanding of the discourses and offering insights into their meanings.

Procedure

Participants were recruited through the Amiens University Hospital in France and the Corasso Association, which is specifically focused on HNCs. To participate in the study, participants had to be at least 18 years old, be fluent in French, have undergone surgery related to HNC with no time limit since surgery, and no longer be hospitalized. Flyers were distributed through the Corasso Association, and participants contacted the principal investigator via email, allowing the interviews to be conducted online. Participants recruited from the hospital were contacted by mail and phone, and the interview was conducted at the hospital with the principal investigator in a designated room.

Reflexivity

To conduct these interviews while adhering to the theoretical foundations of IPA, the researcher adopted a "phenomenological epoché" stance. The concept of "epoché" was developed by the philosopher Husserl, with the goal of eliminating all judgments and preconceived ideas, and promoting a benevolent attitude toward others [51]. Later, the philosopher Merleau-Ponty introduced the concept of "phenomenological reduction," which critiques Husserl's initial concept, arguing that it is impossible to fully eliminate all forms of prejudice. However, Merleau-Ponty emphasized the body and experiential life, which are also influenced by social interactions, a concept he called intersubjectivity [52].

In this study, the researcher aimed to follow the main principles of phenomenological reduction by adopting a nonjudgmental and benevolent attitude toward participants, while being aware of the influence she may have exerted during the interviews. The researcher also practiced reflexivity by adhering to the principles developed by Smith and adopting a critical stance toward her own biases [48, 50]. In terms of interpretation, this approach involved double hermeneutics, meaning that each participant interpreted her experiences through her own lens during the narrative, and then the researcher applied her own analysis to the self-analysis already provided by the participants [50, 53]. No research hypotheses or expected results were preestablished, as one of the main principles of IPA is to begin without preconceived ideas. Data related to autobiographical memory were collected but have not yet been analyzed to avoid influencing the researcher in her IPA.

Researcher background

IPA was conducted by the same person who conducted the life story interviews as part of a doctoral thesis in health psychology. The doctoral candidate holds a master's degree in clinical psychology and has experience as a clinical psychologist, having conducted numerous interviews. All of the steps described below were performed by this individual (interviews, listening, transcription, and analysis).

Ethical considerations

This study was approved by two ethics committees: the Ethics Committee of Lille (reference: 2023-684-S115) and the Ethics Committee of the Canton of Vaud (reference: 2022 – 01937). It was conducted in accordance with the principles of the Declaration of Helsinki. All participants received an information sheet and provided written informed consent. To ensure confidentiality, interviews were anonymized, and pseudonyms were used in the presented quotes.

Results

Thematic analysis

Through analysis, the researcher identified seven themes from the participants' narratives, each integrated into their life stories. These themes can be read in chronological order, which traces the key stages of diagnosis, treatment journey, challenges encountered, and future possibilities.

Themes

The themes identified through the analysis are as follows: Diagnostic Phase, Experience of the Diagnostic Phase, During Treatment, After Treatment, Recurrence, Future Projection, and Personality. These seven themes and their subthemes are summarized in Table 2 (appendix 1). Within each theme, the subthemes can be cross-referenced. For example, the subtheme related to identity appears repeatedly across several themes, as does the theme of social aspects (isolation and seeking connection). **Diagnostic phase: a sudden entry into the medical world** Several subthemes were identified, and many participants explained that they had to undergo numerous medical tests and consultations:

"And so there, my, my tumor and my lymph nodes are sent to the pathologist to see what it is. Anyway." — Aurélie, 31 years old.

Women did not always report genuine kindness from medical professionals in their life stories. Hélène demonstrated how one of her recent exams went:

"And then, in a rush, he tells me, 'Well, we'll redo a biopsy,' and he does it in his office by putting a thread in my tongue like this." — Hélène, 41 years old.

Aurélie explained that she was left alone for a long time while waiting for results at the radiologist:

"...I have a tumor and lymph nodes that are not normal sizes. And so, they did a lot of tests, I stayed more than 4 hours, more than 4 hours at the radiologist. I even remember, it's horrible, everyone went on lunch break. That is to say, the medical secretaries went on lunch break. The office was closed. But I was still there, I had been there since 8:30 in the morning." — Aurélie, 31 years old.

