RESEARCH ARTICLES

Patients' perspectives on promoting tracheostoma self-care: A qualitative study

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ABSTRACT

Objective: To explore patients' perspective about promoting tracheostoma self-care.

Background: Promoting self-care is one of the main areas of intervention for nurses who care for patients undergoing tracheotomy/total laryngectomy. Self-care can improve autonomy, quality of life and reduce tracheostoma complications. To achieve this, interventions need to be evidence-based and sensitive to the patients' needs and preferences. However, little is known about patients' experiences of learning to care for their tracheostoma and their preferences.

Study design and methods: A qualitative descriptive study was carried out through semi-structured, individual, and face-to-face interviews with patients who had undergone tracheotomy/total laryngectomy (n = 17). Purposive sampling was performed with maximum variation. All interviews were audio-recorded and transcribed verbatim, and data were analysed using qualitative content analysis. The study complied with the Consolidated Criteria for Reporting Qualitative Research (COREQ).

Results: This study identified two main themes. The first was the experience of living with a tracheostoma. Participants recognised the implications of the tracheostoma in everyday life, the importance of tracheostoma awareness, critical moments, possible response patterns, and the personal, social, and health-related factors that can affect this experience. The second theme identified was the promotion of tracheostoma self-care. The participants mentioned the rebuilding of autonomy as the main objective, the thematic content that should be addressed by nurses before and after the surgery, the different strategies and resources that can be used, and what determines the appropriate time to intervene.

Conclusion: Despite the challenges of living with a tracheostoma, participants acknowledged the promotion of self-care as crucial for regaining autonomy. Nursing interventions that incorporate contents, methodologies, and implementation moments sensitive to the preferences, needs, and characteristics of each patient, which are maintained over time, appear to be the desired approach according to the participants.

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Implications for research, policy, and practice: This study's findings can help to design and implement nursing interventions to promote tracheostoma self-care that leads to better health outcomes.

What is already known about the topic?

- Undergoing a tracheotomy/total laryngectomy requires adapting to a new condition of life. Promoting self-care in these patients enhance autonomy, and adaptation to the tracheostoma.
- Nursing care for tracheostoma patients is poorly systematised. So, interventions to promote tracheostoma self-care should be created and tested, to improve clinical practice.
- Nursing interventions tailored to the specificities, needs, and preferences of the target population are more likely to be accepted and effective. Therefore, it is important to understand patients' perception and involve them in identifying appropriate interventions.

What this paper adds

- This study can help nurses to understand the complexities faced by people living with a tracheostoma. Recognising the implications, critical events, response patterns, and factors that influence this experience can assist nurses in anticipating care needs over time.
- The study participants emphasised the relevance of self-care for maintaining autonomy. They identified the issues, strategies and resources, and significant moments for promoting self-care for people with a tracheostoma.
- The results of this study can contribute to defining more coordinated, timely, and tailored nursing care models that meet the needs of individuals and improve health outcomes.

Keywords

Content analysis; nursing; patients' perception; qualitative research; self-care; tracheostomy

BACKGROUND

A stoma can be defined as an artificial mouth or opening to the outside of the body, created for therapeutic reasons.[1] In this article, the term tracheostoma will be used to describe an opening to the trachea through the neck to allow breathing, regardless of indication, the technique used (percutaneous/surgical tracheotomy or total laryngectomy) or its duration (temporary/permanent). A tracheostoma may be performed for several reasons: airway obstruction, airway protection or maintenance, airway cleansing, prolonged mechanical ventilation and to facilitate weaning.[2] It is one of the oldest surgical procedures in the history of medicine and is frequently performed in hospitals around the world.[3]

For individuals with a stoma, the promotion of self-care is essential.[4] Stoma self-care can be described as a decision-making process that influences actions related to maintaining the stoma and peristomal skin (the skin right around the stoma), identifying problems and complications, and ways to effectively manage them.[5] Self-care competence in patients with a tracheostoma appears to enhance autonomy, acceptance, and adaptation to the stoma,[6] reducing the incidence of complications, and decreasing healthcare costs.[7]

