



# Surviving cancer following total laryngectomy: a phenomenological study

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## Abstract

**Purpose** Total laryngectomy followed by radiotherapy is a life-preserving treatment for patients with locally advanced laryngeal cancer. This study explored how persons who had undergone total laryngectomy perceived themselves as cancer survivors in the follow-up phase.

**Methods** A descriptive phenomenological approach was adopted. We employed a purposive sampling strategy to collect data through interviews at the otorhinolaryngology outpatient clinics of two research hospitals in northern Italy. The interviews were transcribed verbatim and analysed, following the seven analytical steps of Colaizzi's descriptive analysis.

**Results** The final sample included 19 patients. The following main themes were identified: (i) accepting a life with the "without" to survive; (ii) feeling unpleasant emotions; (iii) getting the hang of communication again; and (iv) reclaiming one's role. Together, they highlight the lived experiences of laryngectomised patients during the follow-up phase and how they perceived themselves as cancer survivors.

**Conclusion** Laryngectomised patients are a uniquely vulnerable population. This study provides insights into how surgical procedures change and affect their lives over time to improve care models, patient education, and support systems. Survivors must be adequately prepared to transition from treatment and return to the community. This preparation should begin before treatment is started. Functional education, accurate information, and psychological support must be arranged and provided before surgery. Regarding the post-treatment phase, it is essential to support voice rehabilitation and peer support, and improve the family network, to ensure these patients' reintegration into society and social recognition.

**Keywords** Laryngeal cancer · Oral cancer · Laryngectomy · Cancer survivors · Quality of life · Qualitative study

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## Introduction

Total laryngectomy (TL) followed by radiotherapy (RT) is a life-preserving treatment in the management of patients with locally advanced laryngeal cancer [1].

The use of primary TL has decreased since 1991. Studies have shown similar oncological outcomes, and survivorship was reached in advanced laryngeal cancer patients treated with concurrent chemoradiation compared to those undergoing surgery and RT [2, 3]. Furthermore, critical consequences that include changing one's appearance due to permanent tracheostomy; risk of wound infection and necrosis; fistulas; dysphagia; loss of natural voice, smell, and taste; and respiration symptoms drive the patients' decision to prefer organ-preserving surgery techniques [4]. The physical changes are also associated with functional declines, such as low physical fitness, problems with food intake, recurrent coughing, and communication impairment [5]. As a result, TL is often considered more emotionally traumatic than other types of surgery because of the resulting psychological and functional impairment [6]. Laryngectomised patients may also experience relational difficulties, and report diminished intimacy and change in their body image [7–10]. Besides, stigmatisation and social exclusion may be perceived as higher in these patients because the surgery outcome is physically visible and hard to hide [11].

Furthermore, individuals who have undergone TL experience significant limitations in their ability to speak, often being limited to hoarse whispers. This further complicates their social interactions and interpersonal relationships [12]. To address these challenges, various interventions and techniques, such as prostheses or specific speech methods (oesophageal speech, tracheoesophageal puncture, and electrolarynx), have been employed [13, 14]. These interventions enable laryngectomised patients to maintain their social functioning without neglecting the other numerous supportive care needs that require attention and care [15, 16].

Laryngectomised patients are a uniquely vulnerable population. Therefore, exploring and better understanding how surgical procedures change and affect their quality of life (QoL) over time is necessary to improve care models, patient education, and support systems [5, 17].

Therefore, this study explored how persons who had undergone total laryngectomy perceived themselves as cancer survivors in the follow-up phase. In this context, qualitative research offers an excellent methodological approach to exploring cancer patients' psychosocial and contextual aspects because it enables a deep exploration of the participants' lived experiences and analysis of the complexities and context of their experiences [18].

## Methods

### Study design

This is part of a larger qualitative study aimed at exploring and understanding the perspectives and lived experiences of laryngectomised patients. The design also included visual-based research, which will be the subject of another paper.

