More than nothing: The lived experience of tracheostomy while acutely ill

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Summary While the physical sensations surrounding tracheostomy tube insertion have been reported within nursing and allied healthcare literature, the lived experience of these sensations is poorly described. This appears relevant given the imminent results of the Tracman study (2008).

A purposive sample of three participants who had tracheostomy tubes previously within a critical care area or still in situ were recruited. They described their experiences in a face-to-face semi-structured interview that were audio taped. The interviews were transcribed verbatim and analysed using Giorgi’s 5 concrete steps of the human scientific phenomenological method (1997).

Findings revealed themes that drew attention to the fundamental aspects of the experience. These were:

1. Necessity of communication
2. Retaining normality
3. Psychosocial discomfort
4. Painful procedures
5. Fear of the unknown
6. Relationships with staff

Practical recommendations draw attention to the organisational support required for staff expected to care for these patients in the ward environment. This involves the introduction of evidence based guidelines and competency based care to promote the acquisition of skills required to perform those essential tasks such as suction and stoma care to a high standard. Protected, formalised skills based teaching is seen as fundamental in this process. Patients’ felt confident in nursing staff that were able to demonstrate proficiency with such tasks and this is seen as crucial when one considers that the tracheostomy tube is a new experience for patients.

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Introduction

Patients require the insertion of tracheostomy tube for a variety of reasons including the facilitation of weaning from
mechanical ventilation within the intensive care unit (ICU). There is unconvincing evidence (Griffiths et al., 2005) that early tracheostomy tube placement may markedly reduce duration of ventilation and shorter stays in critical care and the advent of the Tracman trial (2008) explores this further. This completed multicentre, unblinded, randomised controlled trial investigated early versus late tracheostomy tube placement in the critically ill and is to be published imminently.

While it can be argued that reduction in ICU length of stay has clear advantages for the cost of and quality of care, it is uncertain what impact this intervention has on the whole patient, their experience of being critically ill and any issues during recovery. This illustrates an imperative to investigate peoples’ experience of these tubes so that they may be represented in parallel with the findings of the above studies to gain a human understanding of what has become widespread use of these artificial airways. Nursing staff on the ward and critical care areas are exposed to these tubes currently yet there is little information available regarding the lived experience of tracheostomy.

This information is critical for nursing knowledge given the understanding that the heart of nursing people with any illness is consideration of their needs based on the effect that the illness has on them (Cronin and Rawlings-Anderson, 2004). Therefore investigating a nursing concern, what people have to say about their tracheostomy, permits us to better understand these patients needs and provides a cornerstone for their holistic care along with the practical skills required to care for these people to a high standard.

Literature review

An integrated search for literature was undertaken to determine what is already known about tracheostomy and, in particular the patient experience of these artificial airways. An electronic search was performed of the following databases:

- CINAHL—Cumulative Index to Nursing and Allied Health Literature
- Medline
- BNI—British Nursing Index
- EMBASE Psychiatry

Secondary references were investigated as well as networking with colleagues within the multi disciplinary team and a nationally acclaimed expert in the area of tracheostomy tubes.

Much of the popular nursing literature focuses on maintaining a safe environment with the discussion of suction technique, infection control, humidification of inspired oxygen and cleaning the inner cannula and tracheal stoma (Griggs, 1998; Burglass, 1999; Woodrow, 2002; Docherty and Bench, 2002; Moore, 2003). While others discuss these issues, they also include the relevance of psychosocial issues such as anxiety, communication and expression of sexuality (Hooper, 1996; Day et al., 2002; Bond et al., 2003; Higgins, 2005). These are excellent “how to” guides of the complex care of a person with tracheostomy however they do not give a direct patient account of the experience of these tubes.

There is some evidence that pointed to the lived experience of tracheostomy within critical care however it tended to be unspecific to the tube itself, rather the experience of being critically ill in general. This evidence may be summarised into four broad categories:

- Memory and recall (Green, 1996; Russell, 1999; Stein-Parbury and McKinley, 2000; Adamson et al., 2004; Magarey and McCutcheon, 2005; Lof et al., 2006).
- Transfer out of critical care (Odell, 2000; McKinney and Deeny, 2002; Strahan and Brown, 2005).
- Psychological disturbance (Granberg et al., 1998, 1999; Maddox et al., 2001; Roberts and Chaboyer, 2004).