Despite the recognition of the importance of teaching people how to care for and manage their tracheostoma,[8] there is still no robust evidence to guide and systematise how this should be done. A review of the literature on nursing interventions to promote self-care in tracheostoma patients highlighted the need to develop and test nursing interventions to promote self-care.[9]

In addition to being evidence-based, nursing interventions should be tailored to the characteristics, needs, and preferences of the target population. This means interventions are appropriate to individuals and encourages active engagement and participation in self-care.[10] To date, no study has focused on patients' perceptions of the promotion of tracheostoma self-care. Understanding the individual's perspective can help to build a better understanding of living with a tracheostoma, leading to more sensitive and satisfactory care that meets individual needs.[11,12] Furthermore, it will allow for reporting of experiences, identification of difficulties, service failures, desired topics/subjects to be addressed, appropriate timing, and the intended educational methodology,[12] which could be useful for redirecting care toward more effective, person-centred, and high-quality care.

OBJECTIVE

The objective of this study is to explore patient perceptions regarding the promotion of tracheostoma self-care. It is part of a broader project that aims to develop a nursing intervention programme for the promotion of self-care in individuals with a tracheostoma in Portugal.

STUDY DESIGN AND METHODS

A qualitative descriptive study was conducted. The COREQ checklist for reporting qualitative studies was followed.[13]

STUDY PARTICIPANTS

The study was conducted in the Otorhinolaryngology (ORL) inpatient and outpatient departments of two hospitals in Portugal: a central general hospital and an oncology hospital. These two hospitals were chosen because they serve populations in geographically diverse areas. One hospital has a structured follow-up care model for tracheostoma patients.

To be included in the study patients needed to be 18 years of age or older, to have had a tracheostoma (following tracheotomy or total laryngectomy) less than 2 years ago and be autonomous with self-care or have the potential for this. Purposive sampling with maximum variation was used. Participants with different sociodemographic characteristics (such as gender, age, level of education, area of residence) and clinical characteristics (such as surgical indication, technique/procedure performed, and tracheostoma duration) were included.

The sociodemographic and clinical characteristics of study participants are shown in Table 1.

TABLE 1. CHARACTERISATION OF THE PARTICIPANTS

Demographic and clinical characteristics (*n* = 17)	**% (*n*) or Mean (range; SD)**
Age (years)	58.4 (38–74; 10.37)
30–40	5.88% (1)
41–50	17.65% (3)
51–60	23.53% (4)
61–70	47.06% (8)
71–80	5.88% (1)
Gender	
Female	11.76% (2)
Male	88.24% (15)
Years of education	7.76 (4–12; 2.49)
Type of surgery	
Scheduled Total Laryngectomy (TL)	41.18% (7)
Tracheotomy	47.06% (8)
Emergency Tracheotomy and scheduled TL later	11.76% (2)
Purpose of Surgery	
Neoplasm	82.35% (14)
Laryngeal trauma	5.88% (1)
Subglottic stenosis	11.76% (2)
Stoma duration	
Permanent	52.94% (9)
Temporary	47.06% (8)
Time elapsed since surgery (days)	328.82 (9-683; 259.12)
Interview setting	
Inpatient department of the central general hospital	29.41% (5)
Outpatient department of the central general hospital	11.76% (2)
Inpatient department of the oncology hospital	5.89% (1)
Outpatient department of the oncology hospital	52.94% (9)

DATA COLLECTION

The data were collected through a semi-structured, individual, and face-to-face interview. All interviews were conducted by the main researcher. The main researcher received specific training and guidance on conducting interviews during doctoral studies and from the research co-authors (third and fourth author), who have experience in conducting research interviews. The interviews took place between November 2020 and December 2021 and lasted between 15 and 40 minutes.

An interview script was developed based on the defined objective (see Table 2). The interview script was tested prior to the study to ensure that the questions were clear and unambiguous. As no changes were made to the script, the data obtained in the test were included in this study.

