What matters most to adults with a tracheostomy in ICU and the implications for clinical practice: a qualitative systematic review and metasynthesis

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ARTICLE INFO

ABSTRACT

Purpose: Tracheostomy is a common surgical procedure in ICU. Whilst often life-saving, it can have important impacts on patients. Much of the literature on tracheostomy focuses on timing and technique of insertion, risk factors and complications. More knowledge of patient experience of tracheostomy in ICU is needed to support person-centred care.

Materials and methods: Qualitative systematic review and metasynthesis of the literature on adult experience of tracheostomy in ICU. Comprehensive search of four bibliographic databases and grey literature. Title and abstract screening and full text eligibility was completed independently by two reviewers. Metasynthesis was achieved using thematic synthesis, supported by a conceptual framework of humanised care.

Results: 2971 search returns were screened on title and abstract and 127 full texts assessed for eligibility. Thirteen articles were included for analysis. Five descriptive and three analytical themes were revealed. The over-arching theme was 'To be seen and heard as a whole person'. Patients wanted to be treated as a human, and having a voice made this easier.

Conclusions: Voice restoration should be given high priority in the management of adults with a tracheostomy in ICU. Staff training should focus on both technical skills and compassionate care to improve person-centred outcomes.

1. Introduction

Tracheostomy is a common procedure in intensive care units (ICU) and head and neck cancer, with an estimated 12,000 to 15,000 insertions per year in the UK prior to the COVID-19 pandemic [1,2]. The pandemic has seen figures much higher than this due to the dramatic increase in patients requiring mechanical ventilation and higher rates of tracheostomy in patients with COVID-19 [3,4]. Whilst tracheostomy is often a life-saving procedure, negative impacts on patients occur and include fear and anxiety; temporary or persistent inability to talk; difficulty swallowing; pain due to the tube or stitches; increased work of breathing; and trauma to the trachea which can lead to tracheal stenosis [5–11]. Management decisions and clinical practices such as choice of type and size of tracheostomy tube (TT), cuff deflation, tracheal suction technique, facilitation of communication and assessment of pain, may influence the experience of these [7–10,12]. COVID-19 has presented additional challenges including higher incidence of upper airway swelling, infection exposure risk to staff, and the impact of restricted family visiting and staff use of personal protective equipment on patients [3,13].

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Various initiatives have sought to improve the care of people with a tracheostomy over the past ten years [1,14,15]. It is now widely accepted that high quality healthcare must be patient-centred and that this requires understanding of patient experience and perspectives [16-19]. However, much of the evidence guiding tracheostomy management focuses on incidence, timing and technique of insertion, risk factors and associated complications. A number of quantitative, measurement-focused studies have addressed quality of life (QOL) and mental health outcomes in patients with a tracheostomy [20-22]. While these studies capture prevalence and patterns of symptoms, they are not designed to present accounts of patient experience, which can help to shape future care.

Qualitative methods have been used to provide insights into ICU patient experience of delirium [23] and mechanical ventilation [24-26]. Nakarada et al.'s [27] mixed-methods systematic review described challenges facing patients with a tracheostomy and their caregivers such as poor basic care, speech and communication difficulties, altered body image and reduced social interaction in the community. However, their review was not ICU specific. Tolotti et al.'s (2022) [28] qualitative scoping review addressed nurse-patient communication experiences in patients with a tracheostomy and/or on mechanical ventilation, and Whitmore et al.'s (2020) [29] mixed-methods scoping review of post-insertion ICU tracheostomy management concluded that more research was needed into patient experience of events relating to or impacted by tracheostomy. Further robust evidence and conceptual understanding of the global experience and priorities of ICU patients with a tracheostomy could help improve clinical care and patient-centred outcomes for this group of people.

The aim of this qualitative systematic review and metasynthesis was to describe what matters most to patients with a tracheostomy in ICU, and to consider the implications for clinical practice.

2. Materials and methods

Our qualitative approach to enquiry allowed exploration of behaviours and perspectives that would be unachievable through quantitative research. Our inductive methods encouraged the emergence of descriptive themes from the data rather than reviewers' prior knowledge and beliefs [30]. We included a metasynthesis to go beyond an aggregative synthesis of primary studies and develop new concepts and insights [31-33]. Thematic synthesis as described by Thomas and Harden (2008) [33] allowed us to synthesise multiple datasets whilst retaining individual participant voices. The study protocol was registered prior to data collection with PROSPERO (reg. CRD42020227554).

2.1. Search strategy

Our systematic searches were aided by an expert librarian and included four major bibliographic health databases (Medline, Embase CINAHL and Web of Science). A 'tracheostomy' search construct was developed using alternative spellings, key words and medical subject headings. This was combined with a 'patient perspective' construct, consisting of phrases such as 'patient report', 'patient opinion' and 'lived experience'. The search was first conducted and refined in OvidSP Medline (see supplementary material A for full search strategy), then translated in other databases. We also completed grey literature, citation and journal searches and asked expert ICU clinicians for references of articles on patient experience of tracheostomy in ICU. Searches took place between 23 December 2020 and 18 January 2021. Further re-runs of bibliographic database searches were completed on 29 June 2021 and 6 May 2022.

2.2. Study selection and data extraction

Included articles were written in English and reported qualitative data from the perspective of adults in ICU with a tracheostomy or their non-professional carers (see supplementary material B for inclusion criteria). No date limits were applied. All articles were uploaded to EPPI-Reviewer software for systematic reviews [34], and each was independently screened on title and abstract by the first author (HN) plus one other reviewer (GC, SW, or CS). Disagreements were resolved by referring to a third reviewer (NP). The same process was followed in full-text screening. We piloted a data extraction tool to capture study characteristics (see supplementary material B). No modifications were necessary. All text from 'Results'/'Findings' onward was treated as data for analysis.

2.3. Data synthesis strategy

We followed Thomas and Harden's (2008) [33] thematic synthesis as follows:

1. Line-by-line inductive coding of text; development of new codes and translation between texts as each set of findings from studies were coded
2. Descriptive themes were developed by identifying similarities and differences between the initial codes, then grouped into hierarchical structures
3. The synthesis of selected findings was reviewed and newly developed descriptive themes applied to the review question to develop the analytical themes and metasynthesis from across the dataset, moving the synthesis beyond a collection of reported themes and drawing out collective inferences

During the third stage, a conceptual framework relevant to the preliminary review findings was identified [35] and used as a lens through which to view and shape emerging analytical themes, translate findings into clinical implications and provide a deeper level of analysis.

