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Research article

Quality of life improves for tracheostomy patients with return of voice: A mixed methods evaluation of the patient experience across the care continuum

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ABSTRACT

Objectives: A tracheostomy tube can profoundly impact ability to communicate. The impact of this on patients' self-esteem and quality of life in the care continuum from the intensive care unit to after decannulation has not been reported. Therefore, the aim was to investigate the patient-reported experience regarding change in communication function, communication-related self-esteem and quality of life.

Research design: A mixed methods approach was utilised. Quantitative data were obtained using validated measures of self-esteem related to communication-related quality of life and general health. Data were measured before return of voice, within 48 hours of voice return and six months after tracheostomy decannulation. Qualitative data were collected through structured interviews six months after tracheostomy.

Results: Seventeen participants completed the study. Four themes emerged from the interviews: *It's hard communicating without a voice; What is happening to me?; A storm of dark emotions and More than a response...it's participating and recovering*. Significant positive change occurred in six items of self-esteem related to communication from baseline to return of voice. Overall, positive changes in quality of life scores were observed.

Conclusions: Voice loss with tracheostomy significantly affected participants' abilities to effectively communicate their care and comfort needs. Restoration of voice occurred in conjunction with patient-reported improved mood, outlook and sense of recovery.

Implications for Practice

- Early communication rehabilitation is vital in the intensive care unit, as loss of voice from tracheostomy can negatively affect patient's mood and quality of life.
- Restoration and facilitation of communication for patients are important because they allow patients to participate in their healthcare.
- Provision of education to healthcare practitioners addressing the psychological and social implications of voicelessness/inability to communicate within the intensive care unit is needed, as well as strategies to facilitate an accessible communication culture for voiceless patients.

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Introduction

Patients receiving mechanical ventilation via a tracheostomy often experience a period of voicelessness due to tracheostomy cuff inflation and the diversion of expired breath from the larynx. The duration of voicelessness is variable and may be temporary or permanent (Happ et al., 2004). In a metasynthesis of 12 qualitative studies examining patients' perceptions of voicelessness during mechanical ventilation (Carroll, 2004), only three studies specifically examined the communication experience. Patients perceived that they were misunderstood and disempowered during healthcare interactions. Such perceptions led to feelings of loss of control, unmet needs, dependency, dehumanisation and negative emotions.

More recent qualitative studies have shown that voicelessness also led to changes in communication dynamics (Carroll, 2007) that were not effectively addressed by alternative forms of communication (Foster, 2010).

The direct impact of loss of voice on quality of life (QOL) with critically ill tracheostomy patients is unknown. Hofhuis et al. (2008) reported general QOL in 451 patients admitted to the intensive care unit (ICU). A significant decrease in QOL domains included role limitation due to impaired emotional, physical and social functioning and in general and mental health issues. Phenomenological research into the experience of prolonged mechanical ventilation via a tracheostomy tube demonstrated that loss of effective communication, specifically absence of voice, was traumatic for patients due to an inability to relay intended messages to staff and that strategies such as family support and praising from health care professionals assisted recovery (Arslanian-Engoren and Scott, 2003). However, these interviews were conducted on average, two years after hospital discharge and therefore introduce possibility of recall bias and acceleration or dampening of emotions experienced at the time of mechanical ventilation.

Communication breakdown increased patient vulnerability for delayed responses to care/comfort needs (Hemsley et al., 2001). Therefore, speech has been identified as an important domain to measure in QOL in people who are mechanically ventilated (Pandian et al., 2015) and is an emerging area of ICU research. Although QOL has been examined in critically ill patients, the direct experience of voice change in patients with tracheostomy and associated QOL at recovery time points within ICU and beyond hospital discharge in a single cohort has not been previously reported. Furthermore, this issue has not been examined simultaneously with qualitative and quantitative approaches to provide a holistic understanding of patient outcomes. A mixed methods research approach at various time points including during ICU admission and six months after tracheostomy decannulation may provide new insights into this complex area of patient care. Data taken at varied points accommodate both immediate reporting and delayed recall in which experiences may be described in varied ways and therefore more richly understood.

The aim of this study was to investigate the patient-reported experience of tracheostomy tube placement over time in regard to change in communication function, self-esteem and health-related QOL from ICU to six months after tracheostomy decannulation and discharge home.

Methods

A mixed methods approach was used to address the aims of the study. A qualitative descriptive research design was utilised to address patient-reported impacts of impaired communication during and after ICU admission. Qualitative methods included structured participant interviews (six months after tracheostomy decannulation) and analysis of themes. Quantitative methods were used to address change in scores of patient-reported outcomes of self-esteem related to communication and general QOL.

Recruitment

Participants were purposively recruited from a cohort (N = 30) enrolled in a larger randomised trial of communication intervention following a tracheostomy (Freeman-Sanderson et al., 2016b). For inclusion in the current study, participants were >18 years, had been admitted to ICU, had undergone a tracheostomy, experienced voiceless during mechanical ventilation and were English speaking. Participants were recruited from an Australian tertiary ICU. Ethics approval was given by the local health service Protocol X09-0380 & HREC/09/RPAH/643 and registered prospectively on www.ANZCTR.org.au, protocol number ACTRN12610000075088. Participants were provided with an information sheet prior to collation of data. This sheet detailed voluntary participation and research contact details if further support was required.

Assessment tools

Interview

Structured interview questions were developed by a Speech Pathologist with 14 years of practice with this clinical population. The questions addressed experiences of tracheostomy tube insertion over all time periods. The topics of the questions included: confirmation of hospital admission, communication experience in ICU, restoration of voice, and timing of intervention. Closed and open question formats allowed for a range of responses. For example, "*What was it like to lose your voice*?"; and "*Did return of voice impact your relationship with the doctors*?".

A structured interview was conducted with participants six months after tracheostomy tube decannulation. The interview was conducted via telephone and digitally recorded. One patient was interviewed face to face as she had not been discharged from hospital. The interviewer was a male physiotherapist who was experienced working with this patient population and otherwise independent from the study. An interview script was provided; however, responsive interview techniques, such as reflective listening practices, were used when clarifications of questions or responses were required.

Self-esteem related to communication-related QOL

Patient-reported self-esteem related to communication and QOL was measured with the Visual Analogue Scale of Self-Esteem (VASES) (Brumfitt and Sheeran, 1999) and general QOL was measured with the EuroQol (EQ-5D) (The EuroQol Group, 1990). The VASES (Brumfitt and Sheeran, 1999) consists of 10 items represented pictorially with a bipolar scale. The 10 items include: *not being understood/being understood, not confident/confident, cheerful/not cheerful, outgoing/not outgoing, mixed up/not mixed up, intelligent/not intelligent, angry/not angry, trapped/not trapped, not optimistic/optimistic* and *frustrated/not frustrated.* An evaluation of the scales has shown strong internal validity in populations both with and without neurological injury impacting language function (Brumfitt and Sheeran, 1999). The EQ-5D is a standardised tool to measure the patient's perception of their general health status. The tool contains a descriptive profile of five dimensions of health status (*mobility*, *self-care*, *usual activities*, *pain/discomfort* and *pain/anxiety*) and a visual analogue scale (VAS) of general health status. The VAS is a 20-cm scale anchored by 0 and 100, with a score of 0 = worst imaginable health state to 100 = best imaginable health state. The VASES and EQ-5D were collected during ICU admission (Freeman-Sanderson et al., 2016a) and were also mailed to participants six months after tracheostomy decannulation (approximately one to two weeks prior to interview).

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