A descriptive phenomenology approach was adopted for the present qualitative study because it enabled us to investigate the meanings of individual lived experiences and explore participants' motivations and perspectives [19]. Criteria for reporting qualitative studies have been used [20] and are available as supplementary information.

### Study population and settings

A purposive sampling strategy was adopted to collect data at the otorhinolaryngology outpatient clinics of two research hospitals in northern Italy. The inclusion criteria were (i) being an adult laryngectomised patient ( $\geq 18$  years old); (ii) having completed chemotherapy and/or radiotherapy at least between 3 months and a maximum of 5 years before the interview; (iii) be fluent in Italian; and (iv) being without any physical or cognitive impairments that negatively affect participation. Patients with mental/cognitive impairment, undergoing palliative treatment, with a prior history of another form of cancer, and a tumour recurrence were excluded. As employing a phenomenological approach, we considered having a relatively homogenous sample concerning voice rehabilitation and speech type. Participants were recruited during their follow-up visits.

### Data collection

Data were collected between May 2017 and April 2018 by four trained researchers (H. C., G. C., C. D., E. L., who did not know the participants and were not involved in their treatment) who conducted in-depth, individual, face-to-face interviews guided by a pre-planned guide for interviews to promote inter-rater consistency (Table 1) [21]. The guide included open-ended questions and prompts to support each participant's narrative. No prior theoretical reference was used to define the guide.

At the beginning of the study, two pilot interviews were conducted to investigate if the planned guide was in line with the aim of the study. As minor adjustments were necessary, the two interviews were included in the

**Table 1** The interview guide

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Could you please tell me about your day? How do you feel?
Could you please comment on what the disease brought into your life? Could you give me an example?
Could you please tell me what is particularly emotional to you?
Could you please comment about the relationship with your family/loved ones?
Could you tell me what you experience today when interacting with others? And health professionals?

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final analysis. Socio-demographic information was also collected at the end of each meeting. All interviews were audiotaped and conducted in a room next to each outpatient clinic after the follow-up visits by two trained researchers to promote participants' privacy.

### Data analysis

The interviews were transcribed verbatim and analysed, adopting the seven analytical steps of Colaizzi's descriptive analysis framework [22]: (a) four researchers listened to and read the interviews several times to reach a complete understanding of the participants' experiences and feelings; (b) main significant words and sentences were identified and synthesised in significant statements; (c) for each extracted statement the researchers discussed and formulated the primary meanings; (d) formulated meanings were organised into themes and sub-themes; (e) researchers integrated emerging ideas into a comprehensive description of the studied phenomenon; (f) starting from the comprehensive description, researchers identified statements to synthesised the fundamental structure of the phenomenon; and (g) the researcher invited the participants to discuss the findings and to validate them, and five of them agreed. An expert qualitative researcher checked the whole data analysis process.

### Rigour

Credibility, transferability, dependability, and confirmability were guaranteed to promote the study rigour [23]. The research team systematically applied the analysis framework. During the analysis process, researchers bracketed their potential pre-assumptions [24, 25] to focus on participants' experiences as entirely as possible [26]. An expert in qualitative studies supervised the analysis process, and two researchers who did not participate in the first analysis confirmed the identified findings [27]. Pilot interviews were conducted, and a group of participants confirmed that the study findings reflected their experiences.

### Results

In both research settings, researchers contacted 37 potential participants by phone. Eighteen of them refused the interview: 11 motivated the refusal (they said they would

have felt uncomfortable talking about laryngectomy and subsequent experience), four did not answer our phone call, and three did not disclose their reasons. The final sample included 19 patients who underwent total laryngectomy (15 men and four women) with a mean age of 66.3 years (SD 10.70; range 41–90 years). Their characteristics are shown in Table 2. The interviews' duration was mean 42'.

