



Patient Experience of Communication Options Following Tracheostomy Insertion

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Abstract

The ability to communicate allows us to share our needs, wants, feelings and experiences as well as to pass on information and connect with the people around us. For many patients with tracheostomy in the critical care setting, communication can be challenging. Difficulties communicating can result in psychological and emotional distress, which negatively impact patient experience. We report a single case study detailing the patient experience of communication with a tracheostomy. We explore the range of communication options available to patients with tracheostomy, and the implications for future considerations of care.

Keywords: Intravenous Immunoglobulin; Terrified; Dysautonomia

Abbreviations: SLT: Speech and Language Therapist; OWV: One Way Valve; PMV: Passy Muir Valve; AAC: Alternative and Augmentative Communication; GBS: Guillain Barre Syndrome; ACV: Above Cuff Vocalisation; IVIG: Intravenous Immunoglobulin; NBM: Nil by Mouth; ETT: Endo Tracheal Tube; MDT: Multidisciplinary Team.

Introduction

Communication challenges arising from the presence of a tracheostomy are common in the critical care setting. When the cuff is inflated, the larynx and upper airway are excluded from normal airflow patterns, which render the patient voiceless. Studies have shown that the loss of ability to communicate results in psycho-emotional distress, anxiety, depression, and social withdrawal as well as an inability to contribute to decisions around care [1-3].

The best option for enhancing communication for tracheostomised patients is to deflate the tracheostomy cuff and use a one-way valve (OWV). This valve redirects exhaled air through the vocal cords, allowing for restoration of voice and verbal communication. The benefits of using a OWV have been well documented in the literature. Cuff deflation and OWV use enhances trans laryngeal airflow, required for phonation, cough and swallow [4]. OWV's have been reported to improve communication, swallow function, secretion management, restore sense of taste and smell, aid lung recruitment as well as enhance quality of life [5-7].

Early identification of patients who are appropriate for cuff deflation is an essential part of the role of the Speech and Language Therapists (SLT) within the critical care setting. However, despite early SLT assessment and the introduction of OWV's, many patients may only be able to tolerate limited

periods of cuff deflation initially and subsequently experience periods of voicelessness when the OWV is removed and cuff re-inflated. In addition to this, many hospitals do not advocate the use of OWV's overnight, possibly due to a lack of research into the safety and efficacy of using OWV's during periods of sleep. A study by Diez Gross R, et al. [8]. concluded that using a Passy Muir Valve™ (PMV™ – a type of OWV) overnight was not associated with adverse cardiopulmonary events for tracheostomised patients. Despite these findings, many patients with tracheostomy are denied their voice overnight, both within and outside the critical care environment.

For some patients, it is not possible, comfortable, or safe to deflate their tracheostomy cuff, (for example if they are requiring high pressure ventilation). For these patients, other methods for enhancing trans laryngeal airflow exist in the form of above cuff vocalisation (ACV). This is a relatively new technique that utilises the subglottic port of a tracheostomy tube and delivers a low flow of gas, which travels through the trachea, vocal cords and mouth, producing audible voice for some patients. There are contraindications to ACV (examples include; airway patency concerns, stomal integrity, and suboptimal tracheostomy positioning) and it is not a viable option for all patients with Tracheostomy [9,10].

For patients who are unable to tolerate cuff deflation or ACV, alternative communication options are available. These may include mouthing, gesture, low and high technology alternative and augmentative communication (AAC) options including picture boards, alphabet charts, iPads and eye gaze machines. The use and effectiveness of such methods has yielded contradicting results. A study by Talbot S, et al. [11] concluded that the use of AAC was shown to improve satisfaction, reduce frustration and anxiety and support complex conversations for some patients experiencing mechanical ventilation. Conversely, other studies have highlighted that caregiver AAC training is minimal or absent, and therefore caregivers make little or no use of AAC options [12]. Patients themselves rate verbal communication as the only means of communication that is highly successful, with lip reading being rated the least successful [13].

In the following, we present a single case study, describing a patient's experience of communicating with a tracheostomy within critical care. The patient's experience was captured during a semi structured interview on the day prior to being decannulated. We explore the communication options considered and trialled including the key time points during the critical care journey. We explore the psychological and emotional impact of communication success and failures and consider the clinical implications of the lived experience for multi-professional teams caring for patients with tracheostomy.