While there is mention of tracheostomy within sample characteristics, there is little direct description from the participants therefore a discussion of this work is warranted to support the need for this study.

The theme of communication repeats itself throughout the previously mentioned work though this is appears to be limited in relation to tracheostomy. Johnson (2004), in a report of one theme from a phenomenological study accounts that her participants’ inability to communicate during long term mechanical ventilation was anxiety provoking. While she does not specify whether her participants had a tracheostomy tube in situ, it is likely that some did as all had been ventilated for more than seven days. Magnus and Turkinon’s study (2006) to investigate patient and staff communication in the ICU revealed a disparity between these groups perception of communication. Although they do not state how many of their participants had a tracheostomy tube (n=8), they go on to highlight that 6/8 did not realise that this tube was temporary suggesting that at least six participants did. At least two participants report the tracheostomy tube as being a barrier to communication. They conclude that failure in communication due to the inability to verbally communicate results in feelings of frustration and powerlessness and it is noteworthy that staff skills were reported to be a key factor for success in communication.

This would appear to confirm previous findings (Jablonski, 1994; Haestinsdottir, 1996). Jablonski (1994) also reports that those with tracheostomy suffered intermittent discomfort, dysphagia and burning which supports a previous study by Bergbom-Engberg and Haljamae (1989), where people reported agony, anxiety, fear and panic as significantly related to an inability to talk. They also found that tracheal toilet and suctioning became a more annoying problem as ventilator treatment wore on and that tracheal suctioning was recalled as discomforting for 30% of their respondents. These findings were not specific to tracheostomy tube, rather those who were mechanically ventilated in general. The reviewed literature does not clarify any differences in the experience of endotracheal tube (ETT) or tracheostomy tube although Johnson et al. (2006) mention that the ETT caused gagging and choking and that suction caused great discomfort for one participant. Uncertainty, anxiety and fear related to ineffective communication caused by the ETT are...
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also discussed in this study which is a further report from the same study by Johnson (2004).

Donnelly and Wiechula (2006) investigated the lived experience of a tracheostomy tube change, a procedure not uncommon within critical care areas. They depict their informants’ descriptions of this procedure and established that the need to maintain communication and the ability to speak was significant for their participants. Loss of voice for one of their participants was more of an issue than physical discomfort and they go on to discuss the challenge to the person’s self-concept when the ability to represent oneself is lost in this way.

By inductive reasoning, we can assume that those with tracheostomy do indeed have problems with communication and discomfort during procedures such as tracheal suction. However it is unclear whether these are their only concerns and whether this extends to the ward environment given the assumption that they will be interacting more with their caregivers. Aside from Donnelly and Wiechula (2006) none of the above studies describes directly the experience of tracheostomy tube as lived by our patients. It is therefore argued that the experience of this artificial airway in the context of an acute illness be explored further to enable our understanding of what it is like to live and breathe through this tube.

**Purpose of the study**

The purpose of this study was to overcome this gap in the literature by describing the experience of tracheostomy tube as lived by a group of people who had this tube inserted as a part of their critical illness or as a procedure related to an acute event.

**Methodology**

This study concerns itself with gaining descriptions from the experience of the tracheostomy tube rather than quantifying the experience through measurement or searching for explanations. I share van Manen’s understanding (1990) that from a human scientific perspective, methodology refers to a philosophical framework and the fundamental assumptions and principles of a particular perspective. The philosophy of phenomenology offers such a framework. Phenomenology tries to give a direct description of our experience as it is without taking into account any casual explanations (Merleau-Ponty, 1962).

The phenomenological attitude has evolved to several different methodological approaches within nursing inquiry and would appear to answer many of our nursing questions that cannot be made clear by other means (Madjar and Walton, 1999). The aim of phenomenological investigation is to expand our understanding through first hand description of the way things present themselves to us in and through experience (Sokolowski, 2000). This approach can therefore allow the dynamic, holistic and individual aspects of the tracheostomy tube to be explored and to help capture the experience in its entirety.

The specific approach used here is found in what Giorgi (2000) titles “scientific phenomenology”, wholly appropriate here given the purpose of science is to produce a body of knowledge in an organised way (Parahoo, 1997; van Manen, 1990). This study is scientific in the sense that it seeks to gain knowledge for nursing as a human science using an organised approach based on the fundamental principles of phenomenology. Merleau-Ponty’s work and thinking was used throughout this study. His phenomenological approach sees the body as the self and that consciousness is embodied. This embodied consciousness as the self is the subject of perception in that we perceive our world through our body (Merleau-Ponty, 1962).