Hélène described a certain form of diagnostic wandering:

"And I continued to go from ENT to stomatologist, and each time they said, 'No, no, it's a healing problem." -

Hélène, 41 years old.

Hélène and Jacqueline explained that it took time for the cancer diagnosis to be made, and they *saw many specialists*:

"Well, no wonder, after 8 months, the tumor had time to spread." — Hélène, 41 years old. "In fact, it took a year before we discovered it was cancer." Jacqueline, 53 years old.

The disclosure marking the beginning of the disease was very often reported by the participants. Hélène immediately talked about the stage of her cancer and used quite precise medical terms, thus showing good health literacy:

"And then, it was the diagnosis given by the pathologist or basically, I had stage 3, I had lymph nodes, I had a capsular rupture." Hélène, 41 years old. Manon explained that the diagnosis of her cancer was announced with a casual tone and without tact:

"And then he told me that as if he were announcing that, I don't know, a loaf of bread cost 2 Francs 50. Well, he told me like that, without any tact..." Manon, 26 years old.

Jacqueline, on the other hand, explained that she does not fit the profile of ORL cancers, which are alcohol-tobaccorelated cancers. This subtheme suggested that some interviewees had a stigmatized image of people with ORL cancer, often associated with the alcohol-tobacco profile heavily propagated by society. These prejudices further reinforced the stigma of these cancers and the delay in diagnosis:

And, well, the dentist didn't think about it at all because apparently, I don't fit the profile. It was a man over 60, over 65 years old, alcohol-tobacco user. So I was 45 years old, I was a woman, I'm still a woman, that's for sure. No tobacco, well, I didn't smoke much. A cigarette like that at a party and not alcoholic.

Jacqueline, 53 years old.

The diagnostic process: a quite anxious period

During this initial phase of the disease, related to the appearance of symptoms such as a lump, a spot on the tongue, or loss of voice, some participants did not feel heard regarding their symptoms. They moved from one consultation to another with various specialists. They also had a strong demand for additional tests from doctors. For example, Aurélie was the *initiator of the request for tests*:

"I see this ENT, I insist heavily to get additional tests and with my fingers because I'm like, please go see what it is... I'm so stressed, I have a lump and it's so weird..." Aurélie, 31 years old.

Several participants also explained that their experience of this diagnostic phase was linked to a rather vague period, as if they were caught in a machine that was beyond them. Aurélie and Hélène used the same term "tunnel" to describe this period:

"So the diagnosis was communicated which was, which was heavy but I realize it only now, a year and a half later." Mathilda, 46 years old.

"So, I'm stunned but it's like I've entered a tunnel where I no longer really had a choice." Aurélie, 31 years old. "Indeed, he told me, 'Well, it's cancerous,' and then we went on to the extension assessment, so that was a period when I didn't really think about it, it was a real tunnel." Hélène, 41 years old.

Jacqueline expressed an immense fear of being disfigured and losing her face during this diagnostic phase:

"And I will always remember, before the operation... well, I see a man who had no face. I'm like, where am I, what's happening?? He tells me (the stretcherbearer), 'Oh yes, don't worry, it's a man who has sinus cancer'. And I was going for tests to see if... and I thought, at any moment I might be like that... and it's horrible." Jacqueline, 53 years old.

In general, the experience of this diagnostic phase is very anxious. Aurélie felt like she was losing her sanity:

"But still, I feel that something is wrong so I do a lot of tests that have nothing to do with it. But I'm 27 years old at the time, I go to the cardiologist, I go to the dermatologist, I do my STD tests 3 times, I think, damn, do I have a problem? Well, I, I, I'm going a little crazy." Aurélie, 31 years old.

Hélène talked about a real trauma during this diagnostic phase, which lasted 8 months for her:

"Or it was very traumatic because I had been asking if it wasn't cancerous for several months, each time they told me no, and then they did a rush biopsy and it hurts and then they told me, 'Yeah, it could be cancerous." Hélène, 41 years old.

The experience of the diagnosis could be linked to a sense of injustice for Manon, who was the youngest participant in the study:

"Because when you have cancer at 26, it's not normal. So, they told me all this..." Manon, 26 years old.