Background

A 37-year-old female was admitted to hospital in February 2022 with symptoms including a headache, generalised weakness, and pins and needles in upper and lower limbs. Past medical history included asthma and adenocarcinoma of the cervix, for which she had previously undergone a radical hysterectomy and chemotherapy.

On day 2 of admission the patient developed increased limb weakness, bulbar weakness, decreased respiratory function and difficulties swallowing. She was referred to critical care and started on a course of intravenous immunoglobulin (IVIg) with a diagnosis of Guillain-Barre Syndrome (GBS). She was assessed by a Speech and Language Therapist (SLT) who reviewed her communication and swallowing which revealed mild dysphagia and dysphonia. Normal diet and fluids were recommended with a low threshold for nil by mouth (NBM) given her rapid deterioration.

By day 4 of admission the patient required mechanical ventilation via an endo-tracheal tube (ETT) for respiratory failure. On day 5, she underwent a percutaneous tracheostomy (Tracoe Twist™ size 7 cuffed tube). On the same day the patient was weaned to light sedation and used head nod, shake and blinking to communicate. By day 6 of admission the patient had completed 5 days of IVIg and reached her nadir. She had bilateral facial weakness, almost complete bilateral ptosis as well as dysautonomia. She was observed to blink in response to questions and was showing signs of emotional distress.

SLT reviews were completed on day 9 and 10 post admission. The patient was unable to complete a cuff deflation assessment and OWV placement "in line" with the ventilator tubing at this stage due to the presence of heart failure, frequent desaturations, dysautonomia and high secretion load. She was also not appropriate to trial ACV due to concerns around tracheostomy stoma breakdown. Instead, she was encouraged to continue using head nod/shake and blinking to communicate answers to "Yes" and "No" questions. She was trialled with a partner scanning alphabet chart and a partner scanning basic needs chart, which she was able to use successfully, with one eye covered (due to double vision). On the same day, bedside training was provided to her partner and nurse on how to use these AAC methods. At this point the patient had developed increased head movement and a "BigMac™" switch was ordered to provide a strategy for calling for help. (A "BigMac™" switch is inclusive technology with a large surface activation area and can be programmed to deliver a verbal output when activated).

On day 14 of admission (10 days following intubation and 9 days following tracheostomy insertion) cuff deflation and OWV assessment “in line” with the ventilator was clinically appropriate and successfully completed by SLT and Physiotherapy jointly. Initially, this method was time limited to 30minutes (of cuff down with OWV) twice daily but was increased incrementally as tolerance increased. The “Big Mac™” switch was provided to support the patient to call for help at night. On day 23 post admission, cuff deflation and OWV tolerance had increased to 12hours during the day (8am – 8pm) and was extended until 9pm in the evening to facilitate communication with in-coming night staff. Nursing staff were advised to use short periods of “leak speech” at night if communication was required. Leak speech is a technique where the tracheostomy cuff is partially or fully deflated, allowing some airflow to leak around the tracheostomy tube, through the vocal cords and upper airway. The success of leak speech may be dependent on factors such as adequate space around the outer tracheostomy tube and trachea, airway patency, and functional vocal cords [10]. By day 45 of admission the patient was tolerating cuff deflation for 24hours and using the OWV during day. She was successfully decannulated on day 46 of her admission.

Patient Experience

A semi structured interview captured on the day preceding tracheostomy decannulation revealed three main themes.

The Impact of Voicelessness Overnight

Our patient reported “night times were the worst, waking up with no voice”. She revealed that her inability to communicate resulted in high levels of anxiety but felt these were much worse overnight when she felt “terrified” that she wouldn’t be able to call for help or voice her needs, during a time where she perceived there was less patient monitoring. She reported that her anxiety overnight affected her ability to sleep, which in turn resulted in sleep deprivation, daytime fatigue and challenges engaging in rehabilitation. Our patient also highlighted the negative impact of being able to use the OWV during the day but having this option taken away at night when “my anxiety was highest”.