TABLE 2. SEMI-STRUCTURED INTERVIEW SCRIPT FOR PARTICIPANTS

Interview questions
1. What has it been like caring for/learning to care for your tracheostoma?
2. Tell me about the cursing care you received before undergoing the tracheotomy/total laryngectomy. *
3. Describe how you were prepared/are being prepared for caring for your tracheostoma during your hospital stay.
4. What was it like caring for your tracheostoma like when you returned home? *
5. Tell me about the follow-up nursing care after you were discharged from hospital. *
6. What needs and/or difficulties have you experienced over time in caring for your tracheostoma over time?
7. What factors have made it easier for you to learn to live with and care for your tracheostoma?
8. What factors have made it more difficult to learn to live with and care for your tracheostoma?

* Questions may not have been asked, given the participant's perioperative stage or clinical context.

Interviews continued until no more relevant information was obtained, i.e. until the research team considered that data saturation had been reached. The study therefore had a total of 17 participants.

DATA ANALYSIS

Interviews were audio recorded. Six participants had aphonia (due to damage to the vocal cords or because they were not yet able to communicate with the voice prosthesis). In these cases, lip reading was carried out by

the main researcher (who, as an ORL nurse, has extensive experience of caring for and communicating with these patients) and repeated aloud to the participant to confirm that the lip reading had been correctly interpreted and to enable the audio recording. Field notes were also taken of the participants' non-verbal communication during the interviews. Qualitative content analysis of the interviews was then carried out using the technique of categorical analysis.[14] Interviews were transcribed verbatim. The pre-analysis phase began immediately after the transcription of the first interview. Two researchers (first and second author) carried out an overall reading of the transcriptions and field notes simultaneously. The content deemed significant in each interview was extracted and organised into coding units by the two researchers. The emerging categories were then defined. The coding and categorisation carried out by the two researchers were then reviewed by the entire research team, comparing the coding structure with the transcriptions. The coding, final naming of categories, and themes, were discussed among the team until a consensus was reached. The data analysis was facilitated using NVivo 12 software.

ETHICAL CONSIDERATIONS

This study was approved by the two participating hospitals ethics committees (approval number 436-19) and the Universidade Católica Portuguesa (approval number 166). All participants were informed of the scope of the study, its objectives, the voluntary nature of their participation, and the possibility of withdrawing at any time during the interview. Written informed consent to take part in and record the interviews was obtained from the participants.

RESULTS

Two main themes emerged from the data analysis*: the experience of living with a tracheostoma* and *the promotion of tracheostoma self-care*. Participants' quotations supporting each category identified are presented throughout the text. Each quote is referenced by the letter P (participant) and a unique identification number ranging from 1 to 17.

THEME: THE EXPERIENCE OF LIVING WITH A TRACHEOSTOMA

The experience of living with a tracheostoma, identified the following categories: *implications of living with a tracheostoma*, *tracheostoma awareness*, *critical moments*, *response patterns*, and *conditioning factors*, as presented in Table 3 and expanded upon below.

Implications of living with a tracheostoma

Participants said that living with a tracheostoma has '*multiple and challenging consequences*' for breathing, communication, appearance, swallowing, smell, taste and activity tolerance. These physical and functional consequences of the tracheostoma '*make them different*' from who they were before the surgery. "*We become different* [following the creation of the tracheostoma], *don't we? The way we speak changes (…) speaking is different now. (…) I have to chew my food properly* [to make it easier to swallow]. *At first I had no flavour* [referring to the loss of taste after surgery], *now I do. I also have no sense of smell. (…) I had to stop working…*" (P12, underwent total laryngectomy in January 2020)

TABLE 3. THEME: THE EXPERIENCE OF LIVING WITH A TRACHEOSTOMA

Categories	Subcategories
Implications of living with a tracheostoma	Multiple and challenging consequences that make them different
	New and complex care
Tracheostoma awareness	
Critical moments	Returning home
	Confronting the change in self-image
	Confronting difficulties or complications
Response patterns	Autonomy in tracheostoma care
	Becoming a habit/routine
	Building confidence
	Returning to usual/previous life
	Self-acceptance
	Forgetting the difference
	Negative emotions: fear, shame, complex, anger, saturation, frustration, hopelessness
Conditioning factors	Related to the person
	Related to family, community, and society
	Related to healthcare resources

Participants also found that living with a tracheostoma requires '*new and complex care*'. For example, the person must learn to care for the tracheostoma and its devices. "*… it's all very new and complicated. If it were in a leg or an arm. But here* [pointing to the neck], *everything scares us, cleaning, changing, whatever it may be, we get anxious, short of breath.*" (P4, underwent tracheotomy in July 2019)