2.4. Reflexivity and rigor

We followed the ENTREQ checklist [36] to ensure transparency of reporting (see supplementary material C). Search results and study selection have been presented using the PRISMA flowchart. To enhance dependability and credibility, two reviewers undertook these stages independently, coming together to review codes and themes and discuss potential new analytical themes, repeating this in an iterative cycle [37].

Our research team included researchers with extensive experience in qualitative methods. Feedback on descriptive and analytical themes from the wider study team and patient and public involvement (PPI) group was incorporated into the findings. The PPI group was convened to support the first author's PhD project. PPI members had all experienced tracheostomy on ICU and had either responded to a request for support via ICUSteps (patient support charity) [98], been a patient of the first author or were recruited via word of mouth. Together, the measures described above enhanced Lincoln and Guba's (1985) [38] concept of trustworthiness, credibility, confirmability, and transferability. The lead author/researcher was motivated by clinical experience as a Speech and Language Therapist in ICU.

3. Results

3.1. Study selection

The search returned 2971 records. Following de-duplication, 2395 articles were screened on title and abstract. Full text screening was conducted on 127 articles. Thirteen articles were included in the review and metasynthesis (see Fig. 1.). The main reasons for exclusions were insufficient focus on tracheostomy (for example, mentioned only as an outcome) or no qualitative data. One article was excluded due to difficulty distinguishing between data relating to intubated or tracheostomised patients [39].
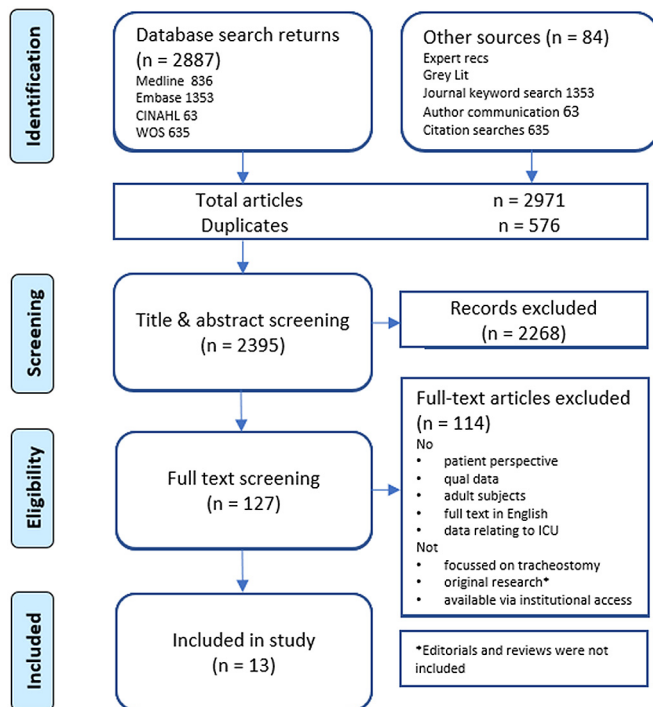
Fig. 1. PRISMA flow diagram of search results and article selection process.

3.2. Study characteristics

This metasynthesis covers data published between 2003 and 2019 from 203 participants across 7 countries (see supplementary material D). Sample sizes ranged from to 3 to 81. Sample breakdown by age, sex and ethnicity was not provided by all authors. Data was collected via interview in 12 of the 13 studies. Research questions related to the lived experience of tracheostomy ($n = 8$) or mechanical ventilation ($n = 4$) and eating and drinking ($n = 1$) in patients with a tracheostomy.

3.3. Risk of bias assessment

Quality assessment of selected articles was completed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative research [40] (see supplementary material E). Following the example of Lachal et al. (2017) [41], a relevance weighting of one to three points was added depending on how closely studies met the criterion of reporting on patient experience of tracheostomy in ICU (all studies included some data on this). No articles were excluded, however, a sensitivity analysis reviewed the impact of including studies with lower CASP or relevance scores (see supplementary material F). Weighted scores ranged from 13 to 18 (out of 20). One study had only three participants and was completed by a single author, limiting credibility of findings [42]. The balance of participant quotes to author interpretation and provision of contextual information varied across studies, impacting credibility and transferability of findings. There were nuanced differences between studies based in long-term settings versus acute settings in terms of patients' experience of anger due to communication difficulties and issues of autonomy and self-identity.

3.4. Descriptive themes

The five major Descriptive Themes (DTs), developed from participant quotes and study author interpretations from the 13 selected studies, are presented with illustrative quotes in Table 1 below. Fig. 2 shows

the analytical process post initial coding, including thematic maps of high-level descriptive and analytical themes.

3.5. Analytical themes (ATs)

The analytical themes and inferred answers to the research question were derived through methods described above [33]. Similar to "best fit" framework synthesis [55], we combined inductive and deductive methods in our review. In contrast to this method, we selected and chose to incorporate a conceptual model after developing and in response to the DTs from stage 2 of our thematic synthesis. We had noted human aspects of experience and care in the descriptive themes and sub-themes and used Todres et al.'s (2009) [35] Humanisation Value Framework for healthcare to help shape a cohesive conceptual model of the experience of having a tracheostomy in ICU. Todres et al.'s (2009) eight dimensions of humanisation are shown in Table 2 (see supplementary material G for a table showing DTs against eight dimensions of the Humanisation Value Framework). This step helped reveal the interplay between DTs and move from surface level findings to higher level themes and conceptual understanding of patient experience of tracheostomy in ICU. It also aided interpretation of implications for practice. Analytical themes were cross-checked with original texts and descriptive themes to ensure they captured and explained the core concepts identified. Implications for clinical practice were also identified.

The three analytical themes identified were: 'Being seen as a whole, unique, autonomous person'; 'Making sense of it, coping, and connections'; and 'Patients' voices as a key currency in humanising care' (see Fig. 2.). These are described further below and presented in Table 3 with corresponding implications for practice. The overarching analytical theme was defined as 'To be seen and heard as a whole person'. Patients wanted to be treated as a human, and having a voice made this easier.

