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The experience of communication difficulties in critically ill patients in and beyond intensive care: Findings from a larger phenomenological study

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Summary Communication difficulties in intensive care units (ICU) with critically ill patients have been well documented for more than three decades. However, there is only a paucity of literature that has explored communication difficulties beyond the ICU environment. This paper discusses the experience of communication difficulties in critically ill patients in ICU and beyond as part of findings from a larger study that explored the lived experiences of critically ill patients in ICU in the context of daily sedation interruption (DSI).

The aim of the study was to describe the lived experience of people who experienced critical illness in ICU using a hermeneutic phenomenological approach in the DSI context. Twelve participants aged between 20 and 76 years with an ICU stay ranging from 3 to 36 days were recruited from a 16 bed ICU in a large regional referral hospital in New South Wales (NSW), Australia. Participants were intubated, mechanically ventilated and subjected to (DSI) during their critical illness in ICU. In-depth face to face interviews with participants were conducted at two weeks after discharge from ICU and at six to eleven months later. Interviews were audio taped and transcribed. Thematic analysis using van Manen's (1990) method was completed. The overarching theme; 'Being in limbo' and subthemes 'Being disrupted'; 'Being imprisoned' and 'Being trapped' depict the main elements of the experience.

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This paper discusses communication difficulties in critically ill patients as one of the main findings relating to the theme 'Being trapped'. Participants' reports of communication difficulties in ICU are similar to those reported by patients in other studies where DSI was not used. However, not many studies have reported ongoing communication difficulties after ICU hospitalisation. Recommendations are made for new models of care and support to mitigate critically ill patients' communication concerns in ICU and for further research into the causes and treatment to benefit this group of patients. Most importantly, extra care is recommended not to damage vocal cords during intubation and cuff inflation in the course of mechanical ventilation.

Implications for Clinical Practice

- Greater effort is needed to find better and more effective ways of communicating with critically ill mechanically ventilated patients.
- It is important to establish effective communication for the ICU patients as that is their way of relating with others and of being in the world.
- Although the importance of and the need for more models of communication have been extensively recommended elsewhere (Happ, 2000; Almerud-Österberg, 2010) more use of communication aids such as charts, communication boards and writing pads could improve communication (Beraldo, 2009)
- Routine assessment by a speech therapist of individual patients' communication needs before leaving ICU and beyond would help inform restorative functional activities and provision of appropriate communication aids.
- Nurses' communication skills could be improved through ongoing education and practice development activities. This would be especially useful for new graduates who may be inexperienced in communicating with intubated patients (Parker, 1997).
- Technological solutions such as computer generated voice devices (LifeVoice™) are needed as they have proved beneficial elsewhere (Beraldo, 2009).

Introduction

Studies that have examined the impact of technology and ventilation for patients have demonstrated the distressing nature of being ventilated, either through an endotracheal tube (ETT) or tracheostomy. Mechanically ventilated critically ill patients' distress is associated partly with the inability to speak and communicate effectively with staff and family. In addition, communication difficulties are related to feelings of powerlessness and vulnerability resulting in frustration, anxiety and possibly delirium (Happ, 2001). Compounding factors have been linked to nurses' busyness and inability to lip read and patients' personality and inability to write (Happ, 2001).

Findings from previous research on communication difficulties in mechanically ventilated patients have led to the introduction of various communication assistive devices. However, their use and effectiveness remains to be established. Furthermore, the quest to improve patient experience and ICU outcomes have resulted in technological advancement and innovation in ICU practices such as new ventilators and daily sedation interruption (DSI). Reports that a more wakeful patient will be able to communicate and participate in decision making of their care (Mirski et al., 2010; Wunsch and Kress, 2009) have been cited. However, perceptions of patients about communication under such conditions have not been documented.

Background

Various phenomena have been associated with communication difficulties in mechanically ventilated critically ill patients. Granberg et al.'s (1999) seminal work found that many critically ill patients fail to communicate due to demanding nurses' workload. The authors conducted a hermeneutic phenomenological study in Sweden which comprised nineteen participants who had been mechanically ventilated in ICU. The authors interviewed participants at one week and at eight weeks after discharge from ICU. Their aim was to explore and expose patients' experiences of acute confusion, disorientation, wakefulness, dreams and nightmares during and after their stay in ICU. Granberg et al. (1999) found that communication difficulties were associated with difficult thought processes that resulted in patients failing to find the right words to communicate. In addition, the authors found that nurses were not patient enough to wait for the patients to find the right words to express themselves. Communication difficulties consequently resulted in patients failing to share horrible delusional experiences with the nurses because the nurses were too busy to listen. The study further revealed that patients became frustrated and angry at their spouse and the nursing staff for not understanding what they were saying. Granberg et al.'s (1999) study provides insight that communication difficulties can lead to feelings of loneliness, resentment, feelings of fear, vulnerability, agitation, anger, delirium and violence. Follow-up after ICU to establish on-going problems and change in initial recall was a strength of this study. Granberg et al. (1999) interviewed participants on the ward and in their homes four to eight weeks later. They did not report on-going communication difficulties post discharge.

Evidence showing the use and benefit of communication assistive devices is anecdotal. This is evidenced by a study conducted by Happ et al. (2011) in the two ICUs in the USA. Happ et al. (2011) conducted a non-interventional