Treatments: an ordeal with major impacts

Treatments occupied an important place in the participants' life stories and appeared in the major themes. These treatments played a crucial role in the experience due to their heavy physical and psychological consequences. They represented a real battle. Madeleine expressed real psychological distress during the treatments:

"And my doctor at that time gave me an antidepressant, anxiolytics because I felt like I wouldn't make it, well, you see, I was... So he said, 'You need something to help you in the immediate.' So he gave me something, I needed it to get through at least the period of radiotherapy.' Madeleine, 53 years old.

The consequences and side effects of treatments were very often mentioned by participants. Thus, themes related to pain, burns, difficulties with eating, weakness, fatigue, and numerous functional deficits and psychological consequences were found. Aurélie and Madeleine recounted particularly difficult experiences, leading to critical situations where treatments became severely problematic, such as in terms of nutrition:

"Because, you see, we try to force, well, force, we try to put a tube to feed me directly but I can't stand it. I pull it out. We try for 30 minutes to an hour and actually, it's torture so we give up." Aurélie, 31 years old.

Or burns:

"So, for 2 months I couldn't eat, I was burned, I had trouble speaking, well, and that was very, very hard." Madeleine, 53 years old.

Madeleine explained that the radiotherapy necrosed part of her cheek and created a hole; she explained this while miming the situation:

"And then I went home, 2 weeks later, not even, I had a hole, a hole in my cheek. While eating, I had the food going out there. I went back to the hospital urgently and they said, 'Well, we'll... we'll reoperate you." Madeleine, 53 years old.

Aurélie explained that she was forced to continue radiotherapy sessions despite her skin being completely burned on her neck:

And especially at that moment, after 3 weeks or a month, my skin starts to be completely burned and I ask them to stop because my skin is peeling off, well, I'm raw and I have to go back every day on raw skin. Aurélie, 31 years old.

Consequences of treatments: between the loss of femininity and feminine symbolism

The youngest participants mentioned the necessity of undergoing egg retrieval due to fertility issues caused by treatments (surgery and radiotherapy). Manon explained that she had to act quickly even though she had not even considered having children given her young age: "After the cancer diagnosis, I went to a friend's place, and then my ENT called me, so it was 7 p.m. My ENT called me, he said 'Listen ******' because he speaks informally to me, 'You're going to start chemotherapy next week, it will make you sterile, do you want to have your things, well your eggs, an ovary, etc. removed?' So, overnight, I found myself asking the question of whether I needed to... Oh, so I think I might not be able to have children. So, two days later, I had surgery and managed to remove one ovary. I didn't have the opportunity to remove the eggs because I didn't have the time, as things had to be done quickly." Manon, 26 years old.

Aurélie, on the other hand, questioned two major feminine symbols. She explained that she felt stunned having to both undergo egg retrieval and prepare to cut her hair:

"Because my chemotherapy, well, chemotherapy can make you sterile, and so that requires me to go to the hospital every two days because, in fact, there are lots of, there are lots of blood tests, anyway, I don't know if you know how it goes, but it's a bit crazy. So, I'm stunned (...) In the evening, I inject myself with hormones for my egg retrieval, and my hair, which was just below my navel, is falling out (...) I'm going to have chemotherapy that will make me lose my hair, so I have to run to the hairdresser." Aurélie, 31 years old.

Whether surgical, radiotherapeutic, or chemotherapeutic, treatments have consequences on identity and femininity. Manon explained that she had to learn to live with a different appearance, despite being so feminine:

"So, I, who had hair up to there and was very feminine, had to learn to... well, I had to remove my nail polish, I did my nails, well, I have it again, but I had to remove my semi-permanent nail polish, I lost part of my eyebrows, lost my hair, so I had to learn to live with a different face, a different body, well, a different face rather." Manon, 26 years old.

Aurélie, on the other hand, felt as if she had been brutally altered by her surgery, reflecting a harsh and violent image:

"I come out with this feeling of having been slashed. My neck is swelling, it looks like I weigh 150 kilos if you only see my head like that. Physically, I'm changing." Aurélie, 31 years old.