3.5.1. AT 1: Being seen as a whole, unique, autonomous person

The evidence suggests that it is greatly important to patients to be seen for who they are as a person, not just for their medical needs. In the studies reviewed, not being able to speak threatened this through changing interactions between patients and staff. It made patients feel invisible [53], not valued as a human being [45-47,51,53], or treated as "just a 'body' on which people act" [53].

> 'they talked as if I weren't there at all. As if I were deaf, or not quite right in the head.. that sort of thing, a bad situation. It was degrading' (direct participant quote) [51].

> 'Common to all participants were the communication challenges that occurred while they were in ICU on the ventilator. Their compromised ability to communicate resulted in feelings of frustration, vulnerability, isolation, and a diminished sense of self' (author quote) [44].

Perceptions of staff not making an effort to communicate with voiceless patients, not attempting to correct misunderstandings, or jumping to conclusions about a message [42,43,45,46,49,51,53], were deeply upsetting to patients, and can be seen as dehumanising . In contrast, Flinterud and Andershed's (2015) [48] study highlighted the value of caring, attentive staff who acknowledged communication difficulties, took time to try to understand, were present at the bedside and communicated through verbal and non-verbal means. Patients wanted to have some control or influence over care and management decisions. This extended from immediate concerns, such as getting basic needs met [43-45,48,53], to longer term decisions around rehabilitation or discharge destination [44,49]. Family was seen to be hugely important to patients [43,48,50,53]. In the terms of humanisation, families afforded patients agency through interpreting communication more easily and acting as advocate for patient needs. Functional activities such as eating and drinking were seen to be important to patients for physical and

Table 1
Descriptive themes, sub-themes, and illustrative quotes.
[a]AAC = Augmentative and Alternative Communication, for example, writing, alphabet charts, high-tech communication aids
[b]TT = tracheostomy tube
[c]ICU = Intensive Care Unit

Themes	Sub-themes	Facets of theme	Studies	Illustrative quotes (direct participant quotes in italics)
Voice and disrupted communication	How it feels to be voiceless in ICU	Profoundly negative experience and leads to frustration, fear, anger, uncertainty, withdrawal	(42-53)	*Yes, it was a really overwhelming feeling when I couldn't make myself be understood, that they didn't understand me, and that I couldn't tell them anything. That, that was just so distressing.. .it was simply my temper that came, when I realized, I couldn't manage it.* p2298 (48)
		Being misunderstood/people mis-guessing is infuriating	(42, 45,49, 53)	*They often just put words in my mouth, that would have nothing to do with what I was saying and that was really annoying. I remember I would just shake my head really strongly and mouth 'no!'* p13 (49)
		Being able to speak again brings great relief	(42, 49, 50, 52)	
	AAC is a poor substitute for speech	Mouthing, head nod/shake, banging on table, throwing things, gestures, writing	(42, 44-49, 53)	*I wanted to talk but I couldn't…my friends said try to write…but I was too weak to write and not sufficiently conscious to write a whole sentence…I couldn't do anything* p27 (53)
		AAC can allow basic messages but is slow, effortful, and often unsuccessful AAC is dependent on good limb strength, cognition, and skills/patience of listener	(42, 45-49, 51-53)	Paula explained that the content of her communication was simplified due to loss of voice '*Of course if you could talk it would be different. I was still reading off using the letters. I couldn't do long sentences but could answer basic needs or basic things I wanted to say*' p13 (49) *It got very frustrating. Especially when I wanted people to lip read what I was saying and they couldn't understand me.* P505 (52)
		Lip reading preferred method of communication after voice by patients	(45, 53)	
	Speech functions: implications of impaired communication	Having their voice is of fundamental importance to patients	(42, 44-41, 49, 51, 53)	Interpretation/metaphorical: Communication or least the ability to speak is a fundamental need for most people; for Brian the stress of not being able to speak '*drove me nuts*'. P1121 (46)
		Speech allows interpersonal exchanges	(42, 44-46, 48, 49, 51, 53)	Several participants described how they were screaming inside because of pain, but were unable to communicate their pain to healthcare professionals. One participant described this sentiment well: *Then it hurt so much I almost screamed my head off. Well, inwardly. But I didn't get out a damn thing. It really hurt. So, it sucks when you can't say anything.* p2299 (48)
		It is difficult for patients who cannot talk to ask for information and flag needs	(42, 44, 45, 47, 49, 51)	
		It is difficult to express personality and correct misassumptions without speech	(42, 43, 45, 47, 51, 53)	The inability to speak made it difficult to interact with other people, and this generated in patients a sense of isolation linked to a feeling of 'counting for nothing' (i.e., worthlessness). "*… I felt as if I counted for nothing… I could not say anything… I couldn't interact…*" p28 (53)
		Speech helps form and maintain relationships	(44, 45, 50, 51)	

