RESEARCH ARTICLE

By the patient, for the patient. Determining key quality of care measures for improving tracheostomy care.

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Abstract

Around 20,000 new tracheostomies are inserted annually in the UK. Quality of care may be measured by structure, process, outcome and patient experience. Our pilot work demonstrated the robust utility of quantitative quality indicators in measuring process (referral times, times to vocalisation and first oral intake) and outcome (patient safety incidents, lengths of stay). Our objectives were to further investigate qualitative and quantitative data that could describe the tracheostomised patient experience. Defining their baseline psychological wellbeing and the baseline satisfaction level with their care allows us to evaluate the impact of improvement programs.

Following ethical approval and adoption onto the National Institute of Healthcare Research Portfolio, UK NHS Trusts were selected to participate, recruiting adult and paediatric patients with experience of tracheostomy. Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) and Hospital Anxiety and Depression Scale (HADS) tools collected data, with a thematic analysis conducted to analyse free text entries.

A total of 142 and 120 patients from 10 hospitals completed HADS and HCAHPS questionnaires respectively. Qualitative analysis identified themes focussed on oral intake and vocalisation. Tracheostomy patients demonstrated high levels of psychological distress: 98 (69.0%) were classified as having at least borderline anxiety or depression, with 36 (25.4%) meeting criteria for both anxiety and depression. There was a significant difference between HCAHPS ‘top box’ scores assigned to the tracheostomy-relevant questions between sites (p=0.01) indicating varying satisfaction with care.

Our baseline data demonstrates that whilst psychological distress is prevalent, tracheostomy patients generally report positive experiences about their care, although the highest satisfaction scores are achieved in less than half of all categories. These metrics can track the impact of improvement efforts such as through the Global Tracheostomy Collaborative (www.globaltrach.org). Improvement efforts should focus on (and measure) times to oral intake, vocalisation and duration of care, all identified as important to our patients.

Keywords: Airway-Tracheostomy; Patient experience; Quality Improvement

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1. Introduction

Placement of tracheostomy is a frequent invasive procedure performed in the critically ill and head and neck surgical population. In the United Kingdom (UK), around 20,000 new tracheostomies are inserted annually,[1] most commonly providing airway access for patients requiring relatively prolonged mechanical ventilation.[2,3] Acute and often life-threatening complications (tube displacement, obstruction, pneumothorax and major haemorrhage) have been highlighted by reports from the National Patient Safety Agency,[4,5] the National Confidential Enquiry into Patient Outcome and Death,[3] and the Fourth National Audit Project in the United Kingdom (UK).[6] Considerable work has been undertaken to improve safety; for example, the National Tracheostomy Safety Project (NTSP) pioneered in developing guidelines and multimedia resources in the management of tracheostomy and laryngectomy airway emergencies.[7,8] Whilst patients reliant on tracheostomies are vulnerable to adverse events, they often have prolonged illnesses, lengthy hospital stays and have difficulties in vocalising and swallowing due to the presence of an inflated tracheostomy tube cuff.[9] This can impact upon the psychological wellbeing of patients and is an important area to investigate. Studies have shown that tracheostomised patients often feel frustrated, angry, powerless, restricted, fearful and experience a loss of control.[10,11,12] This group of patients require complex and multidisciplinary care from multiple healthcare professionals.[13] Therefore, it is important to set up and maintain systems that provides consistent, coordinated and effective multidisciplinary services, as delays or inconsistencies of patient care can worsen frustration for patients and families.