Tracheostoma awareness

Participants mentioned the significance of the day-to-day experience of living with a tracheostoma and the implications. They must learn what the tracheostoma is and what it means in their lives. Even if the person is prepared for what is to come, it is only through experience and trial that they can understand what the tracheostoma means in their life. "*They explained to me very well what would happen after the operation. But I wasn't fully aware, I had never seen it before, and I couldn't imagine what they were telling me. (…) It was only after the surgery that I found out what it was. (…) Now that I have been through it, I understand, it makes sense to me (…)*" (P12, underwent total laryngectomy in January 2020)

Critical moments

Participants highlighted the significant and challenging events of the experience of living with a tracheostoma. '*Confronting the change in self-image*' was described as a critical moment in the experience of living with a tracheostoma. "*Confronting myself with that image in the mirror, seeing that hole in the mirror, and having to insert a tube in there…it really affected me, I felt very nervous, I couldn't do it.*" (P11, underwent tracheotomy in January 2021)

'*Returning home*' was identified as another critical moment, as participants no longer had the support of professionals to care for the tracheostoma. "*Especially because when you go home, you have to do everything yourself, there's no support.*" (P2, underwent tracheotomy in August 2020)

'*Facing difficulties or problems/complications*' was also described as a significant moment. *"Once, when I was taking a shower, a drop of water got in and I was very distressed. My wife helped me. It was terrible. Now I'm very careful."* (P8, underwent tracheotomy in February 2020)

Response patterns

'*Autonomy as a result of self-care*' was identified as a positive response to the experience of living with a stoma, as participants were able to manage their tracheostoma independently. Caring for the tracheostoma as a '*habit or routine*' was also suggested as a positive response to living with a tracheostoma. '*Gaining confidence*' in stoma care was also mentioned as a positive response pattern. *"And of course, as time went on and I gained confidence, there was no longer a need to have someone there."* (P11, underwent tracheotomy in January 2021)

Participants suggested that '*accepting*' the tracheostoma was a positive response to the experience, as they came to understand that the stoma was necessary and that they needed to integrate it into their lives. '*Resuming life*', especially daily activities and adapting to the constraints of the tracheostoma, was another possible positive response to living with a tracheostoma. *"I'm going out, I'm living my life, I'm spending time with my friends, no problem at all… I'm carrying on, within the bounds of what's possible."* (P7, underwent total laryngectomy in April 2020)

Other participants suggested that '*forgetting about the difference*' was a positive response to living with a tracheostoma. In some cases, the selection and suitability of stoma devices to meet participants' needs was the driving factor behind this outcome. *"It's totally different now with the speaking valve, sometimes I even forget* [about the tracheostoma]." (P14, underwent tracheotomy in February 2021)

Finally, the participants emphasised another possible pattern of response to the experience of living with a tracheostoma: the presence of '*negative emotions*'. Some highlighted feeling ashamed or self-conscious about having a tracheostoma, especially at an early stage after the surgery. *"Then, gradually, I freed myself from that complex. I feel calmer, psychologically I feel better. (…) But the adaptation was difficult."* (P9, underwent total laryngectomy in October 2019) Others expressed fear of not being able to care for the tracheostoma or fear for the future. *"There was also the fear that it would get worse* [the disease may get worse]." (P14, underwent tracheotomy in February 2021)

Other negative emotions such as anger, frustration, and tiredness were mentioned, both because to the constant need for tracheostoma care and because of having to deal with the consequences of having a tracheostoma, particularly the change in communication. A sense of hopelessness about the consequences of living with a tracheostoma was also suggested. *"I'm tired of dealing with this…Psychologically, it is not easy at all. It's hard to explain…I feel like I ripping it out* [referring to the tracheostoma tube]." (P4, underwent tracheotomy in July 2019)

Conditioning factors

In the category of '*conditioning factors*', the participants identified factors related to the individual, the family, the community, and society, as well as factors related to healthcare resources that can affect the experience of living with a tracheostoma.