Most participants ( $n = 14$ ; 73.7%) were retired and living with a partner. The time since diagnosis varied; many participants had received the diagnosis five or more years earlier ( $n = 7$ ; 36.8%), followed by those who received the cancer diagnosis in the last year ( $n = 6$ ; 31.6%). About half of the participants underwent RT after the surgery, and two also underwent chemotherapy. All the participants attended voice rehabilitation sessions and communicated using oesophageal voice, but one female participant, recently diagnosed (a year), with a pseudo-whispering voice.

By analysing the interviews, the following main themes were identified: (i) accepting a life with the “without” to survive; (ii) feeling unpleasant emotions; (iii) getting the hang of communication again; and (iv) reclaiming one's role. Together, they highlight the lived experiences of laryngectomised patients during the follow-up phase and how they perceived themselves as cancer survivors.

### Theme 1: accepting a life with the “without” to survive

Receiving the diagnosis, the treatments and having undergone a TL marked a sharp divide in the life of the participants. At the follow-up, they were realising the “bill to be paid” — a steep bill that marked a new existential phase. Some admitted that they initially thought of committing suicide to overcome a sense of utter despair.

“It was bad at first. I was going a little crazy. I was already thinking of the worst. It happened... I still have a knife like that [he opens his hands to show the length of the knife]”. [patient 8 RE]

However, by declaring they had not done so, meant that they had taken the first step towards taking their lives back into their own hands. Our participants described how they reacted to the consequences of their laryngectomy: they

**Table 2** Participants' characteristics ( $n = 19$ )

Characteristics	$n$ (%)
Age range in years	
41–50	2 (10.5)
51–60	3 (15.8)
61–70	5 (26.3)
71–80	8 (42.1)
81–90	1 (5.3)
Gender	
Female	4 (21)
Males	15 (79)
Education	
Secondary	14 (73.7)
Tertiary	4 (21)
Post-graduated	1 (5.3)
Family status	
With partner	14 (73.7)
Without partner	5 (26.3)
With children	7 (36.8)
With grandchildren	9 (47.4)
Employment	
Employee	4 (21)
Not employee	1 (5.3)
Retired	14 (73.7)
Years since diagnosis	
1	6 (31.6)
2	3 (15.8)
3	3 (15.8)
5 or more	7 (36.8)
Treatment after surgery	
Radiotherapy	8 (42.1)
Radiotherapy and chemotherapy	2 (10.5)
No treatment	9 (47.4)
Speech type	
Oesophageal voice	18 (94.7)
Pseudo-whispering voice	1 (5.3)

felt they were forced to accept living a life with many “withouts” — without a larynx, without a voice, without the usual communication skills, and without the social role, they were used to have.

The interviewees reported a sharp drop in their self-esteem and negatively evaluated their ability to handle such a situation. However, this was interpreted as a temporary condition occurring at the beginning of this new journey.

“Of course, since I’ve gone back to work, I’ve gone back to the same rhythm as before, so I go out in the morning at nine, nine-thirty very calmly and go back

home very calmly, unfortunately, even in the evening from the office, during the weekend I can’t go out, but I rest at home... nothing special”. [patient 2 GE]

In this regard, the interviewees described how accepting their new condition was their only chance to react and survive the consequences of the disease and the treatments they received.

From their experience of illness, some participants learned how to move forward, drawing lessons for their own lives.

“The first thing is that I really don’t care. I move on... Of course, the thought is not that it’s not there. But when I realise it, I don’t say: ‘I can’t do this’. I think of it, but I face it”. [patient 1 GE]

Other participants declared how they found an acceptable balance by integrating their new condition into their existence, triggered by the feeling that they were lucky overall. Some reported they felt they were lucky to be still alive or to have been more fortunate than other people with the same disease.