The Global Tracheostomy (Quality Improvement) Collaborative (GTC) is a worldwide group of healthcare providers, patients and families tasked with improving care. Formed in 2012, the GTC provides validated resources and support for participating institutions to implement changes to improve safety and quality of tracheostomy care.[14] Examples of GTC recommendations include multidisciplinary tracheostomy steering groups, ward rounds and bedside teams, standardisation of tracheostomy protocols, staff education and meaningful involvement of patient and family. In the UK public sector National

Health Service (NHS), efforts have been made to implement the resources of the GTC into hospitals providing tracheostomy care. Published outcomes to date have focussed on prioritising the variety of interventions available and not necessarily on patient-focussed outcome measures.[15]

The NHS publication *High Quality Care for All* stated that "in order to work out how to improve we need to measure and understand exactly what we do".[16] Quality of care may be measured by structure, process, outcome and patient experience.[17,18] In this study, we aimed to investigate surrogate metrics that describe the patient experience around tracheostomy care, defining suitable tools to evaluate the impact of Quality Improvement (QI) programs. Our previous pilot QI program demonstrated the robust utility of quantitative quality indicators in measuring structure (provision of inpatient speech and language therapy (SLT) service), process (referral to SLT, time to vocalisation and first oral intake following new tracheostomy) and outcome (patient safety incidents, overall length of stay).[19] The objectives of this study were to further investigate qualitative and quantitative data that could describe the patient experience. Defining the baseline psychological wellbeing of the tracheostomised patient and the baseline satisfaction level with their care allows us to evaluate the impact of tracheostomy QI programs.

2. Methods

Following ethical approval (IRAS Project-ID-206955, REC-Ref-16/LO/1196) and adoption onto the National Institute of Healthcare Research (NIHR) Portfolio (CPMS ID-31544), UK secondary or tertiary NHS Trusts who were managing tracheostomy patients were selected to participate and to collect baseline data. Adult and paediatric patients (and/or their families) who had experience of a tracheostomy (including recent decannulation during the admission) or laryngectomy during the index hospital admission were considered eligible for the study. Informed consent was taken by local staff. The following tools were used to determine wellbeing and satisfaction:

2.1 Psychological wellbeing

The Hospital Anxiety and Depression Scale (HADS) was used to collect the experiences of adult patients and/or their families who had recent experience of tracheostomy or tracheostomy care during the index hospital admission. HADS consists of fourteen questions, each scored 0-3, with seven questions each focussing separately on anxiety and depression (Table 1).[20] Total scores of seven or less are considered as ‘no case’ (for depression/anxiety) in each category; scores of 8-10 inclusive are ‘borderline’; and scores of 11 or over are ‘cases’. HADS was not used with paediatric participants.

Table 1 Hospital Anxiety and Depression Scale (HADS) patient questionnaire.

Anxiety
I feel tense or ‘wound up’: Answers (scores): Most of the time (3); A lot of the time (2); Time to time, occasionally (1); Not at all (0)
I get a sort of frightened feeling like ‘butterflies in the stomach’: Answers (scores): Not at all (0); Occasionally (1); Quite often (2); Very often (3)
I get a sort of frightened feeling like something awful is about to happen: Answers (scores): Very definitely and quite badly (3); Yes, but not too badly (2); A little, but it doesn’t worry me (1); Not at all (0)
I feel restless as if I have to be on the move: Answers (scores): Very much indeed (3); Quite a lot (2); Not very much (1); Not at all (0)
Worrying thoughts go through my mind: Answers (scores): A great deal of the time (3); A lot of the time (2); From time to time but not too often (1); Only occasionally (0)
I get sudden feelings of panic: Answers (scores): Very often indeed (3); Quite often (2); Not very often (1); Not at all (0)
I can sit at ease and feel relaxed: Answers (scores): Definitely (0); Usually (1); Not often (2); Not at all (3)
Depression
I feel as if I am slowed down: Answers (scores): Nearly all of the time (3); Very often (2); Sometimes (1); Not at all (0)
I still enjoy the things I used to enjoy: Answers (scores): Definitely as much (0); Not quite so much (1); Only a little (2); Not at all (3)
I have lost interest in my appearance: Answers (scores): Definitely (3); I don’t take as much care as I should (2); I may not take quite as much care (1); I take just as much care as ever (0)
I can laugh and see the funny side of things:

Answers (scores): As much as I always could (0); Not quite so much now (1); Definitely not so much now (2); Not at all (3)
I look forward with enjoyment to things: Answers (scores): A much as I ever did (0); Rather less than I used to (1); Definitely less than I used to (2); Hardly at all (3)
I feel cheerful: Answers (scores): Not at all (3); Not often (2); Sometimes (1); Most of the time (0)
I can enjoy a good book or radio or TV programme: Answers (scores): Often (0); Sometimes (1); Not often (2); Very seldom (3)