In the factors '*related to the person*', having faith/hope, motivation/willpower, staying calm, having high self-efficacy, and a leisure activity/hobby as therapy were identified as factors that can improve the experience of living with and caring for a tracheostoma. *"The best part of this process was me, what I did for myself. We have to fight* [referring to the illness], *face its consequences and have the strength to deal with it. The willpower and joy of living cannot be lost, this is where it comes from* [points to the head]." (P7, underwent total laryngectomy in April 2020) *"Finding a therapy, a leisure activity is important."* (P9, underwent total laryngectomy in October 2019)

Having a temporary tracheostoma, living far away from the hospital, undergoing stoma surgery due to an oncological condition, experiencing a recurrence of the oncological disease, facing complications, undergoing other adjuvant therapies, and having a voice prosthesis located in a difficult-to-see and care for position were identified as challenging factors in the experience of having a tracheostoma. *"If I knew it was permanent, my attitude and way of dealing with it might be different. I would have already defined an adapted life plan for it. As it is, I'm always waiting."* (P5, underwent tracheotomy in May 2019) *"The person is already weakened by the situation, and the complications are demotivating."* (P9, underwent total laryngectomy in October 2019)

In the conditioning factors '*related to family, community, and society*', the presence of supportive family and friends, as well as sharing experiences with individuals who have gone through the same situation, were stated as facilitators.

"Family support is crucial to overcome this situation." (P6, underwent tracheotomy in August 2019 and total laryngectomy in September 2019)

Social stigma was mentioned as a hindrance, as individuals feel excluded and discriminated against by society. *"People who don't have* [health] *problems, or maybe even have more serious ones, discriminate against us. On buses they move away."* (P4, underwent tracheotomy in July 2019)

Regarding the conditioning factors '*related to healthcare resources*', the reimbursement for stoma devices, support from healthcare professionals, and the existence of a multiprofessional model of care for individuals with a stoma were suggested as facilitators of a better experience. *"The health professionals who treat us are very important in helping, teaching, and supporting us."* (P6, underwent tracheotomy in August 2019 and total laryngectomy in September 2019) *"This system* [referring to the hospital's multi-professional clinical circuit/pathway for patients with tracheostoma] *works well as a whole, with a system and circuit in place. I go to one office, then move to another, and everything is taken care of at the same time. Everyone is working towards the same goal. This was not how it worked in the other hospital."* (P14, underwent tracheotomy in 2013 and again in February 2021)

Finally, the lack of experience of community healthcare staff, the lack of systematisation in the care of individuals with a tracheostoma, and the short length of hospital stay were identified as challenging factors in the experience of living with a tracheostoma. *"The nurses at the community health centre mentioned that they didn't receive any training to deal with it* [referring to tracheostoma and tracheostoma devices], *and it was always here* [in the outpatient department] *that they would see how things were going."* (P6, underwent tracheotomy in August 2019 and total laryngectomy in September 2019)

THEME: PROMOTION OF TRACHEOSTOMA SELF-CARE

'*Promotion of tracheostoma self-care*' identified the following categories: objective of self-care promotion, desired contents, strategies and resources, and the appropriate timing for intervention, as presented in Table 4.

Objective of self-care promotion

'*Rebuilding autonomy*' was identified as an objective in promoting self-care for individuals with a tracheostoma. This autonomy enables the person to take care of themselves independently and maintain their routine. *"...I think it's important for me to be able to do everything by myself... Wherever I am, at any time, I can take care of whatever is necessary..."* (P12, underwent total laryngectomy in January 2020)

TABLE 4. THEME: PROMOTION OF TRACHEOSTOMA SELF-CARE

Categories	Subcategories
Objective of self-care promotion	Rebuilding autonomy
Desired contents	The surgery and its consequences
	Caring for the tracheostoma and the devices
	Prevention, detection, and management of complications
	Encouraging care participation
	Improving self-efficacy perception
	Involving and empowering the family for care
	Device selection and availability
	Stoma assessment
	Surveillance and follow-up support
Strategies and resources for tracheostoma self-care	Face to face
	Written information
	Telephone
	Video
	Materials and devices
	Spotlight
Proper intervention moment	Pain free
	Airway clearance
	Initiated awareness

Desired contents

In the category of '*desired contents*', the participants identified the topics that should be addressed when promoting self-care for individuals with a tracheostoma.