Challenges of using AAC

During our patient’s admission, she was provided with a range of AAC including a partner scanning alphabet chart, partner assisted picture charts, a “BigMac™” switch and yes/no flowcharts. Our patient described how the use of AAC was ‘slow and frustrating’. On the use of the “BigMac™” switch she reported “The switch was useful in being able to get help, but then the nurses were not able to lip read what I wanted help

for”. She also reported that the alphabet chart was successful with the SLT and she found it useful, but it “fell apart” when being used by other MDT/family members. She also reported members of staff reporting a dislike for using AAC and there were times where she was not given the opportunity to use them despite not being able to communicate verbally, which left her feeling “vulnerable”. She also reported frustration at how late she was given AAC options and how her anxiety was only revealed during her first SLT session whilst using the partner assisted alphabet chart. This was 5 days post tracheostomy insertion.

Impact of the MDT

Our patient described how she felt her overall treatment was impacted by her inability to communicate. She felt she was not included in discussions or decisions with the MDT and family surrounding her care. She reported a lack of explanation or reassurance when people were manipulating her tracheostomy or ventilator leaving her feeling “scared”. She also expressed feeling ‘terrified’ that members of the MDT would tell her they could not lip read or use AAC, leaving her with no communication options. Attempts to call for help were often “ignored or not heard”. She expressed that these feelings changed considerably once she was able to communicate verbally, 9 days following tracheostomy insertion.

Discussion

Studies have shown that the loss of ability to communicate in tracheostomised mechanically ventilated patients results in psycho-emotional distress, anxiety, depression, and social withdrawal. Patients report minimal control over their treatment or ability to contribute to decisions around their care [1-3]. Ineffective communication between tracheostomised patients and health care providers can result in patient-clinician interactions being focused on topics deemed important by the clinician but not necessarily by the patient. This in turn, can contribute to poor psychological and emotional outcomes. Crucially, the result of such outcomes can impede recovery and rehabilitation once critical illness resolves [14].

Our patient’s tracheostomy journey continues to highlight the challenges of effective communication despite a range of options being trialled and utilised. Multiple factors influenced these communication options at various time points in her journey (e.g., OWV vs ACV vs AAC). For example, she was initially not appropriate to trial voicing techniques (OWV, ACV) due to unstable and fluctuating medical status. In addition, at her GBS nadir she was unable to implement or use AAC successfully due to her physical and sensory limitations. Once AAC was established, her limitation became the MDT

surrounding her, who through lack of confidence, skills or knowledge struggled to use the AAC options available.

This experience highlights the importance of the MDT's communication competence for the successful implementation of an individual patient's communication options, particularly when that patient is unable to use their voice. This experience also highlights a gap in competence and confidence in MDT members utilising AAC systems. In turn, this lack of competence and/or confidence resulted in our patient being excluded from discussions about her care and receiving information that was important to her.

There was also a long delay between our patient being intubated and when she first received (and was able to successfully use) her AAC (6 days). This is a long period of time for a cognitively intact patient to be unable to communicate successfully. With a diagnosis of GBS and a rapid deterioration in function from admission, the likelihood of this patient requiring mechanical ventilation was high. Therefore, pre-emptive discussion around communication options, establishing a yes/no response, or practising use of AAC systems prior to intubation may have supported the establishment of communication options that could be utilised immediately they were required.

Ultimately, this patient's feedback reinforces the importance of verbal communication. Once voice was restored successfully using an OWV, she was able to call for help, felt included in her care and was able to engage in discussions that were important to her, positively reducing her anxiety. However, she was not given the option to communicate verbally overnight during her entire tracheostomy experience (41 days), which she felt contributed to prolonged and ongoing anxiety and feelings of terror.

The lack of OWV use overnight was not due to our patients' inability to tolerate or use the OWV but was related to a long-standing recommendation discouraging OWV use overnight. Despite the well documented benefits of cuff deflation and OWV placement in the tracheostomy literature supporting communication and swallow function prior to liberation from a ventilator, there is limited research into the safety and efficacy of OWV use overnight. Two existing studies, in both paediatric and adult critical care cohorts have concluded that overnight use of a PMV is not associated with adverse cardiopulmonary events, apnoea's or significant desaturation [8,15]. It is likely that more research is required to confirm the safety of overnight OWV use, particularly since protective airway reflexes and swallowing function may be reduced during periods of sleep.

In our patient's experience, the psychological impact

of not being able to communicate overnight was high, and resulted in psychological distress, sleep deprivation and loss of motivation to rehabilitate. Since adequate sleep provides restorative, protective and energy conserving functions, a disturbance in the quantity or quality of sleep is linked to poor physiological outcomes, diminished cognition, depression, anxiety, and reduced quality of life which negatively impact a patient's recovery [16,17].