2.2 Patient satisfaction

The Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), a patient satisfaction survey, was used to measure patients' satisfaction level in their received tracheostomy care. It consists of 31 questions grouped into themes: nursing care, medical care, environment, experiences, discharge, understanding and an overall rating of the hospital. Table 2 summarises the questions and the re-coding used to provide the scores used in the analyses. Eight questions most relevant to tracheostomy care (Q2,3,4,6,7,19,22,24) and a ninth, overall satisfaction score (Q21; 0-worst to 10-best hospital) were used to generate summary scores. When re-coded, the highest score possible from the eight-question subset is 23. The remaining questions (Q1,5,8,9,10,11,12,13,14,15,16,17,23,25) describe more general hospital experiences and were used to generate non-tracheostomy question aggregate scores. HCAHPS is also usually summarised by 'top box score'; a binary score added only if the respondent selects the highest scoring response. In addition, there were three free text questions, asking participants to report good and bad aspect of their tracheostomy care and provide additional comments.

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Table 2 The Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) patient satisfaction survey. The questions which formed the aggregate tracheostomy care satisfaction score (*).

Nursing care
Q1 During this hospital stay, how often did nurses treat you with courtesy and respect? Answers (scores): Never (0); Sometimes (1); Usually (2); Always (3)
* Q2 During this hospital stay, how often did nurses listen carefully to you? Answers (scores): Never (0); Sometimes (1); Usually (2); Always (3)
* Q3 During this hospital stay, how often did nurses explain things in a way you could understand? Answers (scores): Never (0); Sometimes (1); Usually (2); Always (3)
* Q4 During this hospital stay, after you pressed the call button, how often did you get help as soon as you wanted it? Answers (scores): Never (0); Sometimes (1); Usually (2); Always (3); I never had to press the call button (4)
Medical care
Q5 During this hospital stay, how often did doctors treat you with courtesy and respect? Answers (scores): Never (0); Sometimes (1); Usually (2); Always (3)
* Q6 During this hospital stay, how often did doctors listen carefully to you? Answers (scores): Never (0); Sometimes (1); Usually (2); Always (3)
* Q7 During this hospital stay, how often did doctors explain things in a way you could understand? Answers (scores): Never (0); Sometimes (1); Usually (2); Always (3)
Environment
Q8 During this hospital stay, how often were your room and bathroom kept clean? Answers (scores): Never (0); Sometimes (1); Usually (2); Always (3)
Q9 During this hospital stay, how often was the area around your room quiet at night? Answers (scores): Never (0); Sometimes (1); Usually (2); Always (3)
Experiences
Q10 During this hospital stay, did you need help from nurses or other staff in getting to the bathroom or in using a bedpan? Answers (scores): Yes (0); No (1 and Go to Q12)
Q11 How often did you get help in getting to the bathroom or in using a bedpan as soon as you wanted? Answers (scores): Never (0); Sometimes (1); Usually (2); Always (3)
Q12 During this hospital stay, did you need medicine for pain? Answers (scores): Yes (0); No (1 and Go to Q15)
Q13 During this hospital stay, how often was your pain well controlled?