Firstly, the participants emphasised the importance of individuals being prepared for '*the surgery and its consequences*'. *"Before the operation, they explained to me what the surgery was about...and they explained to me exactly how I would become, what condition I was going to be in... Of course, this issue has to be clear, it has to be explained well..."* (P9, underwent total laryngectomy in October 2019)

The person should also be able to '*care for the tracheostoma and the tracheostoma devices*'. *"The nurses taught me how to remove the tube, clean it, clean the skin, and put the tube back in place."* (P9, underwent total laryngectomy in October 2019)

'*Prevention, detection, and management of complications*' related to the tracheostoma, peristomal skin, and phonatory prosthesis, if applicable, were stated as another element to be addressed in promoting self-care. *"Regarding complications, they explained things in a more general way, but then they'd explain things to me as they arose, either by coming here or by explaining how I should resolve them."* (P9, underwent total laryngectomy in October 2019)

Participants also mentioned the need for '*encouraging care participation*', so that the person is supported to take the initiative in caring for their tracheostoma. *"At first, it was the nurse who did it. And then, he'd say, "You have got to start doing it too. Remember, there won't be anybody else at home." So, I started doing it with him in front of the mirror. There was no choice; I had to learn."* (P6, underwent tracheotomy in August 2019 and total laryngectomy in September 2019)

'*Improving self-efficacy*' by repeating procedures, as well as the nurse praising the person's performance, was mentioned as necessary to promote self-care. *"Training and time are important. The more we repeat these procedures, the better we get at them. Standing in front of the mirror, and repeating, practising."* (P2, underwent tracheotomy in august 2020)

'*Involving and empowering the family in care*' was recognised as essential in promoting self-care for individuals with a tracheostoma. *"It's important to have someone in the family who is familiar with the issue. Knowing that we have someone at home who knows how to help, who can provide support and assistance if, for example, the tube comes out or the tape comes off, is very reassuring."* (P5, underwent tracheotomy in May 2019)

Another element identified as indispensable in promoting self-care was the '*selection and availability of tracheostoma devices*'. It is important to provide guidance to the person in choosing the most appropriate device for their characteristics and tracheostoma. *"...And it is important to inform people that there are alternatives to devices. They need to be told what options are available for their condition."* (P5, underwent tracheotomy in May 2019)

'*Tracheostoma assessment*' by nurses was identified as necessary to avoid potential complications as the condition of the stoma and peristomal skin can affect self-care and the selection of devices.

Finally, the importance of '*ongoing surveillance and follow-up support*' was identified. This ensures reinforcement of information previously provided, provides reassurance, and motivates the person to maintain tracheostoma care and offers support in solving problems and difficulties that arise over time. *"It is good to be accompanied* [by nurses] *here, especially at the beginning, to feel supported and reassured."* (P11, underwent tracheotomy in January 2021)

Strategies and resources for tracheostoma self-care

In this category, participants identified the approaches nurses used to promote patient self-care.

The '*face-to-face*' strategy employed by nurses was reported by all participants as the most significant for acquiring skills in tracheostoma care and device change. *"They* [nurses] *would do it, teach us, and then my wife and I would repeat… I think the most important part is the practical aspect, doing it, the more the better, with the help of the nurses."* (P9, underwent total laryngectomy in October 2019)

'*Written information*' was suggested as a useful complementary method, particularly information about what changes with the surgery and the sequence of activities to perform in tracheostoma care. *"It is indeed helpful to have written information to follow the steps in case something goes wrong. I think it is always useful to have information on paper."* (P4, underwent tracheotomy in July 2019)

Another strategy identified was the '*telephone service*', especially for problem solving and addressing difficulties when individuals are at home. The possibility of using the telephone as a planned method in the first few days after returning home was also suggested. *"Whenever I have a problem or doubt, I call. I ask to speak to the outpatient department, and they either solve the problem on the phone or ask me to come in person."* (P6, underwent tracheotomy in August 2019 and total laryngectomy in September 2019)

The use of instructional '*videos*' about the tracheostoma and tracheostoma care was another possible strategy suggested by participants. *"Perhaps a video of a patient caring for themselves would be a good idea. It would allow people to see how it's done, overcome fear, and understand that they can learn to do it themselves..."* (P4, underwent tracheotomy in July 2019)

For '*resources*', participants identified the importance of having a '*spotlight*' near the mirror to help visualise the phonatory prosthesis, if it exists. They also stated the importance of having different '*devices for tracheostoma*' available in the health unit so that people know about them, can experiment and choose the ones they prefer.

