



The work undertaken by mechanically ventilated patients in Intensive Care: A qualitative meta-ethnography of survivors' experiences



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ABSTRACT

Background: Mechanical ventilation is a routine intervention for the critically ill but patients' experiences of this intervention are largely hidden from clinicians. A comprehensive understanding of Intensive Care Units survivors' accounts is required to provide health professionals with evidence about the patients' experience to deliver patient-centred care.

Objectives: To synthesise qualitative findings from international studies to understand Intensive Care Unit survivors' experiences of mechanical ventilation, clarify the components of patient-centred care from the patient perspective and understand what can be done by health professionals to improve care processes.

Design: A meta-ethnography of qualitative evidence following ENTREQ recommendations for reporting systematic reviews.

Data sources: Eight databases (MEDLINE, AMED, CINAHL, PsychINFO, Scopus, WileyOnline, PubMed Central, TRIP) were systematically searched using a piloted strategy described in a published protocol. Searches were completed on 31.8.16 and no date restrictions were placed. Searches were updated on 25.4.17.

Review methods: Two researchers independently reviewed studies against pre-determined inclusion criteria to assess their eligibility. Studies were included if they reported on the adult patient experience of mechanical ventilation and used qualitative data collection and analysis methods. All included studies were quality appraised. Participant quotes and concepts, described within the categories and themes of published studies, were extracted by one reviewer and coded by two reviewers. A process of constant comparison, which is central to meta-ethnography, facilitated the re-interpretation of data by a team of researchers to generate the final qualitative synthesis. The Enhancing Transparency in Reporting the Synthesis of Qualitative (ENTREQ) statement was used to ensure that all synthesis stages were comprehensively reported.

Results: Findings from 38 studies, with 608 participants, informed a patient-centred trajectory model; three overlapping stages; alienation, hidden work and recovery characterised the experiences of mechanical ventilation survivors. Health professionals could positively influence the patient experience by promoting 'trust' and being vigilant so that patients felt 'safe'. Care provision that promoted 'personalisation' helped participants to retain their identity as unique human beings.

Conclusions: For the first time the pooling of qualitative findings from international studies, using meta-ethnography, has provided a patient-centred model of mechanical ventilation survivors' experiences of their care processes. Patients may actively engage or passively endure the treatment burden associated with mechanical ventilation.

What is already known about the topic?

- Patient-centred care for mechanically ventilated patients in the Intensive Care Unit is challenging due to the patients' communication difficulties making their care needs hard to determine.
- Patient centred care in Intensive Care Units has generally been

conceptualised using the perspectives of health professionals rather than patients.

- Published qualitative studies about patients' experiences of mechanical ventilation in Intensive Care Units exist but findings have not been pooled, using meta-ethnography, to draw out the key implications for practice, policy and education.

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What this paper adds

- A patient centred trajectory model has been developed that explains three stages patients experience during mechanical ventilation and highlights how the ‘personalisation of care’ and ‘trust’ in health professionals influences care experiences.
- Cognitive and physical ‘work’ is necessary for patients to cope with the physical sensations and emotional sequelae of mechanical ventilation in Intensive Care settings, and patients can view their experiences to generate either positive or negative meaning.
- Findings illustrate the ‘hidden work’ that patients do during mechanical ventilation and weaning; this evidence will enable health professionals to strengthen patient-centred care and develop supportive nursing interventions.

1. Introduction

An important part of evaluating the way in which healthcare is provided to patients and their families is to assess the quality of care processes. Care processes include the acceptability of health professional-patient communication and interactions as well as the care that is received (Donabedian, 2005). Patients cared for in Intensive Care Units do not usually have the opportunity to provide direct feedback on their experiences of care processes. More often than not they are unable to communicate as they are sedated and ventilated rendering them unable to verbally communicate their care needs and preferences (Carruthers et al., 2017). Therefore, we have rather limited information about the patient experience of Intensive Care Unit care processes which represents an obstacle to both person-centred care and quality improvement initiatives. Most importantly the care processes that patients receive in hospital are known to be linked to their health outcomes (Anhang Price et al., 2014).

If we consider Intensive Care Unit survivors psychological outcomes it is noteworthy that many report negative emotions and psychological distress (Engström et al., 2013; Khalaila et al., 2011). It is estimated that 28% of Intensive Care Unit survivors report significant depressive symptoms (Davydow et al., 2009) and 14–27% post-traumatic stress reactions (Rattray and Hull, 2008). Moreover, a high level of emotional distress in Intensive Care Unit patients is a predictor of post-traumatic stress disorder (Wade et al., 2012). This suggests that Intensive Care Unit care processes may save lives but also contribute to poor psychological outcomes for survivors.