Answers (scores): Never (0); Sometimes (1); Usually (2); Always (3)
Q14 During this hospital stay, how often did the hospital staff do everything they could to help you with your pain? Answers (scores): Never (0); Sometimes (1); Usually (2); Always (3)
Q15 During this hospital stay, were you given any medicine that you had not taken before? Answers (scores): Yes (0); No (1 and Go to Q18)
Q16 Before giving you any new medicine, how often did hospital staff tell you what the medicine was for? Answers (scores): Never (0); Sometimes (1); Usually (2); Always (3)
Q17 Before giving you any new medicine, how often did hospital staff describe possible side effects in a way you could understand? Answers (scores): Never (0); Sometimes (1); Usually (2); Always (3)
Discharge
Q18 After you left the hospital, did you go directly to your own home, to someone else's home or to another healthcare facility? Answers (scores): Own home (0); Someone else's home (1); Another health facility (2 and Go to Q21)
* Q19 During this hospital stay, did doctors, nurses or other hospital staff talk with you about whether you would have the help you needed when you left the hospital? Answers (scores): Yes (1); No (1)
Q20 During this hospital stay, did you get information in writing about what symptoms or health problems to look out for after you left the hospital? Answers (scores): Yes (1); No (1)
Overall rating of the hospital
Q21 Using any number from 0 to 10, where 0 is the worst hospital possible and 10 is the best hospital possible, what number would you use to rate this hospital during your stay? Answers: 0-10
* Q22 Would you recommend this hospital to your friends and family? Answers (scores): Definitely no (0); Probably no (1); Probably yes (2); Definitely yes (3)
Understanding
Q23 During this hospital stay, staff took my preferences and those of my family or caregiver into account in deciding what my health care needs would be when I left. Answers (scores): Strongly disagree (0); Disagree (1); Agree (2); Strongly agree (3)
* Q24 When I left hospital, I had a good understanding of the things I was responsible for in managing my health. Answers (scores): Strongly disagree (0); Disagree (1); Agree (2); Strongly agree (3)
Q25 When I left the hospital, I clearly understood the purpose for taking each of my medications. Answers (scores): Strongly disagree (0); Disagree (1); Agree (2); Strongly agree (3); I was not given any medication when I left the hospital (4)

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Patient
Q26 In general, how would you rate your overall health? Answers (scores): Excellent (0); Very good (1); Good (2); Fair (3); Poor (4)
Q27 In general how would you rate your overall mental or emotional health? (This question is not applicable to children) Answers (scores): Excellent (0); Very good (1); Good (2); Fair (3); Poor (4)
Q28 Was there anything particularly good about your tracheostomy care?
Q29 Was there anything particularly bad about your tracheostomy care?
Q30 Would you be happy to have a 'bed head sign' around your hospital bed space that displayed safety details about you and your tracheostomy that could be referred to in an emergency? Answers (scores): Definitely no (0); Probably no (1); Probably yes (2); Definitely yes (3)
Q31 Please add any other comments below:

2.3 Data analysis

For quantitative data, summary scores and categorical cases were examined using Microsoft Excel and IBM SPSS 22.0, presented as median (IQR, range) or as simple counts. Kruskal-Wallis H test was used to examine differences between sites. Mann-Whitney U test was used to explore the differences between the tracheostomy-specific and general HCAHPS questions.

The internal consistency (reliability) of HADS and the quantitative data of HCAHPS were evaluated by Cronbach's alpha, generating a composite score.[21,22] Cronbach's alpha coefficients range from 0 to 1; an alpha of 0.9 and above is considered as excellent reliability, $0.8< \alpha< 0.9$ good, $0.7< \alpha <0.8$ acceptable, $0.6< \alpha <0.7$ questionable, $0.5< \alpha <0.6$ poor and $\alpha <0.5$ unacceptable reliability.

Free-text comments of HCAHPS questionnaire were analysed using thematic analysis in order to identify, analyse and report patterns (themes) within the free text responses received.[23] The narrative was initially read line by line and coded into categories. No formal validation or double coding of qualitative data was conducted. The different codes across our data set were grouped and merged together to develop themes that represent participant experiences and perceptions.

3. Results

A total of 58 patients completed both HADS and HCAHPS questionnaires, with a further 84 completing HADS alone (142 total from 10 sites) and 62 completing HCAHPS (120 total from 9 sites).

3.1 Psychological wellbeing

A median of 9 (8, 7-23) patients per site completed HADS questionnaires. Table 3 details the breakdown of score categories. Ninety-eight patients (69.0%) were classified as having at least borderline anxiety or borderline depression, with 36 patients (25.4%) meeting criteria for both anxiety and depression together. There were no significant differences between the sites for either anxiety or depression (p=0.46 and 0.09 respectively). The Cronbach's alpha coefficient of the overall score was 0.86, considered good reliability.