“I was lucky not to have had radiotherapy or chemo, and once operated on, I didn’t take any medicine for my illness... I did all the check-ups I had to do, and they always went well... my body always responded to the maximum, so I returned to my normal life”. [patient 3 RE]

Thanks to the passing of time, many of our participants accepted their new life and dealt with everyday life differently. In this regard, some survivors reported they could change their attitudes towards life because even in misfortune, it was possible to find something positive to help them to overcome difficulties.

“Despite everything, I love life. I am a happy person... I have found in this world my way of being, of expressing myself, of being happy and above all, and returning home at night very tired but saying: ‘What a great day it has been today’”. [patient 5 RE]

The acceptance path of living with laryngectomy was eased by the support they received from their faith, their family members, and health professionals.

“The message is never to give up, to keep going and to thank Our Lord, and obviously also the doctors because they are instruments of the Lord”. [patient 9 RE]

Most interviewees stated that their family and friends’ support was crucial for them, and the support provided by the healthcare providers during the hospitalisation and rehabilitation phases.

“Both my very praiseworthy wife and my colleagues, really, they were all very nice. They all stood by me like I would have liked someone by my side!” [patient 2 GE]

Despite the difficulties caused by the disease and treatments, all participants were grateful to those who helped.

## Theme 2: feeling unpleasant emotions

Our participants' acceptance dynamics did not exclude an ongoing unpleasant emotional aspect. When they described their changes, they mainly associated them with unpleasant feelings of threat, psychological distress, and worry. Some even had suicidal thoughts, but with the help of their loved ones, professionals, and their motivation, they turned their despair and resignation into a new way of reacting to and managing their existence.

“I was outraged. Please don't ask me why, but this was how I felt. Even with myself”. [patient 7 RE]

The laryngectomy resulting in the mutilation of a visible part of the body caused a radical change in the body's function and psychological problems. Starting to see oneself in the mirror, especially after surgery, caused a sense of estrangement:

“The aftermath of the operation was hard. When I looked at myself in the mirror, I didn't recognise myself; I didn't know who I was”. [patient 2 RE]

Accommodating the new identity and body image was very hard: accepting the pristine condition and starting to deal with it did not cancel the shame. This feeling was reported both for loved ones and unknown persons.

“For example, presenting myself to a woman... is no longer the same as before... It is difficult to speak, there is phlegm, there is the stoma, which is not a beautiful presence or sight to see, and consequently, it disturbs one's intimacy there too”. [patient 3 RE]

For some participants, the body changes also impacted their attitudes. Many participants reported becoming less tolerant of others. Anger was exacerbated if they felt they were not understood during a conversation — something described as unacceptable.

## Theme 3: getting the hang of communication again

All the participants suffered from the loss of voice due to the TL. At the time of the interview, they spoke using an oesophageal voice. Only one who was recently diagnosed communicated with a pseudo-whispering voice. The participants shared this functioning impairment which greatly

conditioned their sociality. Their inability to speak caused discomfort and misunderstanding, with consequent anger and frustration.

“I was a chatterbox before the operation, but not so much now”. [patient 6 GE]

Most respondents reported that communication, primarily verbal, slowed down and required more effort to be performed than before.

They often felt uncomfortable and had to ask another person for help to make themselves understood or to devise different communication techniques. Nonetheless, they did their best to return to communicating and defining strategies to deal positively with the loss of their voice.

“It is obvious that when lots of noise surround me, my voice is not enough to make myself understood, so I have to find other solutions... like writing notes”. [patient 9 RE]

## Theme 4: reclaiming one's role

Once accommodated to their new condition, many participants stated their strong desire to reaffirm themselves as persons, claiming they were still “useful”, trying to reach the normality they were used to have.

“We are not scraps to be thrown away. We can still be useful...” [patient 1 RE]

Many attempted to normalise the illness challenges and mainly tried to avoid being pitied by their relatives and friends for their physical condition.

“I've cut ties with many people, so it doesn't matter anymore... I can't take it anymore. They're all hypocrites”. [patient 5 GE]

Some participants reported that they felt comfortable again when doing their daily activities and neglected the glances of others.