Perception allows us to experience our world. The qualities that we glean from seeing, touching or hearing something gives us our sensation of it and underpins our experience of it. Experience is not only sensing an object, it is the quality perceived from the associated sensations of it. Perception of the same object can give rise to different experiences depending on how and when it is perceived and from what standpoint. Thus we come to an understanding of his way of looking at things as a foundation for this study. There are unquestionably several views from the different perspectives of the phenomenon of being acutely unwell with tracheostomy tube. These several views may give rise to similar experiences; therefore a commonality of experience may enable our understanding.

**Participants**

Three adults participated in this study of which two were male. All had been hospitalised within an acute NHS Trust in the United Kingdom. Table 1 summarises participant characteristics and provides some context to the findings. Potential participants were initially identified as those who had a tracheostomy tube inserted within the ICU. However the complexity of surviving a critical illness involving

<table>
<thead>
<tr>
<th>Name</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Reason for tracheostomy</th>
<th>Length of time with tracheostomy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angela</td>
<td>Female</td>
<td>White British</td>
<td>Facilitate weaning from mechanical ventilation following severe sepsis</td>
<td>36 days</td>
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<td>Barry</td>
<td>Male</td>
<td>White British</td>
<td>Facilitate mechanical ventilation for type II respiratory failure</td>
<td>14 days</td>
</tr>
<tr>
<td>Colin</td>
<td>Male</td>
<td>White British</td>
<td>Symptomatic relief of tracheal compression from thyroid tumour</td>
<td>Permanent</td>
</tr>
</tbody>
</table>

a Names coded to maintain confidentiality.
lack of recall, distressing memories is well documented (Green, 1996; Hupey, 1999; Stein-Parbury and McKinley, 2000; Papathanassoglou and Patiraki, 2003; Adamson et al., 2004). This limited recruitment to those able to articulate and reflect on their experience therefore a decision was made to broaden inclusion to those who had a tracheostomy tube inserted as an unplanned or semi-planned procedure. This is in keeping with the purposive sampling method used where the sample may be selected according to the potential participant’s knowledge on the research topic as the study progresses (Morse, 1991; Coyne, 1997). The sample was small, though consistent with the phenomenological approach where the sample tends to be small due to the large amount of verbal data that is analysed (Polit et al., 2001).

Ethical issues

This study operated with the principle of doing no harm to others, a concern highlighted by Jones and Lyons (2003) who discuss the difficulties of researching the experience of being critically ill. Professional standards of the Nursing and Midwifery Council NMC (2004) and the Royal College of Nursing RCN (2004) also guided this study. Approval to proceed was granted by the Local Research Ethics Committee in parallel to organisational approval in terms of research governance required by the Trust were the research took place. Post-interview counselling was offered as a means of reducing the harm caused by the revisiting of potentially distressing memories or the unpleasantness of remembering at all.

Information about the study was given verbally with and without significant others’ present. Written information was offered in simple everyday language, in large font with double spacing given the concerns that Jones and Lyons (2003) have regarding the poor concentration and focus of some survivors of a critical illness. Consent was both written for and given verbally which was recorded at beginning of interview. Interviews were conducted in private either at the participant’s home or in a well ventilated room with a closed door on a ward. Audio tapes were coded immediately following interview, were kept in a locked cupboard and heard only by the researcher.

Data collection

Data was collected between July 2007 and November 2007 using semi-structured, audio taped, face-to-face interviews. Previously reported sensations related to tracheostomy tubes cited in the literature provided the framework to give specific descriptions of these. For example, while Oermann et al. (1983) describe physical sensations following tracheostomy as reported by their sample of 34 patients a fuller description of these is not detailed. These sensations provided a basis in which to build a semi-structured interview schedule so that fuller descriptions could be elicited. To capture the experience in its entirety, general, open ended questions were included to allow discussion outside of these boundaries. The purpose of this semi-structured approach suits Merleau-Ponty’s thinking. There is no tracheostomy tube in isolation but it is there in relation to the many aspects of being acutely ill. Thus the situated context of the experience was considered while harvesting thoughts, memories and feelings from that period of these peoples’ lives. Participants were interviewed once each and interviews ranged from 48 to 63 min.