Reclaiming identity: between acceptance, mourning, and reconstruction

Once the treatments are finished, one must learn to live differently. The way of being in the world, behaving, and acting in response to the adversity caused by cancer and its treatments varied greatly from one participant to another. Adaptation strategies were unique to each individual, highlighting the importance of considering each person's experience in its singularity. Jacqueline, for example, expressed the need for surgery to reconstruct herself. This surgery seemed to be the means that would allow her to return to a so-called social norm and thus gain a sense of belonging. However, she described a before and after that requires acceptance:

"So, well, then it's all about the reconstruction, both mental and physical. I had cosmetic surgery. Here. And it did me good. Even though you never fully return to how you were, it did me good. I needed it for myself... for my children. There you go." Jacqueline, 53 years old.

Recourse to surgery is subjective and unique to each person. Indeed, some people expressed a real need for it to rebuild themselves, while others did not. This observation underscores the importance of considering each person's subjective experience and the necessity, or lack thereof, of undergoing so-called reparative and reconstructive surgery. It also raises questions about connections and relationships with others and how a person will fit under the gaze of others. What is interesting to note here is that resorting to surgery was not always associated with greater well-being. Madeleine explained that she has undergone 17 cosmetic procedures, pointing to her face and saying that it was worse before than it is now:

"Afterwards, well, life went on, it was very, very difficult to accept myself. Now, I've had several reconstructive surgeries, they put implants in me (...) They added some fat to reshape me a bit... Around the lips and all that because in 2017–2018, it was really worse than this." Madeleine, 53 years old.

The notion of mourning appeared in several forms. The emotions expressed were often related to feelings of injustice and anger. Manon explained that during a preoperative consultation with the medical staff, she became aware that she would no longer be the same person after the surgery, and that the doctors had prepared her for the worst scenarios and potential sequelae:

"In fact, it was an operation planned to last from 9 a.m. to 12 p.m. [...] So, they were going to do a skin graft and a bone graft. They were going to take the fibula and place it in the mandible. They were going to cut from here to there to clean. And since they had to cut there, it could make me swell from the inside, so to allow me to breathe, they would have to perform a tracheostomy [...] To avoid this, they told me they would put me in a 24-hour coma after the operation to see if it swells; if it doesn't swell, they wouldn't make the hole [...] And they told me they would cut a nerve in my mouth, so my mouth would droop like this. So, well, I was told this on April 26, the day before my surgery, and I thought I wouldn't have the face I had anymore..." Manon, 26 years old.

Amid these significant changes, patients attempted to reclaim their lives as best as they could, as evidenced by Hélène's statement, in which she stated that it was important for her to return to work:

"And for me, it was extremely important to go back to work because I love what I do, I love teaching, and actually, it's also a way to reclaim my life." Hélène, 41 years old.

Returning to work also means resuming an activity that raises questions about social connections, which leads us to the final part of this analysis.

Support and social withdrawal: between disruption of social ties, seeking support, and maintaining connections Social aspects appeared in several themes. For some indi-

viduals, seeking social support seemed to be an instinctive reaction, as seen with Manon, who immediately reached out to her friends:

"I was told that I might have cancer... I just sent a message to my group of friends; there are 10 of us, and I sent a message asking if anyone would like to... because they knew, my friends knew that I was going to get the results of my tests... I just wrote, please, can we go have a drink afterward, I need you." Manon, 26 years old.

In other narratives, it was family relationships that were prioritized. Madeleine revealed the complexity of this support-seeking process from her husband, who was very present at the beginning of the illness but gradually became absent:

"So my husband, who was there at the beginning, was very, very... Well, in the beginning, the first two months, he was really, uh... I was very surprised because it was not at all his nature. But he supported me a lot the first two months, and then it kind of turned around, I mean, he had a bit of a special character and then, well, he kind of let me, well, manage on my own, actually." Madeleine, 53 years old.

Aurélie explained that the symptoms related to her cancer and the health context led her to gradually isolate herself from her social circle:

"It's a bit strange, really, I can't talk anymore, my social life is completely disrupted (....) And then especially it's the lockdown, so actually, since my surgery, I haven't seen anyone because of COVID since I'm weak, and in total, I will have stayed more than 10 months like this, only seeing my boyfriend, my sister, and my parents." Aurélie, 31 years old.

