### Att vårdas vaken med respirator -

## Patienters och närståendes upplevelser från en intensivvårdsavdelning

Akademisk avhandling som för avläggande av filosofie doktorsexamen vid Sahlgrenska Akademin vid Göteborgs Universitet kommer att offentligt försvaras i Hörsal 2118, Arvid Wallgrens backe, Hus 2, Göteborg, fredagen den 20 januari 2012 kl. 09.00

av

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- I Karlsson V. Lindahl B. Bergbom I. Patients' statements and experiences concerning receiving mechanical ventilation: a prospective video-recorded study. Nursing Inquiry, DOI: 10.1111/j.1440-1800.2011.00576.x Accepted 6 July 2011.
- II Karlsson V. Bergbom I. Forsberg A. The lived experience of adult intensive care patients who were conscious during mechanical ventilation: a phenomenological hermeneutic study. *Intensive and Critical Care Nursing, DOI: 10.1016/j.iccn.2011.11.002 Accepted 12 November 2011.*
- III Karlsson V. Forsberg A. Bergbom I. Communication when patients are conscious during respirator treatment – a hermeneutic observation study. Submitted 11-09-27.
- IV Karlsson V. Forsberg A. Bergbom I. (2010). Relatives' experiences of visiting a conscious, mechanically ventilated patient – a hermeneutic study. *Intensive and Critical Care Nursing*, 26, 91-100.

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# BEING CONSCIOUS DURING MECHANICAL VENTILATOR TREATMENT – PATIENTS' AND RELATIVES' EXPERIENCES IN INTENSIVE CARE UNITS

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### Abstract

In recent years, light or no sedation has become a common approach in patients who require mechanical ventilation (MV) when cared for in an intensive care unit (ICU). This new approach has resulted in medical advantages as well as a shorter time on MV and in the ICU.

Aim: The overall objective of the thesis was to describe, illuminate and interpret patients' and relatives' experiences of caring and communication in connection with MV while the patient is conscious.

Methods: The data collection methods were inductive and included interviews and observations, both audio-taped and video-recorded. The study group consisted of patients and relatives; fourteen patients in paper I, twelve in paper II and nineteen in paper III as well as ten relatives in paper IV. In paper I, the video-recorded interviews were analysed using content analysis and hermeneutics. The text in paper II was analysed using the phenomenological-hermeneutic method inspired by Ricoeur. The observations in paper III were analysed by means of a hermeneutic approach based on Gadamer's philosophy. In paper IV, relatives were interviewed on two occasions. The text from these interviews was also analysed using a hermeneutic method inspired by Gadamer.

Results: The patients experienced an overall sense of being breathless. While conscious, they were aware of the mechanical ventilator as a life saver. Besides being breathless, being voiceless was considered the worst aspect. Communication was difficult and awkward as it demanded all their will power. Patients' communication patterns varied but there were commonalities; they also developed an individual style of communication. Being subjected to someone else's will and direction meant being patifully aware of one's dependency. Despite this, the patients struggled for independence in various ways as part of the recovery process. Being conscious while receiving MV demands caring communication, which in turn requires proximity, presence and constant attention by a nurse who is "standing by" and prepared to take care of the patient whatever happens. The patients' non-verbal communication through their gaze and facial expression was interpreted as sadness and sorrow, understood as expressions of unuttered suffering. The overall struggle and primary existential aim of relatives in the ICU is to be in contact with the patient, a need which overshadows everything else.

Conclusion: Being conscious during MV means being painfully aware of one's dependency while voiceless and helpless. It is possible to endure this situation when the caregivers are "standing by", attentive to the patients' expressions, prepared to act to make sure that the patients are feeling better and do not leave them unattended. Caring for a conscious patient on MV presupposes nurses' ability to understand and be able to "standing by". If this approach is not possible, consciousness might be too painful and sedation should be considered.

**Keywords:** Intensive care, mechanical ventilation, conscious, patient, communication, relatives, experiences, standing by, hermeneutics, phenomenological-hermeneutics, content analysis

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