Table 3 Hospital Anxiety and Depression Scale (HADS) and Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) results. HCAHPS Trachy Q's (Q2,3,4,6,7,19,22,24) and General Q's (Q1,5,8,9,10,11,12,13,14,15,16,17,23,25). Values are median (IQR, range) unless otherwise stated.

Categories	Median score	No case (n)	Borderline case (n)	Case (n)
HADS Anxiety	8 (8)	65 (45.8%)	26 (18.3%)	51 (35.9%)
HADS Depression	9 (9)	63 (44.4%)	24 (16.9%)	55 (38.7%)

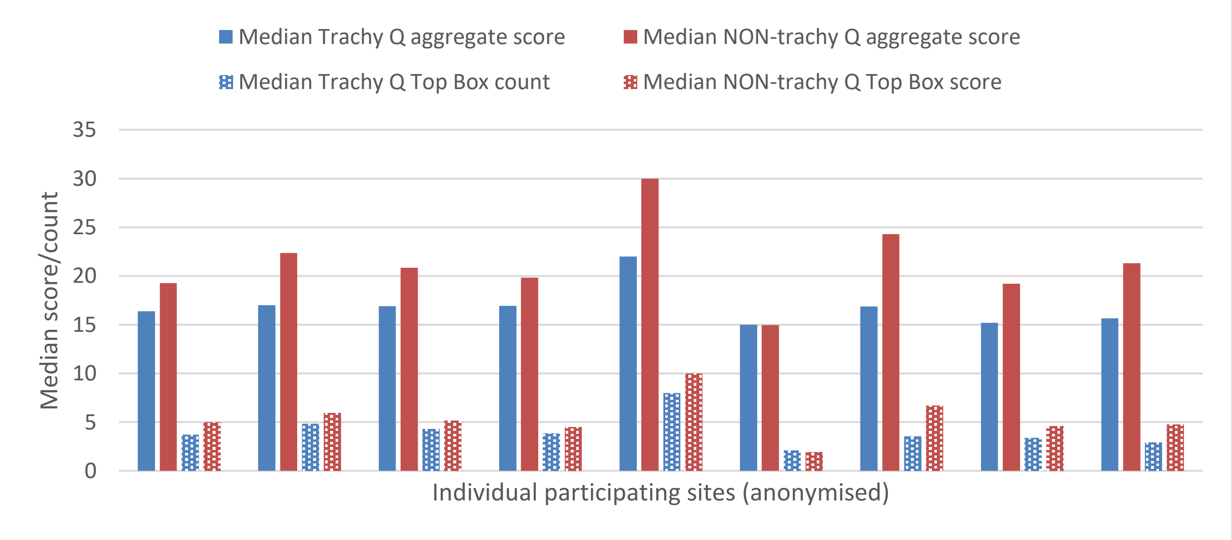
	Trachy Q's		General Q's	
	Median	Count (%)	Median	Count (%)
HCAHPS Top Box counts	3.5 (3, 0-8)	435/960 (45.3)	5 (5, 0-10)	562/1680 (33.5)
Difference between sites p	0.01		0.01	
HCAHPS Aggregate scores	17 (3, 7-23)		20 (8, 7-32)	
Difference between sites p	0.37		0.01	

3.2 Patient satisfaction

A median of 17 (12,1-20) patients per site completed the HCAHPS questionnaires. Q21 overall hospital rating median score was 8 (3,0-10) out of highest possible score of 10. Median score for aggregate tracheostomy care satisfaction questions was 17 (3,7-23) out of highest possible score of

23, with no significant differences between sites (p=0.37, Figure 1). When considering the number of ‘top box’ scores assigned to the eight tracheostomy-relevant questions, there were 435 ‘top box’ scores (median 3.5 per respondent [3,0-8]) out of a total of 960 question responses (45.3%), with a significant difference between sites (p=0.01). When considering the general (non-tracheostomy) questions and all survey questions together, there were significant differences between the sites for both aggregate scores and top box scores (p<0.1 and p<0.1 respectively).