Data analysis

Collection of verbal data is the first step in Giorgi’s 5 concrete steps of the human scientific phenomenological method (Giorgi, 1997) (Box 1). He believes that certain modifications from the philosophy of phenomenology have to be introduced for scientific analysis. This thinking has brought forth his method to provide structure and allow a systematic and rigorous approach in terms of phenomenological inquiry. While the steps are linear in progression there was the same revisiting of things in a cyclical fashion that is championed by van Manen (1990), Munhall (2001) and Giorgi himself (1997, 2000, 2005). It is this way of delving in and out of each step and back again that is consistent with the principles of phenomenological methodology in that this approach, while using pre determined steps, has not been totally governed by the way that they have been sequenced.

The audio taped interviews were transcribed verbatim as soon as was possible following the interview itself. The transcripts were read at first in isolation of the audio tape and then read while listening to the audio taped interview. While Giorgi (1997) does not specify how many times one must re-read the transcripts ‘many times’, this was done until a sense of the descriptions was understood. A slower re-reading of the transcripts enabled a breaking up of the data into parts; ‘meaning units’ were discriminated from the descriptions using the open attitude gained through the phenomenological reduction described below. These meaning units are in the everyday language of the participants and are derived from their descriptions relating to the sensations of their tracheostomy tube. These meaning units (summarised in Table 2) were further transformed to describe them as broad themes from a nursing perspective (step 4). From a phenomenological view, the experience of their tracheostomy is entwined within the whole experience of being acutely ill, therefore to remain true to their descriptions, meaning units were derived from other relevant data. These are summarised in Table 3, are separated for convenience and mentioned here because they are part of the whole experience.

Box 1 Giorgi’s 5 concrete steps of the human scientific phenomenological method (Giorgi, 1997).

1. Collection of verbal data
2. Reading of the data
3. Breaking the data into some kind of parts
4. Organisation and expression of the data from a disciplinary perspective
5. Synthesis or summary of the data for purposes of communication to the scholarly community
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<table>
<thead>
<tr>
<th>Category</th>
<th>Meaning unit(s) (step 3)</th>
<th>Broad theme (step 4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>Anger (2)</td>
<td>Necessity of</td>
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<tr>
<td></td>
<td>Destructive</td>
<td>communication</td>
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<tr>
<td></td>
<td>Horrible</td>
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<td></td>
<td>Frustrating (2)</td>
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<td></td>
<td>Concern</td>
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<td></td>
<td>Relief</td>
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<td></td>
<td>Surprise</td>
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<tr>
<td>Coughing</td>
<td>Minor discomfort</td>
<td>Retaining</td>
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<td></td>
<td>Annoying</td>
<td>normality</td>
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<td></td>
<td>Irritating</td>
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<td></td>
<td>Frightening</td>
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<td></td>
<td>Knackered</td>
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<tr>
<td>Suction</td>
<td>Horrible</td>
<td>Psychosocial</td>
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<td></td>
<td>Disgust</td>
<td>Discomfort</td>
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<td></td>
<td>Relief</td>
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<td></td>
<td>Painful</td>
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<tr>
<td>Swallowing, eating &amp; drinking</td>
<td>Spiteful</td>
<td>Painful procedures</td>
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<td></td>
<td>Very pleased</td>
<td></td>
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<tr>
<td></td>
<td>Grateful</td>
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<tr>
<td>Reason for tracheostomy tube</td>
<td>Frightening</td>
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<tr>
<td></td>
<td>Scary</td>
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<tr>
<td></td>
<td>Grateful</td>
<td></td>
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<tr>
<td>Realisation</td>
<td>Frustrating / Good v bad</td>
<td></td>
</tr>
<tr>
<td>Decannulation</td>
<td>Scar</td>
<td>Fear of the unknown</td>
</tr>
<tr>
<td>Stoma care</td>
<td>Spiteful</td>
<td></td>
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<tr>
<td></td>
<td>Tender</td>
<td></td>
</tr>
<tr>
<td>Positive experiences</td>
<td>Grateful (2)</td>
<td>Relationships</td>
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<tr>
<td></td>
<td>Confidence</td>
<td>with staff</td>
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<tr>
<td></td>
<td>Knowing the wrinkles</td>
<td></td>
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<tr>
<td>Negative experiences</td>
<td>Patience</td>
<td></td>
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<td></td>
<td>Bloody cheek</td>
<td></td>
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<tr>
<td></td>
<td>Nasogastric tube insertion</td>
<td></td>
</tr>
<tr>
<td>Unreal experiences</td>
<td>Quite ridiculous</td>
<td></td>
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</tbody>
</table>