Stéphanie, on the other hand, found herself isolated for professional reasons following her job loss related to her illness. Despite being very invested in her professional field, she expressed real suffering from this change in status:

"So, I wanted to go back to work, but it was very complicated. Even with therapeutic part-time work, even part-time, social security didn't want to and put me on disability." Stéphanie, 48 years old. "Completely removing me from the social framework of my job, for which I had invested 1000%, completely desocializing me." Stéphanie, 48 years old.

The consequences of the surgery sometimes made interactions difficult. This was the case for Mathilda, who expressed having to be careful when talking to someone:

And I'm someone who speaks very easily but always having this feeling of a dry mouth, having to pause, being careful not to drool, and things like that. So, it kind of puts me in a bit of a distressing situation. Mathilda, 46 years old.

Discussion

The results of this analysis show that HNC and the associated treatments have significant consequences for the individuals encountered in this study. The themes identified from the participants' narratives follow a chronological order, which traces their diagnostic and treatment journeys. The chronological aspect present in life stories may correspond to a sense-making process of participants' experiences and journeys. Indeed, individuals who have received treatment for HNC encounter disruptions in their body image and identity [54]. Integrating a chronology within their life story related to HNC could help individuals make sense of their stories and journeys in order to better integrate their identities [55]. This initial observation can be interpreted as a factor of resilience. By making sense of their experiences, individuals demonstrate resilience and attempt to better understand themselves [56]. Furthermore, meaning-making is closely linked to emotional expression and social connections. The ability to articulate emotions and make sense of significant life events through verbal narratives helps individuals structure their experiences, validate their feelings, and share their journey with others. This process fosters better mental health and stronger social connections, both of which are crucial for resilience in the face of HNC.

Fairly convergent discourses are found around the diagnostic phase. Thus, some women visit multiple specialists. The time elapsed to obtain further tests and a diagnosis is long for some of them. One reason for these delays in care is that their symptoms are not taken seriously [57]. The medical community more readily associates psychological symptoms such as anxiety with women than with men [57]. Another reason that could explain these diagnostic and care delays is that these women do not fit the typical profile of someone diagnosed with HNC. HNCs more commonly affect alcohol and tobacco users than they do women [58]. Stigmatization and prejudices associated with HNCs could thus lead to delays in diagnosis for individuals who do not fit the profile, especially for women, whose symptoms are often minimized. Furthermore, one study showed that diagnoses of these cancers are often made at relatively advanced stages of the disease, representing a major public health issue [59]. Another recent study of 100 patients showed that only 20% were diagnosed at an early stage [60]. Several hypotheses could be proposed regarding the issue of late diagnoses. The first relates to the so-called typical profiles (alcohol and tobacco users) of people who are often distant from healthcare systems and delay seeking help when the first symptoms appear. The second hypothesis regarding late diagnoses could be linked to profiles that differ from the "expected" profile, such as a healthy young woman without risk factors (alcohol, tobacco, and age). Therefore, it is essential for medical staff to receive training on biases and potential prejudices that could influence diagnoses, such as gender bias, as well as the stigma associated with the alcohol- and tobacco-related profile of these cancers. The results of our study align with existing literature. The process of meaning-making is particularly complex for participants in this context, given their diagnostic odyssey, their deviation from the typical profile (alcohol and tobacco use), and a persistent sense of not being heard by healthcare professionals. This multifactorial context significantly hinders these women's ability to make sense of their experiences.

Another critical moment in the course of the illness is when a person is diagnosed with cancer. Communicating a cancer diagnosis is a challenging step that raises many questions and anxieties for which healthcare professionals may not have immediate answers or certainty. The analysis of the interviews highlights that empathy, support, and kindness are essential during the delivery of the diagnosis which otherwise becomes traumatic not only because of the bad news, but also because of the manner in which it is delivered. A meta-analysis has highlighted a significant link between oncologists' empathy and various patient outcomes [61]. However, some participants in our study reported that the diagnosis was delivered abruptly and without sensitivity confirming alarming findings. Indeed, a study of 100 patients found that a quarter of them never met the doctor who delivered the diagnosis, and the suspicion of cancer was expressed before the final diagnosis for only 50% of them [60], which contradicts best practice guidelines (reference on guidelines for delivering bad news). These elements highlight the importance of continuous training for healthcare professionals in best practices for delivering bad news. It is easy to understand how distressing it can be for patients to face both a cancer diagnosis and the abrupt communication of bad news. In such situations, feelings of anger and injustice may dominate, further complicating patients' ability to process their experience.