Themes	Sub-themes	Facets of theme	Studies	Illustrative quotes (direct participant quotes in italics)
Autonomy and self-identity	Agency and self-determination	Impaired communication prevents patient participation in decisions	(42, 44, 45, 47, 49, 51, 53, 54)	Patients reported that they felt invisible in relation to the inability to communicate with others ad not being involved in the care plan, as if they did not exist. Some patients felt uneasy when the physicians did not speak directly to them as if the absence of their voice blocked any form of communication, including information. *"…the doctors…never spoke to me. Until recently, they just didn't speak to me…now if I ask a question they give me an answer. All was well with the nurses, I didn't have any problems."* p28 (53)
		Awareness of dependency on others leads to sense of loss of control and powerlessness	(42-48, 51-53)	
		Opposing priorities of patients and care teams may lead to focus on physical safety over independence	(44, 48)	[on return of voice] *I could say 'no, that I didn't want to be in this position', 'no, I didn't want that pillow behind my back', 'no, I didn't particularly want another nasogastric tube', things like that.* p14 (49)
		Self-determination as 'having control' and/or a mental attitude	(43, 41, 54)	*If it wasn't important, I wouldn't repeat it. If it was something important enough that it was bothering me or aches or pains, I would repeat it over and over and over until they got the message… And I'd keep persisting and persisting if it was important enough. If it wasn't important, I'd just forget it.* p1171 (45)
		Perseverance in communicating a message vs giving up/withdrawal affected by the perceived importance of message or sense of futility	(42, 45, 48, 49, 53)	
		Families as key patient advocates and motivators	(43, 53)	*…very often they didn't understand me…they thought I had a tic or a problem with my head instead I was trying to tell them that something was hurting me there… in the end I gave up* p27 (53)
	The self and connecting with others	Feeling incomplete without a voice	(42, 44-46)	Participants understood the concern for their safety, yet as those concerns prevailed, they spoke of a changing sense of freedom, independence, and a self that was, once again in jeopardy: *"I was feeling caged, being very smothered and stifled, and that I was losing my own sense of who I am and that, you know. And it was making me hurt inside"* p61 (44)
		Risk of dehumanisation and focus on physical needs in absence of voice	(42, 44, 47, 51)	*I had expected to feel better. But it was just the opposite. I was laid down, now and then washed and combed. At six in the morning someone came and just started…did all sorts of things that I didn't want.* p1106 (51)
		Importance of relationships with others to mitigate isolation	(44, 45, 48, 53)	
		Families act as intermediaries between patients and staff	(43, 53)	*Some care assistants are more concerned about the ventilator than me* p334 (47)
		Praise for staff when patients felt well-looked after both physically and emotionally	(42, 43, 45, 46, 48, 50, 51, 53)	Participants wanted to connect with others, and to do so, they found various voiceless ways to fill the void left from the impaired communication process. Participants attempted to express themselves in physical ways, often using a variety of communication means, even though this was arduous for them. p1170 (45)
		Staff speak to patients more when patients can speak	(53)	

Themes	Sub-themes	Facets of theme	Studies	Illustrative quotes (direct participant quotes in italics)
Cognitive, psychological, and emotional needs and experiences	Fear, anxiety and mental wellbeing	Being on ICU with a TT is a frightening experience	(42–54)	*The final distinct negative theme was fear and anxiety (3 reponses, 6%). They described tracheostomy experiences as "mentally difficult and anxious", "scared" and "frightening".* p15 (50)
		Sources of fear: fear of death; difficulty breathing; TT blockage or dislodgment; not being able to talk; choking/aspirating; uncontrolled pain; the unknown; TT changes	(47, 48, 50, 52)	*I was shaking.... Interviewer: What did they do to relax you? Oh nothing they just calmed me down a bit they just said relax, its nothing major, or anything...its gonna be quick* [tracheostomy tube change] p1119 (46)
		Patients often experience shock of waking on ICU with a TT, preparation and information can help mitigate this	(43, 44, 48, 49, 51, 54)	*The shock of waking up, not knowing what had happened and being unable to speak, evoked feelings of frustration and despair. Some did not understand that they could not speak; thus, they tried to talk louder and louder and became increasingly stressed out* p2299 (48)
		Voicelessness and insufficient information make patients feel vulnerable, helpless and unable to cope	(42, 43, 45, 46, 48, 50, 52)	
		Anxiety can be lessened by: Tailored information; Caring attitudes of staff; Presence of family; Return of speech		
	Information needs and situational awareness	Patients who understand their situation recognise ICU treatment and TT mean difference between life and death	(42, 44, 50–52)	*Despite the frustrations and discomfort that all the participants described, all of them appeared to understand the need for a tracheostomy. They emphasized that they had no choice. They viewed the tracheostomy as a means of survival* p505 (52)
		This may help acceptance of restrictive ICU treatments such as TT but also engender fear, e.g. of TT blockage or dislodgement and aspiration or choking	(42, 45, 46, 53, 54)	*All I'm worried about is coughing this thing out, (indicates tracheostomy tube) which I nearly did!... p40 (42)*
		Voiceless patients are offered less information and not always able to ask questions; some staff do not talk directly to voiceless patients	(49, 51, 53)	[on regaining voice] *I could communicate. I could tell people what I needed and ask questions about what was happening and people don't think you want to know why, so they would say this is what happened but afterwards you could ask why, I, well, I could ask questions.* p14 (49)
		Being well informed helps build sense of safety	(48, 52)	*When I came out of the coma it took me a while to fully understand what was going on. Also because you are in a confused state, you forget where the buzzer is sometimes and*
		In the absence of information, patients struggle to make sense of what is happening and fear they will remain in ICU and/or voiceless forever	(45, 47, 48, 53)	*(I) was also getting medication, which was given to me that also doped me up a little bit more. Even though I was conscious I was very confused and so the lack of speech makes it worse (Roger)* p13 (49)

Themes	Sub-themes	Facets of theme	Studies	Illustrative quotes (direct participant quotes in italics)
Physical needs and experiences	The experience of time	Confusion and memory impairment reduces patients' ability to make sense of the situation or retain information	(42, 47, 49)	
		Being on ICU with a TT poses an existential challenge to some patients, who question what events mean for their life and them as a person: their identity, autonomy and where they will live after discharge	(44, 45, 54)	
		Time slows in ICU for patients with a TT	(44, 45, 54)	*A participant reflected on the time when she was voiceless and stated that time passed "very badly. Slowly. And to me, it would never end. Then I was starting to think— I said, 'Oh, my God. This [pointing to tracheostomy, indicating not having voice] could go on and on and on forever.* p1170 (45)
		Slowing of time is worse when patients are non-verbal or are afraid of never being able to talk again	(45)	*In ICU there isn't really any routine or pattern, it's just twelve hours of blur. Whereas, with eating, it breaks this up and makes it more like your normal day. The routine helped as I had a set pattern and knew what to expect. It also really helped me in getting ready to be transferred to the ward.* p149 (54)
		Lack of routine or structure to the day slows time and causes boredom	(45, 52-54)	
		Mealtimes can bring back routine and sense of normality and help pass the time	(54)	*'It's a life-altering transition for me, but a positive life-altering transition in that I can be me again right now. You know, I take this whole disease day to day.* p62 (44)
		Patients' experience changes over time as they make sense of and adapt to their new situation	(45, 48)	
		Good communication systems or voice can help adaptation	(45, 48)	
		The experience of those with chronic disease may differ as they feel relief of symptoms alongside new restrictions	(44)	
	Physical sensations related to tracheostomy	Patients feel pain at the stoma site, from stitches, on dressing changes, tube changes, suctioning and due to large tubes	(42, 46, 50, 52)	*Ahhh! That's when you get a bit of pain, because around this bit (indicates the tracheostomy stoma)... is very tender.... You can feel it all the way around because when you cough, you're retching at the same time.. and then it is painful!* p40 (42)
		Swallowing feels different and many patients experience inability to eat or drink which is physically and psychologically challenging	(42, 44, 46, 50, 52, 54)	all the participants commented on difficulties with swallowing and some problems with eating and drinking *[Swallowing] was awkward too. Very difficult. It still is actually (Pt B)* *I was uncomfortable with it because every time you tried to swallow you could feel this lump there (Pt C)*
		Dry mouth, thirst and cravings can be intense	(52, 54)	