A rigorous phenomenological approach

The trustworthiness of this study may in part be determined through the use of criteria for qualitative data (Lincoln and Guba, 1985):

- **Credibility.** Participants with specific experience of tracheostomy tube were chosen and a rigorous phenomenological approach used to gain descriptions of their experience. The term rigor is understood here to pertain to a robust and systematic approach used within the epistemological and theoretical principles of phenomenological inquiry, a convincing argument put forward by Rolfe (2006) and a belief pre dated by van Manen (1990). Three phenomenological principles were used so as not to sever the spirit of this study from its philosophical foundation. These were:

  - **Description.** Descriptions in this study are obtained from the participants from the perspective of their world or their experience.

  Assuming the phenomenological reduction. The attitude of the phenomenological reduction allowed me as a researcher in this study to place myself outside of my "natural attitude". Placing myself outside of my own natural attitude after 12 years of critical care nursing was not beyond possibility with the help of two phenomenological principles, the use of which was essential given that the method used for data analysis does not require the use of peer or member checking.

  The first was to "bracket" my own past knowledge and experience of tracheostomy to examine my own prejudices during data analysis. This takes the participants’ memory as what happened precisely as described (Dowling, 2007) and allowed me to be truthful to what they said without my own presuppositions influencing how I analysed what they had to say. A "reflective diary" suggested by Wall et al. (2004) was helpful during data analysis to remind myself to be ever present to the descriptions. The second principle was to withhold any existential claim which means to consider the description as precisely the concrete experience presenting itself. That is, when interview-
ing, reading transcripts and listening to the interviews I was present to how the participants’ construe their situation as their reality rather than any other perspective of events, including my own.

A search for scientific essences. While the philosophical method of phenomenology seeks universal philosophical essences, Giorgi (1997) emphasises that his human scientific method cannot be universal as what is unique is not a universal truth as such but depends on a particular disciplinary perspective. The search for “scientific” essences in this study relate to a nursing perspective where what is of scientific interest is peoples’ experience of tracheostomy tube and how this impacts on their life.

• Dependability and confirmability. This study was an academic endeavour; the transcripts and reflective diary were under scrutiny of my research supervisor. An audit trail of sorts was evident throughout this study as the verbatim transcripts and reflective diary were submitted with the final dissertation which was checked by a second marker. The addition of tables to illustrate participant characteristics and how meaning units were derived demonstrates transparency within my approach and therefore an auditable trial of decisions made throughout data analysis.

• Transferability. I have submitted sufficiently rich descriptions in order to have resonance with those caring for people with tracheostomy tubes in acute settings and perhaps those working in long term residential type care also. Only they can decide whether my findings are applicable to those areas.

There is however some tension with the exclusive use pre-set criteria in this way. My use of one of many approaches and a belief that reality is constructed through several viewpoints determines that the trustworthiness of this study may go beyond the above criteria. While I can demonstrate trustworthiness in this way, I would like to think that it is also revealed within the writing of the text where the quality of this study is also subject to your keen insights and judgement as a reader (Emden and Sandelowski, 1999; Sandelowski and Barosso, 2002; Rolfe, 2006).

Findings and discussion

Six broad themes were derived from the data analysis and these convey an understanding of what it is like to live and breathe with a tracheostomy tube.

Necessity of communication

This theme was central to all of the participants’ experiences. The meaning of verbal communication as being a fundamental aspect of social interaction appears to be clear. This resonates clearly with the findings of Donnelly and Wiechula (2006) when they describe that the ability to speak is a fundamental need for most of us. Speaking allows us to be explicit, be understood and allows others to recognise us as the people that we are. Colin was surprised but pleased to be able to speak particularly once he was able to use a speaking/phonation valve.

Colin, “I was very, very pleased! …when you gave me this (speaking valve), one hell of a difference!”

In contrast to this, Barry and Angela relate very different accounts. Both were offered a common, alternative form of

| Table 3 Meaning units of other relevant experiences. |
|-----------------|-----------------|-----------------|
| Category         | Meaning Unit(s) (step 3) | Broad theme (step 4) |
| Nasogastric tube insertion | Horrible (2) Spiteful Painful | Painful procedures |
| Unreal experiences | Disconcerting Slightly odd Weird Frightening Pleasant | Acceptance |
| Physical sensations | Disconcerting | Relationships with staff |
| Care | Knowing the wrinkles Grateful (2) | Retaining normality |
| Complications | Not getting better quickly | |
| Recovery | A small victory | |
| Mobility | Spiteful Disconcerting | |
| Feeling down | Longing | |
The lived experience of tracheostomy

Barry, "...the first thing that I do remember about the tracheostomy was towards the end... a great frustration about being unable to talk."