Figure 1. Median count of aggregate scores (solid bars) and top box counts (checked bars) for both tracheostomy-specific (blue) and non-tracheostomy-specific (red) questions, by site.



There was a significant difference between the median aggregate scores for tracheostomy questions (17) and that for the non-tracheostomy questions (20, 8, 7-32, Mann-Whitney U p<0.01). This difference persisted when considering top box scores, with the non-tracheostomy questions recording significantly more top box responses than the tracheostomy questions (median scores 5 versus 3.5, p<0.01).

The Cronbach’s alpha coefficient of tracheostomy care aggregate score and top box score were 0.72 and 0.77 respectively, considered as acceptable reliability.

3.3 Free text analysis

Out of the 120 respondents completing HCAHPS questionnaires, 81 (67.5%)

submitted at least one free-text comment. A total of 120 comments were themed into positive (67 comments), negative (49) or neutral (3). Overall, more positive than negative comments were made, with a ratio of 1.4:1.0.

3.3.1 Positive comments

Themes emerged from the positive comments are summarised and illustrated with quotes in table 4. Ten (15%) comments were *generally positive*, lacking specific detail as which aspects of the experience were particularly valued by the respondents. The majority of identifiable themes of positive experiences, related to *staff care* (27 responses, 40%). Within this theme, most respondents praised the *general staff care* received from nurses, physiotherapists and doctors. The *hygiene care* provided in tracheostomy management and *aftercare* were also appreciated.

Table 4 Summary of the positive free texts.

Themes	**Sub-themes**	**Number of comments**	**Quotes**
Generally positive		10	*“Overall we are happy with the tracheostomy.”*
Staff care	General staff care	19	*“The ward is NHS at its best, dedicated smiley professional staff that helped me through two weeks of a trachy with closed end stent. I couldn’t have asked for better attention, the staff and I became friendly and I appreciated their support and expertise throughout my three-week, two day stay.”*
	Hygiene care	6	*“Kept clean, tubes regularly changed”*
	Aftercare	2	*“Meeting the aftercare team”*
Clinical management	Technical skills	5	*“It was performed to the highest standard and without any infection.”*
	Comfort	4	*“Didn't know about it, it didn't bother me.”*
	Management of	2	*“I had stent in throat with closed end so trachy was only breathing source. I was near nurses*

	complications		*station room and when four times my trachy blocked on different occasions and pressed my panic button nursing staff came quickly thankfully to unblock my tube."*
Communication & information	Patient education	7	*"Was well looked after and talked through each part when needed"*
	Staff communication	2	*"Communication between patient, nurses and doctors about treatment"*
Necessity		7	*"Helped me breathe and saved my life"*
Speech restoration		3	*"Fantastic to be able to speak with my family and also more comfortable"*

The second positive theme was *clinical management* (11 responses, 16%). Within this theme, nearly half of the comments were regarding the *technical skills*, for example; tube changes, transferring the oxygen supply system, performing associated procedures and suction. Around half commented on *comfort*, describing procedures as "comfortable" and with "no pain". Two responses within the theme praised the *management of complications*; one on management of tube blockage and the other on stoma stenosis management.

Communication and information was also derived from responses (9 responses, 13%). Within this theme, most respondents commented on *patient education*, whereas the remaining comments related to *communication* between patients and staff. Further positive comments focussed on *necessity* (7 responses, 10%), with respondents appreciating that tracheostomy is a lifesaving procedure. The final distinct positive theme was *speech restoration* (3 responses, 4%) by speaking valves and other means.

3.3.2 Negative comments

Themes emerging from the negative comments are summarised and illustrated with quotes in table 5. Three (6%) were *generally negative*, without specifying which aspects of experience were poor.

Comments on negative experiences described physical discomfort and limitation (14 responses, 29%), relating to *pain and discomfort* caused by the stitches or harsh material of the tube, coughing during tube change or suction, and inability to eat. Other comments focussed on an *inability to communicate*, relating to inability to vocalise or to use non-verbal communication.