“I don't know, but at the beginning, I did, and now it has become normal, and I don't pay attention to it anymore. I don't think any more of those who say: ‘Look at that unfortunate guy’, so I don't have any fears or problems”. [patient 3 RE]

## Discussion

The present study is one of the first studies exploring patients' perspectives with TL about their experiences as cancer survivors in the follow-up phase, adopting a phenomenological approach. Even though participants reported

their living changes and restrictions, many of them tended to downplay the challenges caused by their disability. They showed a positive attitude, gratitude, and self-esteem, as mentioned elsewhere [28]. As reported by Swore Fletcher and colleagues [29], one explanation for this reaction could be the need to change their life perspective due to experiencing something unexpected and adapting to survive. Survivors often reflected on the meaning of life and values as a guide to finding a sense of purpose [29]. Furthermore, for many survivors, the need to face the challenges of their health conditions positively represents “the price to be paid” to live without cancer [30].

TL alters some physiological functions such as airway and nasal function, swallowing, smelling, tasting, and the ability to speak. These changes affect patients’ psychological and emotional status, the quality of their lifestyle, and social and family interactions and roles [15, 31]. As shown elsewhere [31], our participants also described concerns about their physical changes. Some admitted having thought about suicide in the first period of the disease. The suicide rate amongst head and neck cancer survivors is double concerning other cancer survivors, about four times higher than in the general population [32]. Consequently, although the survival rate for these patients has improved over time, their risk of suicide remains a concern.

The support provided by the patients’ families helps to face this challenge. When family members understand the patients’ difficulties, are tolerant, and offer their help, survivors report more confidence in life and a reduction of feelings of anxiety and depression [33]. Similarly to other studies [29, 31, 34], our findings confirm the crucial role of the family and relatives in supporting the recovery of laryngectomised patients. Conversely, when social support is poorly accessible and available, those patients have reduced access to support resources and relevant information, particularly when they have communication difficulties [35]. This suggests that if early supportive interventions to encourage how patients could cope with changes in physical function after surgery are lacking, their reintegration into society could be more complicated [31]. Moreover, our findings underlined the importance of fostering permanent support during the whole disease and survivorship trajectory, creating a triadic relationship between survivors, families, and healthcare professionals [36].

A significant challenge reported by participants was the communication alteration and the efforts experienced to find and adopt new speaking methods. Communication difficulties increase after surgery, gradually improving after a year [37]. Nonetheless, whilst dealing with communication difficulties, patients are bothered and worried by the absence or quality of their voice [11]. They can also experience isolation and stigmatisation (especially if they are the only persons with these problems in the context of rare cancer).

Our participants “got the hang of communication again” through speech rehabilitation sessions which taught them how to produce the oesophageal voice and helped them return to their daily activities. In this context, peer support groups and voice rehabilitation (including oesophageal voice) have been described as successful helping strategies [11, 34, 38–40]. It has been noted that low speech intelligibility is associated with reduced conversations and social activity [41]. Conversely, the ability to participate in meaningful and social activities is a significant factor for the patient’s QoL [42]. Our study reinforces the findings from a narrative review synthesising the potential impact on patients’ QoL across all communication options [12] after TL. In general, the voice-related factors (e.g. sound quality, the difference to pre-TL, the effort of speaking) and aesthetics of the communication option are reported to influence self-ratings of QoL rather than how well others could understand the patients. Regarding our participants’ communication, the QoL is higher for non-oesophageal speakers in several domains, such as speech impairment, communication activity limitation, and communication participation restriction [12]. This would occur even if unfamiliar listeners of oesophageal voice speakers rate their speech more intelligible and acceptable [43] than other groups of TL patients.