"...I couldn't control my writing which increased my frustration and I can remember throwing it away, across the ward I think..."

Angela, "...my writing was all over the place...I think I was destructive...no one listened; I wanted to lash out and break things. It was horrible!"

Much in the same way described by Johnson et al. (2006) weakness and fatigue impaired their non-verbal communication. A possible residual effect of sedative drugs and/or the state of the illness may also have interfered with the ability to communicate in writing (Jablonski, 1994). A lack of voice either verbal or non-verbal was frustrating for them and this manifest as anger which has been previously reported in those who have been mechanically ventilated (Jablonski, 1994; Hafsteinsdottir, 1996; Magnus and Turkington, 2006).

Barry describes finding it easier to use a picture/alphabet board to communicate,

"...and presented with this and I think that worked a little better."

This has been recommended as an "assistor to successful communication" (Magnus & Turkington, 2006, p. 175).

Angela also describes the apathy reported by Hafsteinsdottir (1996) when her participants gave up trying to communicate because alternative forms had failed, "...because I couldn't communicate, sometimes I didn't bother. I just felt that well, 'I'll just lay here, I can't really be bothered'...and that's what I done, just switch yourself off with things'.

Retaining normality

This theme is situated within the participants' responses relating to deviations of normal communication, coughing, swallowing and diet. This is a similar notion to Johnson et al. (2006) who describe a theme for their participants as living in an unfamiliar body where they told of living in a body that did not respond in its usual or normal way. Barry described an experience related to tracheostomy that he recounted as a part of a collection of vivid, unreal experiences.

"...I mean in this situation, one has some very weird...I wouldn't call them dreams necessarily, it's almost reality...a recurring theme is that there is another doctor whom I imagined my wife was going off with which is very unfair! That doctor had a tracheostomy! He had a hole in his throat...quite ridiculous!"

He also described an alteration in his coughing and swallowing that is so subtle that he is unclear whether the tracheostomy tube caused this or whether it already existed.

"...very, very occasionally I think things are more prone to go down the wrong way than er maybe they should or they did...you tend to say oh, tracheostomy...(Coughs and then laughs) there you are!"

Colin found it annoying and irritating to be persistently coughing because of the need to change the inner cannula frequently. This left him tired, particularly during the day as he had been awake with this coughing in the night.

"The inconvenience of tube out, washing it, brushing it all out, putting it back in and it starts me off coughing again! Sometimes...and sometimes I use the nebuliser and it loosens it all up and I start coughing all over again!"

Due to a constant sore throat and mouth ulcers, Angela had enormous problems eating and drinking and although at time of interview this had resolved, she remained fearful of a recurrence that would disrupt her return to a normal diet.

"I can't bear the thought of having a sore mouth again...I get frightened that it will because that's the worst thing, not being able to breathe and not being able to swallow..."

It would appear that loss of normal body functions albeit temporary has an ongoing impact longer than when the physical discomfort has ended. Johnson (2004) reported that reclaiming the everyday world for critically ill, mechanically ventilated people involves gaining a sense of control or power over the environment to regain life as it was before they became unwell. Perhaps these people with tracheostomy tube have a need to have some form of normality in their life and while this may not be a return to their life as previously lived, control over the things that are important to them may enable this.

There is implicit understanding from the participants’ descriptions that patients experience procedures, events and alterations in body image rather differently than healthcare professionals do. This supports Donnelly and Wiechula (2006) and their contention that it is unlikely that our patients consider anything as just another task.

Psychosocial discomfort

This theme derives from how one participant viewed the procedure of suctioning but also relates to how other effects of the tracheostomy tube impact on our patients’ daily lives.

While she did not associate suctioning with the physical discomfort or choking described by others (Bergbom-Engberg and Haljamae, 1989; Jablonski, 1994; Johnson et al., 2006), Angela felt relieved that it was coming out of her chest. She describes her relief as having something disgusting being taken away rather than the relief at clearing phlegm from her chest to make it easier to breathe.