Further negative themes were *staff care* (10 responses, 20%), within which *general staff care* from nurses and *hygiene care* of the tracheostomy tube were criticised in even proportion. The theme of *clinical management* was also negatively perceived (9 responses, 18%). Six respondents commented on the *insufficiency of staff knowledge*, mostly from ward staff. The rest disliked the *procedures* of changing tube.

Table 5 Summary of the negative free texts.

Themes	**Sub-themes**	**Number of comments**	**Quotes**
Generally negative		3	*"Everything"*
Physical discomfort & limitation	Pain & discomfort	10	*"The one used was too big and was painful and uncomfortable until it was changed."*
	Inability to communicate	4	*"Unable to speak"*
Staff care	General staff care	5	*"A couple of the nurses"*
	Hygiene care	5	*"Oxygen mask falling off. Not being cleaned, flex running down her chest and left there, dried and stuck"*
Clinical management	Insufficiency of staff knowledge	6	*"Lack of knowledge outside of one specialist - more internal training would be useful."*
	Procedures	3	*"The change over from the first tube to the reverse flange"*

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Communication & information	Patient education	4	*"If I knew what to prepare for, it would have been better for me. Not enough knowledge of tracheostomy, did not understand what was happening."*
	Staff communication	4	*"At times communication between my consultant and nursing team could have been better, as there was some confusion about what was required regarding cuff requirement and plan for going home. "*
Fear & anxiety		3	*"Mentally difficult, when I woke up I could not speak. Anxious. Hard to breathe when rolling"*
Involvement of study		2	*"Questionnaire, difficult to complete lots of questions not relevant to ICU"* *"The green boxes on the consent form are hard to write on!"*

Further negative comments mentioned *communication and information* (8 responses, 16%). Within the theme, half of the respondents were unsatisfied with *patient education* with half focussing on *staff communication*. The final distinct negative theme was *fear and anxiety* (3 responses, 6%). They described tracheostomy experiences as "mentally difficult and anxious", "scared" and "frightening".

3.3.3 Neutral comments

Three respondents made suggestions on the free text boxes regarding bed head sign and patient support group as following:

"*The bed head sign should have more detail for doctors and nurses to work by.*"

"*Bed head sign should be compulsory for safety. My child has profound learning disabilities and not all staff seemed experienced or basic life support trained or could communicate effectively with my child.*"

"*I would like someone to come and speak to me who has previously had experience with tracheostomy.*"

(The bed head sign refers to information provided at the bedside regarding essential details of the patient's airway and tracheostomy, including emergency contacts and procedures).

4. Discussion

The main findings from our study showed that patients with tracheostomies reported high levels of psychological distress, identified common themes with their care that impacts on anxiety and satisfaction, whilst reporting generally positive experiences about their care. Patients reported less satisfaction from questions related to tracheostomy care than those describing their overall hospital experiences. There were differences between sites which became more apparent when the binary 'top box' method of scoring responses was applied, as expected. These results present opportunities to improve care and reduce variability, which may be expected to reduce reported levels of psychological distress and improve satisfaction with care.

High Quality Care for All (Department of Health 2008) defined quality in the NHS in terms of patient safety, clinical effectiveness and the experience of patients. It stated that "if quality is to be at the heart of everything we do, it must be understood from the perspective of patients".[16] To our knowledge, this is the first published multicentre project to evaluate the experiences of tracheostomised patients from their own perspective, using psychological wellbeing (anxiety and/or depression) along with satisfaction levels and qualitative thematic analysis.