Themes	Sub-themes	Facets of theme	Studies	Illustrative quotes (direct participant quotes in italics)
Facilitators to wellbeing and recovery	Meeting physical needs	Some patients experience choking episodes and are frightened of aspirating food and drink	(46, 54)	*I couldn't eat properly and I found afterward when I started swallowing again... you could feel where the wound was and you feel as though your throat was bruised (Pt D) p504 (52)*
		Difficulty breathing due to illness, suctioning, blocked TTs, choking or asynchrony with the ventilator is frightening	(42, 44, 46, 50, 52)	*I did want to grab hold of a pint of water and glug it down...it was a bit desperate wanting to have a drink. Food, not so much, but the drinking...'ou're so thirsty'it's unbelievable"* p504 (52)
		Coughing and suctioning are tiring and painful. Pain on suction and can be linked to technique	(42, 50, 52)	
		Removal of secretions brings relief	(42)	
		Voiceless patients are not always able to make needs known which can lead to enduring pain, discomfort, fear and uncertainty over whether needs will be met	(43-45, 48, 49, 53)	Several participants described how they were screaming inside because of pain, but were unable to communicate their pain to healthcare professionals. One participant described this sentiment well: *Then it hurt so much I almost screamed my head off. Well, inwardly. But I didn't get out a damn thing. It really hurt. So, it sucks when you can't say anything p2299 (48)*
		Staff anticipation of needs improves as they get to know patients and communication improves	(45, 48, 53)	Participants described impaired communication causing their needs for toileting, pain medication, and suctioning to go unmet..(....). One woman's silent screams were not heard when her oxygen tank ran out. This resulted in extreme anxiety for her because she felt the constant need to ensure that her oxygen tank was full. p1172 (45)
		Coordinated and competent MDTs provide better, more consistent care	(43, 46, 47, 50, 52)	
		Patients distinguish two equally important types of care: competent completion of tasks, and caring attitudes and behaviours of staff	(43, 45, 46, 48, 50, 51, 53)	*...I must say that the nurses were really good and I will always say this, they were very professional... then we would also joke and laugh... look I say it from the bottom of my heart, because when they passed they said hello and asked how I was feeling and this was comforting for me... there were these people who really cared about me...."* (Agostino) p28 (53)
	Improving communication	Adjustment to breathing and stoma healing post decannulation is difficult for some patients but preparation and information can help	(42, 52)	
		Having your own voice is the best means of communication	(42, 45, 49-53)	[on being told she would get her voice back] *I said "Oh, my God answered by prayer." I was so pleased, so happy. And then the first day I got my voice, it's like a grand opening, you know...and I can relate to [others] what went on during the day. Just instead of sitting there like a bump on a log. p1169 (45)*
		Speech gives patients a sense of freedom, control, ability to join in, request information and ask for things to be done	(45, 49, 51, 53)	

Themes	Sub-themes	Facets of theme	Studies	Illustrative quotes (direct participant quotes in italics)
		In the absence of voice, tailored communication strategies and extra time allow patients to signal basic needs and interact socially	(45, 48, 49, 52)	Several of the participants also highlighted the importance of their relatives being familiar with their usual body language and gestures. This familiarity put them in a good position to understand and relay the participants' concerns to others p2300 (48)
		Knowing patients better aids communication	(45, 48)	Nobody came...nobody was near me (surely they did come)...nobody....no, there wasn't anybody and then my desperation grew more and more...but probably they also didn't have the time... p28 (53)
		Friends and family act as advocates and translators	(43, 48, 53)	
		Patients are sensitive to body language, eye contact, touch and staff presence at the bedside; this non-verbal communication can communicate a sense of calm, safety and interest in patients	(43, 45, 48, 50)	
	Coping strategies and character traits	Patients use various coping strategies such as: Humour setting goals and monitoring progress trying to regain normality to daily lives (e.g. routine of mealtimes, religious activities) using sleep and watching TV as a means of escape	(43, 45, 48, 53, 54)	I think the best way is once you've had it done once and you know you've gotta have is done a second time is just to grin and bear it, really attack it mentally otherwise it'd jut bloody drive you crazy I think p1119 (46) The formulation of goals was recounted by some, often with removal from the technology as the primary goal. Dan illustrated this point: *My number one goal was to get the tracheostomy out p144 (54)*
		Spiritual beliefs and having self-determination can give patients strength, help them cope and encourage recovery	(43, 54)	One participant described conversing with her deceased mother who told her, *"Baby, go back. It's not your time yet. God has something for you to do and you go back."* Another participant recalled an incident where her grandfather, whom she referred to as her *"guardian angel"*, appeared at the bedside. She believed that *"he was there to help"* her and insisted that he *"pulled"* her through this traumatic event. p332 (43)
	Signs that indicate recovery to patients	The removal of attachments is important to patients and signifies recovery	(45, 52, 54)	Bijal reported that getting rid of tubes was important for psychological and moral reasons. He expressed the need to 'start shedding attachments', which enabled him to 'start believing that the end is in sight'. p144 (54)
		Return to normality is important (e.g., showering, using the toilet, taking communion, speaking with family and friends and going home)	(42, 43, 53, 54)	For many, commencing oral intake indicated that they were getting better. It was described as symbolizing the 'road to recovery'. Fred expressed it as *"being very glad to have got to that stage, as it signified that things were moving in a positive way. Therefore, it was a step on the road to recovery, so I was delighted to have got there. It was terribly important."* It would appear that often it is less the need for food, than

