ATTITUDES TOWARDS ORGAN DONOR ADVOCACY AMONG SWEDISH INTENSIVE AND CRITICAL CARE NURSES

Akademisk avhandling

som för avläggande av filosofie doktorsexamen vid Sahlgrenska akademin vid Göteborgs universitet kommer att offentligen försvaras i Wallenbergsalen, Medicinaregatan 20 A, onsdagen den 8 juni 2011 kl 13.00

av

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This thesis is based on the following papers, identified in the text by their Roman numerals:

- I Flodén A, Forsberg A. A phenomenographic study of ICU nurses' perceptions of and attitudes to organ donation and care of potential donors. Intensive & Critical Care Nursing, 2009; 25, 306-316.
- II Flodén A, Rizell M, Persson L-O, Sanner M, Forsberg A. Attitudes to organ donation among Swedish ICU nurses. Journal of Clinical Nursing. In press 2011.
- III Flodén A, Berg M, Forsberg A. ICU nurses' perceptions of responsibilities and organisation in relation to organ donation - A phenomonographic study Submitted 2011.
- IV Flodén A, Lennerling A, Fridh I, Rizell M, Forsberg A. Development and Psychometric Evaluation of the Instrument: Attitudes Towards Organ Donor Advocacy Scale (ATODAS). Submitted 2011.

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Gothenburg 2011



UNIVERSITY OF GOTHENBURG

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Abstract.

End-of-Life Care in the intensive and critical care unit (ICU) involves the rare situation of caring for brain dead persons who, by their death, become potential organ donors (POD). A consequence might be that end-of-life care continues into after-death care in order to facilitate organ donation (OD). In this situation, the concept of organ donor advocacy is critical

Aim: The overall objective was to explore ICU nurses' attitudes towards organ donor advocacy by capturing their perceptions, experiences and approaches and to develop a context-specific instrument for ICU nurses' self-assessment of attitudes towards organ donor advocacy.

Methods: The data collection methods were both inductive and deductive, including interviews and questionnaires, in an effort to seek the unique in each individual case as well as group correlations. The study groups consisted of ICU nurses: Paper I n=9, Paper II n=702, Paper III n=15 and in Paper IV n=502. The interviews were analysed by phenomenography. The data collection instruments comprised a questionnaire to explore ICU nurses' attitudes to OD and the Attitudes towards organ donor advocacy scale (ATODAS), which was developed for this thesis.

Results: The thesis reveals that less than half of the ICU nurses trusted clinical diagnosis of brain death (BD) without a confirmatory cerebral angiography. Almost half considered that caring for a mechanically ventilated POD was a great burden involving emotional strain. Twenty-five percent of the respondents indicated that mechanical ventilation was withdrawn in order to reduce suffering for a presumably dead person and that the issue of OD was never mentioned. In total, 39% had experienced occasions when the question about OD was never raised with the relatives. The participants perceived BD and the diagnostics of BD in four qualitatively different ways. With the exception of one participant, there was an overall perception of a lack of organisation regarding OD in the ICU. A useful approach might be to move from studying attitudes towards OD to investigating attitudes towards organ donor advocacy, in order to respect, represent and safeguard the donor's and his or her relatives' rights and best interests. It is possible to measure attitudes towards organ donor advocacy in three dimensions divided into five factors

Conclusion: Ambiguity and various perceptions of the BD diagnosis seem to be a crucial aspect when caring for a patient who might be a potential organ donor. The lack of structured and sufficient organisation also appears to be a limitation. Both of these aspects are essential for the ICU nurse's possibility to fulfil his or her professional responsibility towards the deceased, next of kin, colleagues and organ recipients.

Keywords: Organ donation, Brain death, Advocacy, Professional ethics, Intensive and critical care, Nursing, Psychometric evaluation