With the documented benefits of OWV use, a tracheostomy weaning plan which considers the individuals physiological, psychological, emotional and communication needs may enhance holistic care and improve the patient experience. In the case presented, short periods of OWV use overnight may have reduced anxiety, enhanced sleep, and improved readiness for rehabilitation participation.

Conclusion

Successful communication in tracheotomised patients is essential for reducing psychological distress and enhancing patient experience in the critical care setting. Communication must be at the centre of care for all members of the MDT. Our patients feedback highlights the importance of adequate MDT training on ways to support successful communication, and the need for considering individualised risk assessments for using OWV's overnight to reduce anxiety and enhance communication competence.

References

1. Khalaila R, Zbidat W, Anwar K, Bayya A, Linto DM, et al. (2011) Communication difficulties and psycho-emotional distress in patients receiving mechanical ventilation. *Am J Crit Car* 20(6): 470-479.
2. Chen Y, Jacobs WJ, Quan SF, Figueredo AJ, Davis AH, et al. (2011) Psychophysiological determinants of repeated Ventilator Weaning Failure: An Explanatory Model. *American Journal of Critical Care* 20(4): 292-302.
3. Salem A, Ahmad MM (2018) Communication with invasive mechanically ventilated patients and the use of alternative devices: integrative review. *J Res Nurse* 23(7): 614-630.
4. McRae J, Montgomery E, Garstang Z, Cleary E (2020) the role of speech and language therapists in the intensive care unit. *Journal of the Intensive Care Society* 21(4): 344-348.
5. Passy V, Baydur A, Prentice W, Darnell NR (1993) Passy-Muir tracheostomy speaking valve on ventilator-dependent patients. *Laryngoscope* 103(6): 653-658.

6. Sutt AL, Cornwell P, Mulany D, Kinneally T, Fraser JF, et al. (2015) The use of tracheostomy speaking valves in mechanically ventilated patients results in improved communication and does not prolong ventilation time in cardiothoracic intensive care unit patients. *J Crit Care* 30(3): 491-494.
7. Sutt AL, Caruana LR, Dunster KR, Cornwell PL, Anstey CM, et al. (2016) Speaking valves in tracheostomised ICU patients weaning off mechanical ventilation--do they facilitate lung recruitment?. *Critical Care* 20: 91.
8. Diez Gross R, Atwood C (2007) Safety of Tracheostomy Speaking Valve Use during Sleep. *Otolaryngol Head Neck Surg* 137(2): 209.
9. Petosic A, Viravong MF, Martin AM, Nilsen CB, Olafsen K, et al. (2020) Above Cuff Vocalisation (ACV): A scoping Review. *Acta Anaesthesiol Scand* 65(1): 15-25.
10. McGrath B, Lynch J, Wilson M, Nicholson L, Wallace S, et al. (2016) Above Cuff Vocalization: A novel technique for communication in the ventilator dependent tracheostomy patient. *J Intensive Care Soc* 17(1): 19-26.
11. Talbot S, McGrath BB (2019) Interventions to improve communication in mechanically ventilated patients: a review. *British Journal of Anaesthesia* 122(3): 49-50.
12. Ten Hoorn S, Elbers PW, Girbes AR, Tuinman PR (2016) Communicating with conscious and mechanically ventilated critically ill patients: a systematic review. *Critical Care* 20(1): 333.
13. Lohmeier HL, Hoit JD (2003) Ventilator-supported communication: a survey of ventilator users. *Journal of Medical Speech-Language Pathology* 11(1): 61-73.
14. Modrykamien A (2019) Strategies for communicating with conscious mechanically ventilate critically ill patients. *Bayl Univ Med Cent* 32(4): 534-537.
15. Barraza GY, Fernandez C, Halaby C, Ambrosio S, Simpser EF, et al. (2014) The safety of tracheostomy speaking valve use during sleep in children: a pilot study. *Am J Otolaryngol* 35(5): 636-640.
16. Miranda Ackerman RC, Lira-Trujill M, Cervantez AC, Clotilde FO, Alejandro GO, et al. (2020) Associations between stressors and difficulty sleeping in critically ill patients admitted to the intensive care unit: a cohort study. *BMC Health Service Res* 20: 631.
17. Matthews EE (2011) Sleep disturbances and fatigue in critically ill patients. *AACN Adv Crit Care* 22(3): 204-224.