9

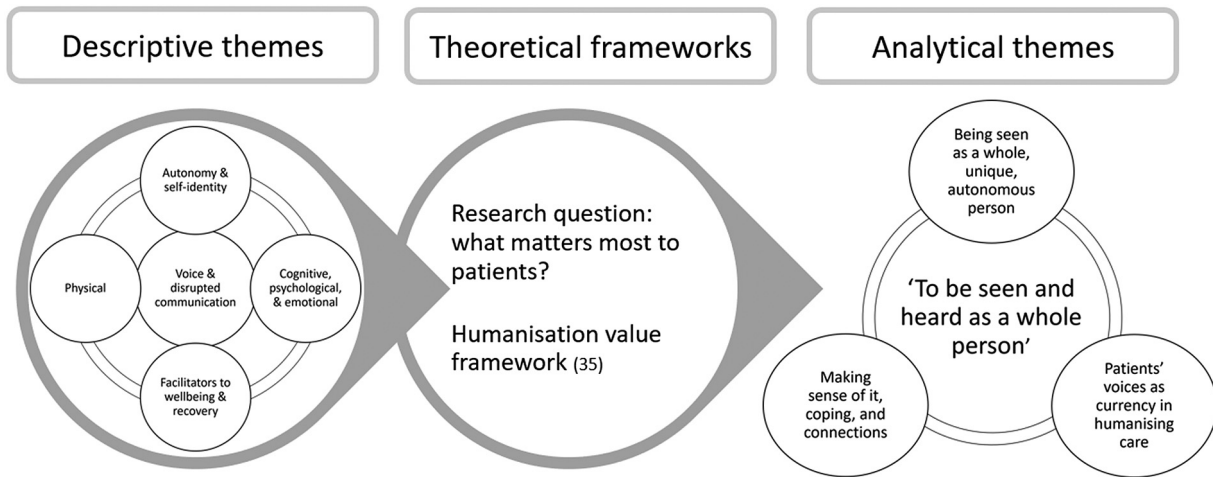| Themes	Sub-themes	Facets of theme	Studies	Illustrative quotes (direct participant quotes in italics)
	Making sense of the situation	Eating and drinking brings pleasure to patients and symbolises return to normality/end of deprivation of basic human needs, however, modified food/drink, absence of family, and the ICU environment can make mealtimes feel medicalised	(42, 54)	what eating signifies that is important. *"Eating is part of normal life, it wasn't like I was dying for a plate of fish and chips, but it represented a return to normality and that was so important."* p144 (54) Charles explained that return of voice was positive but also a sign of recovery of general health status, *"It was pleasing to be able to speak again. Mainly you felt as though you*
		Regaining voice contributes to feeling of getting better	(49)	*were getting better, recovering from the worst of your illness"*. In agree- ment Rodger reported, *"In my opinion that slows your recovery down as you're frustrated and start to go into a shell and it adds to the confusion. In my opinion, talking helped me recover quicker. I'm no doctor but it made me feel a lot better, when you feel better you recover.* p14 (44)
		Provision of adequate information can reassure patients and put them at ease, e.g., in preparation for elective admission, explaining reason for emergency admission, giving information on tracheostomy, and preparing for procedures (e.g., tracheostomy tube change)	(46-48, 50, 52, 53)	Some were satisfied and one HMV user stated: *Yes, I got the information about tracheotomy, we were well prepared* p333 (47) *Was well looked after and talked through each part when needed* p13 (50) *Living independently is like breathing to me. You can't do, go without it. You know it's*
		Ability to speak helps patients get the information they need	(49, 51)	*like having your own self-determination and, uh, to feel you have purpose in life is key to most people, I would think, you know If you feel, a human being feels that they have no purpose, what is, why are we existing then?* p61 (44)
		The ability to live at home and having autonomy is meaningful to patients with a long-term tracheostomy	(44, 47)	
	The essentialness of families and relationships with others	Families provide huge support to patients and act as translators and advocates for patients	(43, 47, 48, 50, 53, 54)	The constant presence of family members and health care professionals provided solace, comfort, and reassurance during a time wrought with uncertainty, stress and fear. In addition to providing emotional support, vigilant family members in this study may have served as a communication conduit for information delivery and
		Families are a source of comfort and motivation to recover	(43, 53)	reinforcement, thus reducing anxiousness and ambiguity. p332 (43) Several participants mentioned the importance of having eye contact and physical
		Staff-patient relationships are important to patients. Eye contact, holding hands, touch, presence at the bedside, talking with patients and getting to know them alongside provision of information makes patients feel well looked after and reassured	(42, 43, 45, 46, 48, 50, 52, 53)	contact: *When the anxiety comes, they were there straight away. They tried to calm you down, held your hand, and spoke to you. Communicated even though I didn't have a voice. And eye contact, that was very important for me then.* p2300 (48) *...I really trusted them, the nurses don't know how good they are, ...they don't realize*
		Trust and sense of safety depends on both competent care and caring attitudes of staff	(42, 43, 45-48, 50, 51, 53)	*how important they are.... they treated me like a baby, they reassured me...* p29 (53)

Fig. 2. The analytical process and thematic maps of high-level descriptive and analytical themes – Table 1 provides detail of each descriptive sub-theme.

psychological reasons and symbolised not only being human but also milestones in recovery [46,50,52,54].

3.5.2. AT 2: Making sense of it and connections with others

The need to make sense of the situation was a strong theme across studies. Patients wanted to understand what had happened to them, their current situation, and what the future held [42-44,46-54]. Reduced situational awareness due to lack of information, confusion and communication or memory impairment could lead to fear, anxiety, and loss of coping.

Connections and relationships with others were highlighted as important to patients and without them patients felt isolated [42-46,48,50,51,53]. Caring staff-patient relationships were powerful in creating a sense of trust and safety. Connections were made verbally but also non-verbally, through eye contact, presence at the bedside, facial expressions, and touch [43,45,48,53]. In this review, connections meant more than simple transfer of information; they meant human contact.

'The importance of being well informed, in conjunction with eye and physical contact, was noted by several of the participants. This conveyed calmness and was very important in fostering a sense of security and safety in the participants. One participant emphasized this feeling:

"But they spoke to me, all of them. I understood that, and it was just fantastic. But I recall that she [the nurse] was also very good at holding hands and using touch. And I found that very comforting so that's really important, you know."' (author/*direct participant* quote).

