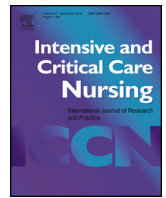




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Original article

The breath of life. Patients' experiences of breathing during and after mechanical ventilation

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ABSTRACT

Introduction: Breathlessness is a prevalent and distressing symptom in intensive care, underestimated by nurses and physicians. Therefore, to develop a more comprehensive understanding of this problem, the study had two aims: to compare patients' self-reported scores of breathlessness obtained during mechanical ventilation (MV) with experiences of breathlessness later recalled by patients and: to explore the lived experience of breathing during and after MV.

Method: A qualitatively driven sequential mixed method design combining prospective observational breathlessness data at the end of a spontaneous breathing trial (SBT) and follow up data from 11 post-discharge interviews.

Findings: Four out of six patients who reported breathlessness at the end of an SBT did not remember being breathless in retrospect. Experiences of breathing intertwined with the whole illness experience and were described in four themes: *existential threat; the tough time; an amorphous and boundless body and getting through.*

Conclusion: Breathing was not always a clearly separate experience, but intertwined with the whole illness experience. This may explain the poor correspondence between patients' and clinicians assessments of breathlessness. The results suggest patients' own reports of breathing should form part of nursing interventions and follow-up to support patients' quest for meaning.

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Implications for Clinical Practice

- Intensive care is evolving toward more awake patients and will further challenge interactions and communication with patients experiencing breathlessness.
- Breathing is not always a clearly separate experience, but intertwined with the whole illness experience.
- Acknowledging the presence and impact of breathlessness validates the experience of patients' sensations, suggesting that nurses should routinely assess and document dyspnoea on each nursing shift.
- A potential link between breathlessness, PTSD and post-intensive care syndrome is an argument for patients' own reports of breathing to form part of nursing interventions and follow-up to support patients' quest for meaning.

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Introduction

Even though the purpose of mechanical ventilation (MV) is to relieve patients' efforts in breathing, breathlessness is one of the most prevalent and distressing physical symptoms experienced by intensive care patients (Schmidt et al., 2011) and for many patients, MV represents a traumatic event regardless of how well weaning proceeds clinically (Rose et al., 2014).

Breathlessness is defined as a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity (Parshall et al., 2012) and medically known as dyspnoea (Johnson et al., 2014). The symptoms of dyspnoea vary between patients and are not fully explained by differences in disease severity (Banzett et al., 2000; Teeter and Bleecker, 1998). This suggests that the perception of dyspnoea is not necessarily linearly related to the sensory input, but is modulated by cognitive and affective factors (De Peuter et al., 2004). Breathlessness coexists with other distressing symptoms such as anxiety, fatigue or pain and relates to experiences of fear (Mularski et al., 2010), and long-time survivors of acute respiratory distress syndrome are at risk of long-term neuropsychological impairment (Kapfhammer et al., 2004; Mikkelsen et al., 2012).

There is a lack of evidence of the ability of health care workers to assess MV patients' experiences of breathing (Schmidt et al., 2014; Banzett and Schwartzstein, 2015). Although communicating about pain, discomfort and other symptoms is a common need for intubated ICU patients (Fowler, 1997), few data show that nurses consistently or accurately interpret nonverbal signals as symptom communication (Puntillo et al., 2008). This was illustrated in a recent prospective multicenter study in MV demonstrating that moderate or severe breathlessness was reported by 62% of patients and that about half of the nurses and physicians underestimated breathlessness compared to the patients' self-reports (Haugdahl et al., 2015). The median intensity of breathlessness numeric rating scores (NRS) scores reported by the patients was five compared to two by nurses and physicians (Haugdahl et al., 2015). This indicates that breathlessness has different meanings for patients and health care personnel. The patients are telling us something about the experience of breathing that we do not really understand. Based on these considerations we decided to further explore a more comprehensive understanding of the experience of breathing.

Thus, for the present study we followed up patients who had participated in the quantitative study of self-report of breathlessness (Haugdahl et al., 2015) and asked them to describe breathing during and after MV.