"It well it's a horrible feeling ... knowing all this muck is being taken from your throat, knowing that it's in there... I was grateful that the more they could take it away, the better I would be."

Colin described his persistent coughing at night as leaving him tired and this affected his life during the day. This prevented him from engaging with people as he once did as he had little energy leaving him to withdraw from social encounters that he once would have welcomed.
"Last night was nearly an hour and I was sore and aching! ...it wears off but then I’m [very tired]"

Barry’s tracheostomy stoma took several weeks to heal which worried him and also made him a focus of attention in his community which he began to feel uncomfortable with.

"...you walk around with this plaster on your throat and you perhaps you would rather people didn’t ask you questions about it"

These issues are not highlighted in previous studies which is unsurprising given that their focus was on mechanical ventilation rather than life after critical care. Aside from the recognised physical sensations associated with tracheostomy tubes, there remains the potential experience that our patients are aware of and suffer disgust, revulsion and loathing of their own pathophysiological processes even though those of us caring for them regard these as ‘‘normal’’ during our working day.

**Painful procedures**

Aside from her mouth ulcers, Angela described dressing of the tracheostomy stoma as painful.

"Oh that was spiteful yeah! That was very sore that was!"

Colin had similar experiences but also developed retching during persisting coughing episodes which made his stoma painful.

"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"

Apart from Arroyo-Novoa et al. (2008) who investigate pain related to tracheal suctioning, there is little description of pain related to procedures though these comments support the sensations reported by Oermann et al. (1983). There is a sense that pain appeared to be accepted as a consequence of the illness for the participants in this study, a part of the ‘‘tracheostomy package’’. The nasogastric tube insertion procedure or stoma pain related to the dressing procedure as examples were endured miseries in the world of recovery where nutrition, infection surveillance and prevention were essential to survive. Responses within this study suggest that tracheostomy dressings are potentially painful, coughing for people with these tubes causes discomfort and that we should communicate this to our patients in preparing them for procedures.

**Fear of the unknown**

While Barry had little recollection of the acute onset of his illness and no memory regarding the reason for the tracheostomy tube, Angela could remember being short of breath as a frightening experience.

"...I was very, very bad at breathing...I know that was my last resort...It was scary but I was very weak anyway"

Colin became concerned that his cough is so strong that he could dislodge the tube, a frightening occurrence which had almost happened previously.

"All I’m worried about is coughing this thing out, (indicates the tracheostomy tube) which I nearly did!..."

Barry faced uncertainty while his stoma took around six months to heal. His concern over this is evidenced by his description of seeking help from his district nurse, pharmacist and GP.

"...it wasn’t really a problem at that time but I think I’m a bit of concern about how long this was going to go on for. And I probably did go back to the local surgery once or twice to get their opinion but it did clear up..."

Fear and anxiety because one is unable to breathe would appear an obvious assumption. While uncertainty has been described in those mechanically ventilated (Hafsteinsdottir, 1996) this was related to the realisation of being intubated and being unable to communicate rather than uncertainty over what we may consider as minor inconveniences. 6/8 of Magnus and Turkington’s (2006) participants reported being uncertain whether their tube was temporary indicating a similar fear of the unknown. The tracheostomy tube was a new experience for these people and as such symbolised a fear of the unknown caused by uncertainty and worry. This was characterised not only by the battle for breath but the long term anxiety over the frequency of the tube changes, length of wound healing and the dread of being without a precious airway that sustains life.

**Relationships with staff**

All participants described positive and negative experiences with staff though these were often related to care that they received rather than the tracheostomy tube specifically.

Colin—"...she was good!...suctions, just looking after me in general, she was good. A lot of them are in there..."

"Sometimes they come straight in but other times, 'I'll be back in a minute'. Yeah, one hour! They got so much to do, they can’t cope with everybody."

Angela—"She used to come in, to your room and if you was reading she would pull the thing off you, if it was telly, she would push the telly out of the way...take the thing out of your hand and I thought, ‘bloody cheek!’"

Barry— "...one of the most useful people that I met was an auxiliary...I just thought she was very helpful, she seemed to know all the wrinkles."

Patient relationships with staff can be complex and reliant on a number of factors, not least open communication. Good relationships with staff were characterised by confidence and trust. This confidence extended to those who were seen as competent and skilled with procedures but also the manner and sensitivity in which they performed them. While Magnus and Turkington (2006) discuss this impact within the ICU, this understanding also extends beyond critical areas where staff are expected to provide a quality of...
The lived experience of tracheostomy provided the motivation to produce an evidence based policy "stepped down" from critical care or be admitted through cheostomy tubes on the ward environment whether they be used to enhance the current care of people with training needs in communication.