Processing and understanding ICU admission is important to patients [42,44-50] as is building and maintaining relationships with those around them [42-44,47,48,50,53]. 'Making sense of the situation' and 'connections' appear to be interdependent; as staff-patient relationships are established, staff convey more information and provide more social and emotional support [45,48]. Some studies highlighted the strength of support derived from relationships with family [43,48,50,53,54].

3.5.3. AT 3: Patients' voices as a key currency in humanising care

Much of what mattered to patients depended on having a voice, both literal and metaphorical. For staff to see the patient as a whole person; understand their worldview; meet their physical, psychosocial, and emotional needs; and for patients to have a say in care, establishing communication was vital [42,44-49,51,53]. Patients communicated in a range of ways. Voice was valued over Alternative and Augmentative Communication (AAC), however, partly due to the efficiency of communication it afforded but also due to its contribution to patients' identities [42,45,46,48-53]. Literal voice re-enforced patients' uniqueness as well as facilitating agency.

'It was a relief; just so, so good being able to speak...It was so good to be able to communicate normally again instead of trying to mouth words. It was just so much easier' (direct participant quote) [49].

"When this woman no longer had her tracheostomy tube and therefore was vocal at all times, she said 'Look, I'm free! I'm so happy'" (author/*direct participant* quote) [45].

4. Discussion

This review suggests a discrepancy between the evidence base on tracheostomy management and the primary concerns of patients; while researchers have largely focused on technical issues of tracheostomy insertion and epidemiology, we found that patients' priority was to be seen and treated as a human. This discrepancy has significant and potentially detrimental impact on the clinical care offered to patients.

4.1. Descriptive themes

The descriptive themes in stage 2 of our analysis provided the building blocks for our analytical themes and the practice implications we inferred. The first theme concurred with previous studies that have found an inability to communicate is one of the hardest things ICU patients have to face and leads to anxiety, frustration, anger, and untreated pain [25,56–59]. Alternative forms of communication and staff training

Table 2
The eight dimensions of the Humanisation Value Framework (Todres, 2009), reproduced under the creative commons licence.

Forms of humanisation	Forms of dehumanisation
Insiderness	Objectification
Agency	Passivity
Uniqueness	Homogenisation
Togetherness	Isolation
Sense-making	Loss of meaning
Personal journey	Loss of personal journey
Sense of place	Dislocation
Embodiment	Reductionist body

Table 3
Analytical Themes and Clinical Implications Primary data = author suggestions and recommendations in primary studies Evidence synthesis = author data and/or interpretation from primary studies supports this review interpretation Highlighted lines can be presented above or below the table, whichever you prefer.

Analytical Theme	What matters most	Data generated clinical implications	Source	
			Primary data*	Evidence synthesis**
Being seen as a whole, unique, autonomous person	Patients need to feel seen as a person as well as a patient. They need to feel they have some control over care and treatment decisions. Treatment plans should take into consideration patients' individual preferences and circumstances. Getting to know patients and their needs and showing kindness and compassion is as important as providing technically competent care and helps patients feel safe.	MDT training should cover a) technical and b) compassionate aspects of care, e.g.,		
		a) suction technique, inner tube removal and cleaning, stoma care, humidification, pain management	(42, 43, 46)	(45, 47, 43, 50-53)
		b) behaviours such as making eye-contact, touch, being present at the bedside, establishing effective communication, social/non task-focussed communication with patients and getting to know them as a person	(43, 46, 43)	(42, 45, 47, 50-53)
		Patients should be screened for tracheostomy related pain		(46, 50, 54)
		Treatment goals should be whole-person centred with full MDT input: functional impact must be considered alongside medical/surgical needs and interventions		(42, 43, 54)
		Ward rounds should address whole person needs, including communication, return to safe eating and drinking, information, and emotional needs	(50)	(43, 52, 54)
		MDT should involve patient in care decisions and activities		(49, 51, 53, 54)
		Team members should gather and share relevant person specific information (e.g., religious practices, interests, preferences) with MDT and incorporate in care plans	(43)	(48, 53, 54)
Making sense of it, coping, and connections	Patients want to know what has happened to them and what the future holds (e.g., prognosis, treatment plans). Not knowing what has happened or is happening can be bewildering and frightening. Feeling connected with others reduces anxiety and the sense of isolation. Family/close friends are the most important social and emotional support to patients. Caring relationships with staff are also important.	Patients should be given education on tracheostomy: anatomy; function; impact on voice, cough, smell, swallow; weaning plans	(42, 46, 47)	(48-53)
		Patients should be given information on what has happened to them and future treatment plans	(46, 47)	(48, 50-53)
		Quantity, content, and repetition of information should be tailored to needs (e.g., delirium, memory, cognitive, patient preference)		(49, 52, 53)
		Patients should be given opportunity to ask questions, with communication facilitated as needed		(46, 51, 53)
		ICUs should be aware of and address social and emotional communication needs of patients with a tracheostomy (e.g., wellbeing rounds)	(42)	(43, 45, 49, 53)
		Family visits and open visiting policies should be encouraged	(43)	(48, 50, 53, 54)

Analytical Theme	What matters most	Data generated clinical implications	Source	
			Primary data	Evidence synthesis
Patients' voices as currency in humanising care	Having a voice is hugely important to patients. Voice contributes to patients' identities and underpins their ability to make needs known, participate in care decisions, seek information, and build essential connections with others.	Voice restoration should be given high priority	(49, 50)	(43, 45, 46, 48, 52, 53)
		MDTs should consider the impact on voice of interventions and aim to maintain/restore voice where possible (e.g. early assessment for cuff deflation and speaking valve use, selection of the appropriate type and size of tracheostomy tube, ENT referral, Speech and Language Therapy (SLT) referral)		(43, 45, 46, 48-50, 52, 53)
		When voice is not possible, personalised alternative methods of communication should be established, with consideration of physical and cognitive ability and referral to SLT if needed	(42, 44, 45, 49)	(43, 48, 49, 51, 53)
	Family/close friends can mitigate the impact of voicelessness through helping staff get to know the person, which in turn facilitates communication and anticipation of needs	Non-verbal communication should be as natural as possible to patient (e.g., lip reading if able to mouth words)	(45)	(51, 52)
		MDT training should be given training on supporting verbal and non-verbal communication and when to refer to SLT	(42)	(49, 51, 53)
		Family and staff should check they have understood the patient correctly to avoid patient frustration		(47, 49, 53)
		All patients with a tracheostomy should be provided a call-bell	(42, 53)	(50)