Our study is not the first to identify psychological distress amongst tracheostomised patients. A previous quantitative study by Breckenridge et al in 2014 compared the anxiety levels of patients during mechanical ventilation with and without tracheotomy by Visual Analog Scale-Anxiety (VAS-A) score, demonstrating that tracheostomised patients were as anxious as the mechanically ventilated.[24] Anxiety is also commonly reported during and following critical illness, including ICU admission. The tracheostomised patients in our study reported higher levels of anxiety (mean HADS-anxiety score 8.4) more prevalently (35.9% anxiety classification) than reports from unselected Intensive Care admission (mean HADS-anxiety score 6.8 in 12-43% of patients) [25] or following stroke (20-30% of patients).[26] McCormick et al in 2015, using a 50-item survey instrument, studied families' perspective on the care given to their tracheostomised family members. They concluded that whilst many reported satisfaction, opportunities remained for improving care.[27] Our study surveyed patients from their own perspective and showed very similar results. Patients generally reported positive experiences about their care, although the highest 'top box' scores were achieved in less than half of all categories.

The purpose of our study was to determine baseline surrogates of key quality indicators of care, measurable from the tracheostomised patients' perspective, that would enable us to evaluate the impact of subsequent initiatives to improve care. The HADS is a popular tool for clinical practice and research because of its validity, simplicity, speed and ease of use.[20] The similarity of HADS scores between sites in our study demonstrate its consistency in evaluating the mental wellbeing of tracheostomised patients, with good reliability (Cronbach's alpha 0.86). The systematic review by Campbell Burton et al showed that when using HADS score to evaluate the prevalence of anxiety, the results were similar if the questionnaire was conducted at different time points. In contrast, the results showed improvements following interventions.[26] These properties demonstrate the potential to use HADS as an outcome measure for future tracheostomy QI projects.

HCAHPS is a patient satisfaction survey commonly used in hospitals in the United States providing Medicaid Services, and used for the NHS Patient Experience Framework.[28] In our setting, HCAHPS proved reliable (Cronbach's alpha 0.7-0.8). The apparent difference of HCAHPS scores between sites may reflect genuine variations in satisfaction with tracheostomy care between sites, although the scores may reflect a degree of more widespread, hospital-wide dissatisfaction. However, these results allow us to benchmark sites embarking on improvement programs, to track the patient experience as improvements are implemented and to evaluate variability between sites as care becomes more standardised.

The qualitative data that describes patient experience have identified the aspects of care that are most relevant to patients. Previous qualitative studies showed that psychological distress could be associated with physical limitation, painful procedures, inability to communicate, fear of the unknown and relationships with staff.[10,11,12,29] Our qualitative data demonstrated similar findings and common themes that contributed to both positive and negative experiences. The most negative theme was physical discomfort and limitation; referring to cough and pain, inability to speak, eat and drink. Speech restoration was identified as one of the most positive experiences by tracheostomised patients, illustrating the potential benefits of early restoration of oral intake and speech. Therefore, in additional to the quantitative quality indicators used in our previous pilot QI program, such as overall length of stay, patient safety incidents, provision of inpatient SLT service, referral to SLT, we propose to explore indicators of oral intake and speech restoration as part of prospective quality improvement strategies:

- Time from tracheostomy to first oral intake (food or drink)
- Time from tracheostomy to established oral intake
- Time from tracheostomy to removal of artificial feeding conduit (eg nasogastric tube)
- Time from tracheostomy to first use of assistive or augmentative communication (eg above cuff vocalisation, communication boards)
- Time from tracheostomy to first cuff deflation (reflects a coordinated multidisciplinary team approach and promotes early vocalisation and restoration of laryngeal function)

Whilst the participating sites in this study are representative of the range of NHS hospitals providing tracheostomy care, they are by definition engaged in improving care and as such, the findings of this study may not be generalisable to all sites, particularly those outside of the NHS. However, the results were consistent with prior publications that describe the patient journey with a tracheostomy.

5. Conclusion

Our baseline data demonstrates that tracheostomy is associated with high levels of anxiety, with specific concerns focussed on communication and oral intake of food and drink. Whilst patients generally report positive experiences about their care, the highest ‘top box’ HCAHPS scores are achieved in less than half of all categories. There are differences apparent between sites which may reflect genuine variability in satisfaction with tracheostomy care between hospitals, reflecting variations in standards of care. By identifying key concerns described by tracheostomised patients, benchmarking indicators of psychological distress and satisfaction with care, and validating measurement tools in this setting, the results of this study can be used to track the patient experience as improvements are implemented.

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