Implications for future research and care

The findings regarding communication, normality and relationships with staff have similarities with those who have described the experience of mechanical ventilation although these studies are inconsistent or not explicit when mentioning tracheostomy within their sample characteristics. Future research could use similar methods to explore the experience of communication in people with tracheostomy on the ward environment further and this may shed light on this particular theme to add to others findings (Donnelly and Wiechula, 2006). The same could be done for any of the other themes and this would add further to our understanding of the experience of the tracheostomy tube. Future research could also expand on Magnus and Turkington’s work (2006) where patients with tracheostomy and staff perceptions of communication are explored further. This may yield more information regarding what they suggest are staff training needs in communication.

The information contained within this study has been used to enhance the current care of people with tracheostomy tubes on the ward environment whether they be “stepped down” from critical care or be admitted through the emergency department with an existing tube. This work provided the motivation to produce an evidence based policy document to guide the care of this group of people and has significantly added to the evidence regarding psychosocial care within the policy. Staff competencies regarding care of the person with tracheostomy are currently being developed in parallel to this to ensure that specific skills of ward staff are of a minimum standard. Nursing staff from specific wards where people with tracheostomy tube are admitted are now provided with mandatory teaching to give them the foundation of theoretical knowledge to support this and the information taken from this study is included on this day.

Recommendations generated from this study for future nursing practice are summarised in Box 2. Organisational support to ensure not only that risk is managed but to sustain a high quality of care for these people is presented in Box 3.

Box 2 Recommendations for practice: nurses caring for patients with tracheostomy tube.

- Acknowledge the lack of voice to the patient
- Engage the patient with alternative methods of communication
- Be mindful that writing is an impaired skill with some survivors of a critical illness
- Be consistent with using the same alternative method of communication
- Anger and frustration may be a sign that communication is not effective
- Learn how to suction and dress the stoma site effectively
- Be aware that the tracheostomy tube presents the person with a new and uncertain experience—the patient does not view suction and stoma dressing as “just another task”
- Prepare patients with information about procedures such as suction, stoma dressings and nasogastric tube insertion as being potentially painful and psychosocially uncomfortable.
- Allow for privacy when suctioning
- Leave the call bell within reach and answer with minimal delay
- Regularly assess need for regular analgesia when tracheostomy tube in situ.
- Offer the option of own clothes/bed garments

Box 3 Recommendations for practice: organisational support of staff caring for people with tracheostomy tube.

- Develop care of tracheostomy competencies
- Provide allocated time for the education of theory and skills for ward staff caring for people with tracheostomy tube to support competency development
- Ensure tracheostomy guidelines are in place
- Allow clinical support and mentorship for competency development
- Introduce patient acuity scoring system Trust wide to ensure safe ward care of people with tracheostomy tube and revise staffing ratios accordingly

Conclusion

Nurses in both critical care and ward environments can be influential in determining how people with these tubes are cared for effectively in the holistic sense. Adequate communication as a minimum can involve a creative, consistent, patient centred approach that involves the patient choosing the best approach for them. Demonstrating proficiency with common skills such as suction and stoma care can engender confidence from the patient and this is seen as crucial when one considers that the tracheostomy tube is a new experience for patients. While Diagram 1 may misrepresent the complexities of the interrelatedness of the experience of tracheostomy, it does enable some understanding of how different aspects of this experience interlink and have meaning with each other.

The essence of the lived experience of tracheostomy within this study therefore is not a single thing or entity rather the interrelatedness of each theme and how this comprises the totality of the experience. The lived experience of living and breathing through the tracheostomy tube is not so much the sum of its parts but a complex blend of these parts and these parts evolve from each person’s perception of the tube against the background of their illness and recovery. This represents a new experience for these people whether they are faced with the unknown, attempt to find new ways...
Diagram 1  Interrelatedness of themes of living with tracheostomy while acutely ill and during recovery.

to communicate, have to put up with the pain associated with it and/or come to terms with a new self-image.

Limitations

This study formed the dissertation module of a recent M.Sc. (Nursing). Recruitment was limited to time constraints, availability of potential participants willing to take part and therefore the number was small.

References


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The lived experience of tracheostomy