In addition, the experience of the diagnostic phase and its examinations seems to converge for many women who describe entering a tunnel, living through a blurry period, and following a headlong process. Nevertheless, the women's discourses diverge in how they face the side effects of treatments and the difficulties caused by them. The body image of patients with HNC is very often disrupted [23, 54]. Some women in our study explained that they take antidepressants and anxiolytics to cope with the illness and its consequences, and they expressed the need to see a psychologist. Indeed, depression and anxiety rates are higher in individuals with HNC compared with those in people with other cancers [35]. Preliminary results show that, compared with individuals with other cancers, those with HNC are more vulnerable to developing post-traumatic stress [62]. Finally, these individuals are at a higher risk of suicide compared to both the general population and individuals with other types of cancer [63, 64] highlighting how difficult it is to make sense of such an ordeal.

The analysis of life narratives reveals that some individuals feel the need to undergo "reconstructive" or "aesthetic" surgery to restore their sense of identity. For them, the process of meaning-making is necessarily tied to facial restoration and, consequently, to reconstructive surgery. However, the experiences of these women following such surgeries are not always associated with better self-acceptance or greater well-being. These results corroborate those of a study on flap reconstructions, which showed that patients who undergo such surgeries, compared with those who do not, undergo more distress related to their body image, social isolation, and social avoidance. Therefore, the use of surgery should be considered subjectively. Some individuals express the need for it in order to rebuild themselves, unlike the case for other individuals. Consequently, these findings raise questions about conformity to social norms, particularly regarding a feminine face, as gender affects the perception of disfigurement. One study of individuals who had undergone laryngectomy showed that there are gender differences in the experience: women describe an emotionally charged journey initially marked by a sense of loss of meaning in their lives but later transformed into a rediscovery of a better version of themselves, whereas men focus more on the loss of function and functional and physical recovery [65]. Another study of individuals with HNC reported that women experience more body image disturbances than men do [66]. Reconstructive surgery should not be regarded as a universal solution, as its effectiveness in alleviating patients' distress and emotional impact varies significantly from one individual to another. Each patient's case is unique, highlighting the need for tailored psychological care and support to address the diverse needs of both men and women.

Subthemes such as "having normal life projects" reflect a complex process shaped by cultural norms rather than individual preferences. This behavior allows individuals to belong to a group, feel accepted, and improve their psychological well-being. Some research highlights the importance of belonging for psychological well-being [67]. However, several studies have shown that HNCs are associated with greater social isolation [22]. Patients with disfiguring cancers also restrict their relationships to their close social circle and limit interactions related to their employment and more distant social relationships [68]. Surgery may thus be a way for some individuals to address these difficulties. Two approaches were identified from the discourses. Some women try to overcome adversity by achieving an appearance that conforms to social norms through surgical practices. Others seek social support and re-engagement in their professional sphere to reclaim their lives. In the first case, surgery enables individuals to regain their facial identity and reintegrate into social life, serving as a pivotal tool for restoring social relationships. This highlights the face's fundamental role as a primary means of communication. In other cases, some individuals appear less concerned with their physical appearance, prioritizing the restoration of their previous life above all else. For them, the meaning-making process seems more focused on reclaiming their life rather than their appearance. It is essential to consider the diverse factors contributing to resilience, ensuring that social and normative dimensions are not overlooked in the care and support provided to these individuals. Social support is a coping strategy that often proves beneficial; a study of women with breast cancer showed a strong positive link between the meaning given to life and social support [69]. Tumor location, social support, and the level of disfigurement are predictors of psychosocial adjustment, with psychosocial adjustment being lower for individuals with higher levels of disfigurement and less social support [70]. Social support, along with the ability and willingness to connect with others, can be found in the professional sphere. Work occupies a central place for some participants who expressed the need to return to work after treatment. One of them expressed a desire to return to work in order to reclaim her life. Another participant, on the other hand, expressed a strong sense of injustice following her placement on disability, as she was deemed no longer capable of performing her job, in which she says she had been deeply invested. Work is not only a vector of social connections, but also a source of validation and integration. On a larger scale, a meta-analysis showed that 67% of individuals with HNC are able to return to some form of work after treatment, 44% need to reduce their working hours or are no longer able to work, and 30% change jobs after treatment [71]. The consequences of HNCs sometimes require adjustments to the workplace or professional reorientation [72]. Returning to work represents a real challenge for individuals experiencing communication difficulties such as speaking and swallowing. Furthermore, studies show that the rate of people returning to work after HNC is lower than that for other cancers, and individuals with HNC take longer to return to work [73]. This is regrettable, as studies show that individuals who return to work have lower rates of anxiety and depression compared with those who do not [71]. This final point underscores the importance of integrating these individuals into the professional sphere and implementing measures to support them in maintaining and pursuing their employment, given the positive impact of work on their mental health.