A common care process delivered in Intensive Care Units is mechanical ventilation. Whilst it is lifesaving, mechanical ventilation survivors often report negative emotions and psychological distress during recovery (Engström et al., 2013; Khalaila et al., 2011). For this reason, we chose to focus upon understanding patients' experiences of mechanical ventilation to clarify the components of patient-centred care from the patient perspective, and understand what can be done by health professionals to improve care processes. In this way mechanical ventilation can potentially be delivered in a way that is more acceptable to patients which may reduce their emotional distress.

Qualitative studies that explore the patient experience of mechanical ventilation in the Intensive Care Unit setting have been published but appear to have had little direct impact on enhancing patient-centred care or informing clinical policy or health professional education. A recent concept analysis of the key components thought to exemplify patient-centred care in Intensive Care Unit settings reported that patient identity, compassionate and professional presence, and biomedical practice were important (Jakimowicz and Perry, 2015). Whilst the model provides a useful start, less than half of the included studies describe the patient perspective (Jakimowicz and Perry, 2015). Therefore, the model presents a view of Intensive Care Unit patient-centred care that focuses more upon the opinion of the health professional rather than the patient.

Qualitative syntheses offer an opportunity to systematically bring

together findings from several studies to provide a robust account that explains the patients' experiences of healthcare processes such as mechanical ventilation. When viewing the body of literature as a whole, new interpretations can be developed (Sandelowski and Barroso, 2006). A rigorous synthesis of multiple qualitative studies can increase the importance, significance and overall contribution of qualitative research to the clinical evidence base that informs healthcare provision, health professional education, policy and clinical guidelines (France et al., 2015).

We located two qualitative syntheses that reported on the patient perspective of mechanical ventilation in Intensive Care Unit settings (Carroll, 2004; Baumgarten and Poulsen, 2014). The main focus of the first synthesis was the experience of being non-vocal rather than the wider experience of mechanical ventilation (Carroll, 2004). Participants described feeling a loss of control and experienced negative emotional responses as a result of being unable to communicate (Carroll, 2004). The second synthesis only included studies published in Nordic countries making it somewhat limited (Baumgarten and Poulsen, 2014). The conclusions from this meta-synthesis described the vulnerability of mechanically ventilated patients, consisting of anxiety, fear and loneliness and the importance of staff being present and supportive.

Given the gap in the current literature, an updated synthesis of international studies of the patient experience of mechanical ventilation in Intensive Care Units is warranted. The purpose of this study was to systematically review and synthesise qualitative findings from international studies to better understand Intensive Care Unit survivors' experiences of mechanical ventilation, clarify the components of patient-centred care from the patient perspective and understand what can be done by health professionals to improve care processes. A comprehensive understanding of the patient experience of mechanical ventilation in Intensive Care Units is important to inform clinical practice, policy, health professional education and models of person centred care in this unique care setting.

2. Methods

2.1. Design

A qualitative meta-synthesis is an interpretive analytical technique in which findings reported from primary research are used as a foundation for a deeper understanding of phenomena (Fingeld, 2003). There are several approaches to qualitative synthesis and one of these is meta-ethnography (Noblit and Hare, 1988). Using this inductive approach, findings from individual studies are re-interpreted, rather than aggregated, to develop a unique synthesis. The construction of the final synthesis gives a 'whole' that is greater than the sum of its parts (Strike and Posner, 1983) with potentially greater explanatory power than the individual studies alone (Noblit and Hare, 1988). This approach was chosen because it is commonly used in health-related research (Hannes and Macaitis, 2012) and is useful for developing concepts, models and theories (Noblit and Hare, 1988).

A study protocol was developed which clearly describes the synthesis stages and is registered on an International Prospective Register of Systematic Review Protocols (PROSPERO) which is freely accessible at https://www.crd.york.ac.uk/prospero/display_record.asp?ID=CRD42017064549. The Enhanced Transparency of Reporting the Synthesis of Qualitative Research statement (ENTREQ) (Tong et al., 2012) was applied (see Supplementary data) to ensure that all stages of the synthesis were comprehensively reported allowing the transparent assessment of the methodological rigour of the synthesis.

2.2. Inclusion and exclusion criteria

Table 1 shows the inclusion criteria and MEDLINE search strategy. Inclusion criteria were refined using the PICOS search tool (Methley et al., 2014) and a full search strategy is available as Supplementary

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