have been shown to improve patient communication [60–64]. However, supporting previous research findings we highlighted that AAC often fails [65], and our data corroborate previous assertions that patients most highly value having their own voice [28,66]. In line with theories of stress and coping [67,68], our second descriptive theme showed that a sense of autonomy and self-determination aided coping whereas lack of control could lead to loss of coping and withdrawal, with implications for rehabilitation and recovery. This theme also described the impact of being on ICU with a tracheostomy on patients' sense of identity and inter-personal connections. We found little other evidence of this in the literature. The third descriptive theme found many patients were fearful and anxious, which is known to be common in ICU patients [69-72]. We found a lack of information and situational understanding contributed to fear and anxiety, and is intensified by voicelessness. Our fourth theme relating to physical experience identified sources of pain and discomfort that have been described elsewhere. However, pain and difficulty breathing were less dominant than experiences of thirst, swallowing difficulties and sense of physical restriction that resulted from being voiceless. We found that the fear of not being able to flag physical needs or call for help could cause more distress than the physical experience itself. Our fifth theme described positive influences on patient experience.

4.2. Analytical themes

The analytical themes moved beyond the initial findings to develop a cohesive, conceptual picture of patient experience and provide interpretations of what matters most to ICU patients with a tracheostomy. This aspect of our metasynthesis of study findings was supported by a model of humanisation (Todres, 2009) [35].

Our finding of the fundamental need to be seen and treated as a whole person fits with philosophical theories of humanism [35,73], phenomenological embodiment [74] and person-centred care [75,76], and contradicts Cartesian views of mind-body separation or Maslow's hierarchy of needs model [77]. We found that psychological, social and emotional needs of ICU patients with a tracheostomy were of fundamental importance, and that ignoring this risked patient dehumanisation. We suggested that the provision of adequate information that is tailored to patients' needs helps satisfy the fundamental human need to make sense of what is happening. This is consistent with the theory of 'facilitated sense-making', which, though developed to guide interventions to support families of ICU patients, states that when faced with crisis humans need to make sense of the situation and of their new role [78]. Participants in our review placed great importance on relationships with others. Family presence brought solace and could facilitate communication, consistent with previous literature [79-81]. In contrast, Halvorsen et al. (2020) [82] found that family presence could in some circumstances be a source of distress, for example when patients were aware of the impact of their own illness on their family, and advocated a tailored approach to family visiting. Additionally, Broyles et al. (2012) [83]identified that families often lacked skills to support their non-vocal relative to communicate, which could be upsetting to both family and patient. Interestingly, a recent development of facilitated sense-making has added 'patient-family communication' to the model [84]. Staff relationships were also important, and patients distinguished between two types of care: competent completion of tasks versus caring attitudes and behaviours, including efforts to communicate with them and being present at the bedside, echoing previous research [85-88]. Presence in turn supports communication and information exchange, allowing staff to get to know the 'person' in the patient. The Humanisation Value Framework [35] concept of 'togetherness' may help explain why nurse and family presence and caring attitudes and behaviours were significant to patients. We found that non-verbal communication from staff such as touch was an important means of connecting which fits with studies of the role of touch in human social bonding, stress and pain relief [89-91].

Our review supports Happ's (2000) concept of 'voicelessness' in intensive care [92], which describes the complex impact of communication impairment on the feelings and actions of patients, clinicians and families. Additionally, we highlight the importance of voice to identity and autonomy, lending support to the theory of voice as an embodied entity as described in one of the selected studies [45]. Interesting parallels are drawn between our study and Pound and Jenson's (2018) [93] investigation of humanising and dehumanising aspects of care reported by aphasic patients. In common with them, we found good communication between staff and patients was key to achieving humanised care. Interestingly, while we found that AAC was often associated with failed attempts at communication, non-verbal communication such as touch and eye contact was powerful in conveying caring and safety. It may be that this fits with findings of patients valuing naturalness of communication. Future research would be useful to investigate the apparent contradiction and explore ways to harness the broader spectrum of human modes of communication [94] to mitigate the impact of voicelessness on adults with a TT in ICU.

4.3. Clinical implications

There are notable similarities between the clinical implications we identified and recommendations from the International Research Project for the Humanisation of Intensive Care Units (HU-CI) [95-97], a Spanish-based group whose aim is to promote the humanisation of ICU through research, training and education and a certification programme for healthcare organisations. Unlike the HU-CI team, we did not identify recommendations for end-of-life care or improving staff experience, which is likely due to our research question and search strategy. The importance of patient communication is clearly reflected in HU-CI's standards [97], however, the principal difference in our findings is the fundamental and specific importance of voice to patients and its role in supporting whole-person, humanised care. We suggest speech and language therapists should be core members of the multidisciplinary ICU team and that voice restoration is included in future outcome measures used to capture quality of care for ICU patients with a tracheostomy (see Table 3).

4.4. Limitations

The quality of review findings re inevitably impacted by the quality and availability of primary data. We noted methodological weaknesses in selected articles and limited ethnic diversity of the pooled sample, which affects transferability of findings. We also acknowledge the change in analytical methods from those outlined in the protocol with the introduction of the Humanisation Value Framework [30]. However, we propose that transparency in reporting of the rationale for this step and its influence on findings justifies the amendment and it enhanced our review findings.

5. Conclusion

Our key finding was that 'Patients want to be seen and treated as a whole person, and having a voice makes this easier'. This finding should be used to inform quality improvement initiatives in tracheostomy care. We recommend that voice restoration take high priority in tracheostomy management decisions such as tracheostomy tube size selection, cuff deflation, and use of speaking valves. Staff tracheostomy training should focus on both technical skills and compassionate, whole person care. Improving technical aspects of tracheostomy management is important, but should be addressed in conjunction with, and not at the expense of, improving human experience.

Funding

CRediT authorship contribution statement

Declaration of Competing Interest

None.

Acknowledgements

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jcrc.2022.154145.

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