Limitations and perspectives

First, it is important to recall that the aim of IPA is not to generalize the results from the sample to the broader population, but to investigate in detail the experiences of a small group of individuals. In addition, the population chosen for this study is affiliated with Western culture. Therefore, the results may not extend to other cultures and regions where norms, representations, and access to techniques of care differ. The participants all underwent surgery related to HNC. However, the time elapsed since the surgery varied from one participant to another, ranging from less than a year to 11 years. Consequently, participants are at different stages of their illness: some are in remission, others are undergoing treatment, and some are experiencing a relapse. Moreover, they have received different surgeries and associated treatments, depending on the type of cancer and the stage of the disease, which leads to varying deficits and difficulties for each person.

Another limitation is related to recruitment, as six of the seven women come from the associative sector. There may be a similarity bias, as these women are involved in the association and share similar resources and convictions. They contacted the principal investigator on their own initiative to participate in the study, unlike the individuals recruited from the hospital who were invited to participate. The data analyzed in this article also came from life story interviews, in which participants were instructed to narrate their lives from birth to the present. It could be assumed that their narratives might have been less chronological and structured if the participants had been asked to recount their illness experience specifically.

This study could be complemented by a comparative study on gender by exploring the experiences of men and women. Conducting a longitudinal study would also be valuable. Because narrative identities can be affected by cancer, it would be pertinent to delve into aspects related to autobiographical memory in individuals who have undergone treatment for HNC.

Conclusion

In this study, we explored the experiences of women who have undergone surgery related to HNC through an IPA, which highlighted the subjective experiences unique to each participant.

The research reveals significant psychosocial challenges. Participants discussed issues related to accepting a new self, the necessary physical and psychological reconstruction, and the need for appropriate psychosocial support to help them overcome the difficulties caused by the treatments. The study also emphasizes the necessity of considering these women's experiences subjectively. Integrating their personal experiences and narratives into their individual follow-up allows for better daily support and the provision of care and interventions that closely align with their needs, both physically and psychologically.

Supplementary Information

The online version contains supplementary material available at https://doi.or g/10.1186/s12905-025-03671-w.

Supplementary Material 1 Supplementary Material 2 Supplementary Material 3

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Author contributions

CV: Study conception and design, data collection, analysis and interpretation of results, manuscript writing; SL: Study conception and design, critical manuscript review, contributions to the interpretation of results; SC: Data collection, critical manuscript review, contributions to the interpretation of results; ST: Data collection.

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Data availability

The datasets generated and analysed during the current study are not publicly available due to the sensitive nature of the qualitative interview data. As the participants shared detailed personal narratives related to their experiences with head and neck cancers, and given the rarity of this condition, there is a risk of identification despite the use of pseudonyms. Data are, however, available from the corresponding author upon reasonable request and for a specific purpose.

Declarations

Ethics approval and consent to participate

The project was submitted to two ethics committees in France and Switzerland. It was approved by the ethics committee of Lille (reference 2023-684-S115) and by the Ethics Committee of the Canton of Vaud (reference: 2022-01937). Each participant received an information sheet and signed a consent form. The interviews were anonymized, and pseudonyms were used in the quotes presented in this article.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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