The aims of this study were to: first, compare patients' self-report of breathlessness obtained during MV with experiences of breathlessness later recalled by patients after hospital discharge and second, explore the lived experience of breathing during and after MV.

Design and methods

We used a qualitatively driven sequential mixed method design that incorporated a core qualitative project (QUAL), complemented by a quantitative component (quan) (Hesse-Biber et al., 2015) (Fig. 1). The quan was based on a previous prospective observational multicenter study on MV patients' perceptions of breathlessness during a spontaneous breathing trial (SBT) (Haugdahl et al., 2015), where breathlessness was measured by a numeric rating scale ranging from 0 (no breathlessness) to 10 (worst imaginable breathlessness). Patients' self-report of breathlessness (Haugdahl et al., 2015) had two purposes for this mix-method study. First, to identify participants for the QUAL (Creswell and Zhang, 2009) representing a broad range of breathlessness experiences. Second, to mix patients' self-reported

breathlessness (NRS-scores) with patients' experiences of breathlessness during and after ICU stay later recalled by the patients in the subsequent interview.

We conducted qualitative interviews to explore the lived experience of breathing during and after MV (QUAL). A hermeneutic phenomenological methodology inspired by van Manen (1990), and Gadamer (1999) was applied. As van Manen (ibid.) and Dahlberg et al. (2008) argue, a phenomenological approach implies reflective studies of the lifeworld, i.e. the world as it is immediately intended and experienced. Such an approach aims at illuminating the meaning embraced in these experiences and their expressions. To further explore the phenomenon of breathing, we used the mixed data of breathlessness as an analytic tool to further explore and discuss the patients' lived experiences of breathing (QUAL).

Settings and participants

One hundred consecutive MV patients (non-invasive ventilated excluded) were prospectively recruited from three Norwegian ICUs from September 2012 to September 2014 (quan) (Haugdahl et al., 2015). From the population of 100, 18 died in hospital and a purposive sample for the QUAL study was selected among 82 patients. To gain examples of experientially rich descriptions (van Manen, 2014:353) and variation in experiences, we purposely recruited participants by the following criteria; low (<4) and high (≥ 4) breathlessness NRS score during SBT and differences in age, gender and time on ventilator.

The 11-point NRS used in the quan study, developed by Powers and Bennett (1999), shows acceptable reliability and validity and is useful in quantifying dyspnoea experienced by patients receiving MV (Powers and Bennett, 1999). The sample came from extremes of the breathlessness experience (SBT) at a time point patients' breathing ability was challenged. Variability in responses was expected to benefit the analyses of the phenomenon of breathing.

Eleven participants, representing the three Norwegian ICUs were included and interviewed between 5 and 14 months after MV (QUAL). The interviews were introduced by the first author with a short briefing of the purpose, followed by an open question; "Can you tell me about your breathing during your hospital stay?" The emphasis was on narratives of concrete situations. An open dialogue was aimed at, including sequences of questions (Dahlberg et al., 2008), such as: "Can you tell me about a time when you felt breathless?", and "Can you give an example/tell me more about...". Interviews were audio recorded, transcribed verbatim and analysed by the first author in dialogue with the last author. The analysis where later discussed and validated by all authors.

Ethical considerations

Ethical considerations concerning the quan study are described elsewhere (Haugdahl et al., 2015). The participants (QUAL) received written information and a request to participate at least one month after hospital discharge. Because not all patients necessarily remember details from their ICU stay, participants were told their experiences were valuable anyway. When written consent was given, the first author called to ask where they preferred the interview to be held. The study was approved by the Regional Committee for Medical Research Ethics (REK – 2013/2078).

Data analysis and triangulation

Descriptive variables and demographic data were reported as absolute numbers, percentages and medians (25th–75th percentiles) (quan). The interviews (QUAL) were individually read and analysed through the following questions: 1. Does the participant experience breathing problems several months after MV? 2. Does the

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