Proper intervention moment

In the category of '*proper intervention moment*', participants described the ideal circumstances for promoting self-care in individuals with a tracheostoma. For this, the person should be '*pain free*' allowing them to be receptive to learning new information. *"In the first few days I was very unwell. I had a lot of pain…no, I couldn't do it… (…) Only later, when I felt better, did the nurse start to teach me…"* (P17, underwent total laryngectomy in November 2021)

Patients should have an effective cough so they can clear secretions and manage '*airway clearance*'. *"…I had a lot of coughing and a lot of mucus. It was only when I started to improve with the coughing that I was able to learn…"* (P1, underwent tracheotomy in October 2020 and total laryngectomy in November 2020)

Participants also mentioned the importance of individuals feeling ready to cope with the change, that is, showing signs of '*becoming aware*' of the new life circumstances and willingness to engage. It was *"Only after two or three days that I started to feel ready to deal with this. At first, I was confused and overwhelmed by it all."* (P6, underwent tracheotomy in August 2019 and total laryngectomy in September 2019)

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DISCUSSION

Living with a stoma means that the person needs to become aware of and adapt to the changes and restrictions that the stoma brings to daily life.[15] The multiple and challenging effects that make people different from who they were, together with the daily care of the tracheostoma, were identified by the participants as the main consequences of living with a tracheostoma. Previous studies suggest that the functional consequences of living with a tracheostoma are often the most valued in the early stages.[16] As their functional status gradually improves, the desire to return to social activities increases. It is at this time that the consequences related to communication and changes in appearance become more challenging to manage.[16] Individuals with a tracheostoma often experience periods of aphonia or are unable to vocalise audibly and quickly. Responses to these challenges vary significantly between individuals.[17] As a result of, or in response to the tracheostoma it is common for people to show impatience, irritability, resentment, frustration, and anxiety due to their inability to communicate effectively with others.[16,18] These findings underline the importance of individuals being prepared for what is to come and receiving ongoing professional support as their needs and difficulties change over time. It also highlights the need for more studies focusing on understanding and managing emotions in people with a tracheotomy/total laryngectomy.[17]

On the other hand, participants identified the factors that influenced their experience of living with a tracheostoma. Having a temporary tracheostoma and undergoing a tracheotomy/laryngectomy due to an oncological disease were identified as personal hindering factors. People with a temporary stoma focus on the temporary nature of their condition, choosing to put their lives on hold until is resolved.[19] The same authors also recognised that a cancer diagnosis can affect a person's experience due to uncertainty about their future. In terms of family and community factors, participants mentioned the perception of stigma or social exclusion due to having a tracheostoma as an additional challenge. A tracheostoma is cosmetically unattractive and is sometimes seen as intimidating by the community.[20] People with a tracheostoma feel that they can be labelled, discriminated against, and not understood because they look different.[16] These findings highlight the need for community awareness interventions to promote social inclusion in the face of differences.

Regarding factors related to healthcare resources, the lack of standardised care, shorter hospital stays, and lack of experience among community healthcare providers were identified as barriers to the experience of living with a tracheostoma. Due to the lack of formalisation of knowledge and standardisation of care for individuals with a tracheostoma, educational interventions are often inconsistent between professionals.[21] It is, therefore, important to improve the systematisation of care for individuals with a tracheostoma and the coordination of different healthcare resources.

Thus, identifying factors that negatively influence the experience of living with a tracheostoma may indicate greater vulnerability and therefore require a more tailored and personalised response from nurses.