Since oral communication serves as the main instrument for social integration and general socialisation with other members of the society [37], also families should be involved in voice rehabilitation from the pre-operative stage [44, 45]. Having family caregivers on the patients’ side would concur to limit the social effects of voice loss [37, 46]. Indeed, social avoidance is a common way to cope with sociality for these patients — our participants’ social behaviours aligned with the results of previous studies [47]. As highlighted by Mertl and colleagues [11], there is no possibility of hiding the inability to speak, and there is a hole or other visible mark in the neck of the patient. Even if our participants adopted coping strategies to contrast what Mertl and colleagues pointed out in terms of others’ disgust, fear, and awkwardness [11], social avoidance was still confirmed in our study. Since patients cannot hide their health condition and the signs left by surgery, they are forced to expose themselves to social judgment and stigma [11]. Our participants experienced “feeling downgraded”: perceived stigmatisation is frequently accompanied by anxiety and loneliness [48].

Finally, our interviewees reported inevitable changes in their social and family roles after TL modified their sense of agency and the need to find and show their new identity, similar to Bickford and colleagues [49]. This finding suggests that patients must be physically and mentally supported regarding their changed conditions to better face the TL’s consequences. Nevertheless, working-age participants returned to their former job after surgery, whilst others developed new roles or assisted other patients who underwent TL. The need for redemption



and reaffirmation of their role is also confirmed by Saeidzadeh and colleagues (2021) [50], where head and neck cancer survivors changed their behaviours and were actively involved in a variety of activities that they believed were important in light of their cancer experience.

## Strengths and limitations

The major strength of this study is the comprehensive, reflexive, and flexible approach from the phenomenological methodology to increase the understanding of lived experiences of laryngectomised patients. This qualitative study was conducted in two centres; data were collected from various healthcare settings with multiple organisations. None of the contexts involved had a survivorship care plan, which gave uniformity to the sampling but required the results to be considered within it. As a consequence, evaluations concerning voice quality needed to be conducted, and we could not discuss the potential correlation between voice quality and lived experience in our study. To explore this aspect in future phenomenological research, as it holds promise for a more comprehensive understanding of the topic, is desirable.

In addition, the two centres were in northern Italy and, therefore, in similar cultural contexts. Promoting studies considering the cultural characteristics and the relationship with different healthcare organisations would be essential. Indeed, the survivorship experience depends on the context and the availability of people supporting these patients. The cultural aspects to be deepened by future research involve the factors that support verbal communication, which in the Western culture is perceived as a symbol and practical manifestation of rational thinking and the ability to be an active part of society [11, 51].

## Conclusion

This study shows some crucial features of the patients' lived experiences, which should be considered to optimise survivors' care. Survivors need to be adequately prepared to transition from treatment and return to the community [52, 53]. In the case of laryngectomised patients, this preparation should begin before treatment starts. Functional education, accurate information, and psychological support must be arranged and provided before surgery. Regarding the post-treatment phase, the data generated through this study emphasise how important it is to support voice rehabilitation, for instance, within a family network, to ensure these patients' reintegration into society and social recognition. Moreover, early speech rehabilitation positively affects the emotional state of laryngectomised patients [34].

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**Author contribution** L. G., G. C., G. P., A. B., and L. S. contributed to the study conception and design. Material preparation, data collection, and analysis were performed by G. C., H. C., C. D. A., D. I., E. L., and C. P. The first draft of the manuscript was written by L. G., G. C., S. S., G. P., and V. B. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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**Data availability** The datasets (in Italian) generated during and/or analysed during the current study are available from the corresponding author upon reasonable request.

## Declarations

**Ethics approval** This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Provincial Ethics Committee of Reggio Emilia (in-house protocol no. 2017/0089494) and the Ligurian Regional Ethics Committee (P. R. 020REG2017).

**Consent to participate** Informed consent was obtained from all individual participants included in the study.

**Consent for publication** The authors affirm that human research participants provided informed consent for publishing their anonymised personal data.

**Competing interests** The authors declare no competing interests.

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