In terms of promoting tracheostoma self-care, participants recognised its importance for maintaining autonomy. Self-care is a key concept in the life of a person with a stoma. Improving the self-care skills helps to increase self-confidence and self-esteem.[16] Tracheostoma patients need to develop self-care skills and a sense of wellbeing to adapt to changes in living conditions and to carry out activities of daily living.[22] Study participants identified the topics that should be addressed when promoting self-care of their tracheostoma. Encouraging self-care performance was recognised as crucial for individual engagement. For this reason, health professionals should encourage individuals to actively participate in self-care.[16]

Education about the surgery, its consequences, how to care for the tracheostoma, and how to prevent and manage potential complications was identified as crucial. In fact, information, training, time, and successful experience in stoma care can increase autonomy.[23] That's why nurses spend a lot of time with tracheostomy patients and their families, teaching, assessing and helping them to manage and deal with difficult situations that may arise at home.[22]

The importance of ongoing surveillance and follow-up by healthcare professionals to maintain motivation, the desired levels of self-care competence, and early detection of complications has also been highlighted.

Other studies suggest that continuity of care after discharge allows for patient education and self-care supervision. This improves self-care competence, satisfaction with health care, and quality of life.[24] Therefore, it is important to ensure access to specialised care and to improve the health care response when they return home.

Finally, this study identified several strategies to promote self-care in tracheostoma patients. Verbal education alone (conventional care) tends to be forgotten and misinterpreted over time, which can lead to inadequate care.[24] Therefore, it is important for nurses to consider the variety of strategies available and to select, combine, and adapt them to the needs and preferences of each individual.

STRENGTHS AND LIMITATIONS

To the authors' knowledge, this is the first study on the promotion of tracheostoma self-care based on patients' perceptions. Understanding individuals' perceptions helps to understand how nursing interventions to promote self-care can be improved in response to patients' needs and

preferences. However, this study has limitations. Participants were selected from a single country, with a specific socio-cultural context. The study was limited to only two different care settings, which may have influenced the results obtained. Furthermore, the differences in results between the two care settings were not explored. Therefore, further qualitative research with individuals with tracheostomas from different clinical and geographical contexts in Portugal should be conducted to corroborate these findings or to identify potentially different outcomes.

CONCLUSION

Having a stoma means adapting to a new way of life. For this reason, healthcare professionals should help individuals to understand and accept the changes resulting from the surgery. They should also empower individuals to manage their stoma, as autonomy helps to improve adjustment and quality of life.[25]

The results of this study have helped to understand the complexity of living with a tracheostoma. Recognising the implications, critical events, response patterns, and factors that influence this experience can help nurses to anticipate care needs over time.

On the other hand, the participants in this study emphasised the importance of self-care in maintaining an autonomous life. They identified the issues, strategies and resources, and key moments to promote tracheostoma self-care. Indeed, understanding individuals' perspectives can help to design nursing interventions that are sensitive to their expectations, preferences, and specific needs.

IMPLICATIONS FOR RESEARCH, POLICY, AND PRACTICE

This study provides a unique insight into patients' perspectives on learning to live with and care for a tracheostoma and adds a new dimension to the existing knowledge on this topic. The findings of this study have several implications. Firstly, it provides an opportunity to explore available interventions for nurses to promote tracheostoma self-care. Therefore, the findings may be useful for nurses to provide better and more tailored support to tracheostoma patients and to reflect on current practice in healthcare settings. Secondly, it highlights the existence of personal, social, and health-related factors that negatively affect the experience of living with a tracheostoma. These factors may indicate greater risk or vulnerability. Therefore, they need to be assessed in all patients with a tracheostoma and once identified, these patients need to receive more attention, time, and support from nurses. Thirdly, this study helps nurses to understand the experience of transitioning to life with a tracheostoma. On the one hand, it identifies the potentially most difficult moments, which therefore deserve greater attention from nurses. On the other hand, it lists the possible responses to this experience, which will indicate whether patients are going in a negative or positive direction in the process of adapting to their new condition. Finally, the findings could inform future interventions to promote tracheostoma self-care. The results of this study, which reflect people's preferences and experiences, should inform the definition of interventions to promote tracheostoma self-care. Indeed, the design of such interventions should take into account the results of existing descriptive studies collected from all the stakeholders (patients, families, and nurses) and the best available evidence. Future studies from other cultures and ethnicities are also recommended to improve the current understanding of tracheostoma self-care experiences.

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