ICU nurses have doubts about the method to establish brain death – An impact on organ donation?

Anne Flodén
Sahlgrenska Academy, Gothenburg University and The Unit for Organ Donation, Gothenburg, Sweden

The thesis Attitudes towards organ donor advocacy among Swedish intensive and critical care nurses, from the Sahlgrenska Academy, Gothenburg 2011, Sweden reveal that more than half of Swedish intensive and critical care unit (ICU) nurses have doubts that a clinical neurological examination can establish that a patient is brain dead.

End-of-Life Care in the ICU involves the rare situation of caring for brain dead person who, by their death, become potential organ donors. A consequence might be that end-of-life care continues into after death care in order to enable organ donation. In this situation, the concept of organ donor advocacy is critical. Previous research has shown that ICU-staff attitude towards organ donation is the most crucial factor that will affect if a potential donor will become an actual donor. But what factors are there underlying these attitudes? This question resulted in the aim of my thesis: To investigate attitudes and actions of ICU nurses in the context of organ donation based on their experiences.

The initial plan for the thesis was to study Swedish ICU nurses’ attitudes to organ donation. However, at an early stage a picture emerged from the data of the ICU nurses’ advocacy act while caring for a potential organ donor. Advocacy performed by the ICU nurse within the organ donation situation seems to vary depending on the relationship with the relatives, the cooperation with the physician, the approach of nursing colleagues and available resources and may also be affected due to how the nurses perceive, understand and trust brain death and the diagnostics of brain death. Irrespective of these factors, organ donor advocacy consisted of a series of specific actions for preserving, representing and/or safeguarding the potential donor’s and/or his or her relatives’ rights, best interests and values. These new findings lead to the development of a context-specific instrument for ICU nurses’ self-assessment of attitudes towards organ donor advocacy.

Participants in all four studies of the thesis consisted of Swedish ICU nurses. 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 interviews were analyzed by the qualitative method phenomenography.

Lack of confidence in the diagnosis of total brain infarction

The most surprising result was that less than half of the ICU nurses (48 percent) trusted that solely clinical neurological examination can be relied upon for determining that a patient is brain dead (gold standard in Sweden) without a confirmatory cerebral angiography. The nurses described a need to understand brain death both intellectually and emotionally. It was considered important for an ICU nurse to have processed the concept of brain death and to be clear about his or her own attitude when caring for the potential organ donor, since nurses will act on the basis of their perceptions, consciously or subconsciously. There was an opinion that the nurses perceptions could also affect the family’s attitude to organ donation.

The data revealed four qualitatively different ways in which the participants perceived brain death and had confidence in the brain death diagnostics.

A. Trust in brain death diagnostics regardless of the method
B. Confidence in the skills of the physician
C. Trust in the brain death diagnostics if present during the diagnostic procedure
D. Felt the need for cerebral angiography to be convinced of the accuracy of brain death diagnostics

It is problematic when nurses responsible for caring for these patients have doubts about the reliability of the methods used to establish death. Maybe is one explanation for their distrust that the concept of brain death challenges most of our preconceptions about death and dying. The deceased patient still has a heartbeat and the body is warm, but is, according to Swedish legislation, deceased.
Caring for the potential organ donor

Caring for a potential organ donor was perceived as more physically and mentally demanding than caring for other ICU patients. The actions of ICU nurses were affected by their strive to safeguard the will and wishes of potential donors. Caring for a potential donor was viewed as a dramatic situation. The professionals described being affected by the often sudden and unexpected death and the family's emotional turmoil. The atmosphere in the unit became heated.

When the question of organ donation arose, 53 percent experienced that their own feelings were influenced in a positive or fairly positive way, while nine percent reported negative or somewhat negative feelings. The participants perceived that their attitude/approach towards organ donation was crucial for the way in which they cared for a potential donor. The extent to which a potential donor received attention could depend on those who were on duty, their sense of commitment or whether they felt insecure in the situation. A colleague's attitude towards organ donation could be discerned from his or her actions. The perception existed that it was controversial to work in the ICU if not in favour of organ donation or aware of one's own attitude and the influence it might have on the potential organ donor's family.

When it became clear that there was a potential donor, a demand was placed on the nurses to take responsibility for the situation, show respect, preserve dignity, conduct the process in a correct manner and exhibit a professional stance. "Nothing must go wrong" was seen as paramount, both in relation to the encounter with the family and the care of a potential donor. The nurses stated that honesty when dealing with the next of kin was fundamental in order to prevent lack of trust. Although the medical care was time-consuming, the participants experienced an even greater sense of responsibility for the family in these situations.

The professional responsibility

The perceptions of ICU nurses' responsibility for after-death care varied. One participant stated that her duty was to care for the living, while other perceptions involved a change of focus from the dead patient to the potential organ donor and the possible organ recipients.

Organ donation was considered to be a teamwork, despite the fact that the physici- 

Perceived lack of organization

There was a disappointment due to the lack of structure and guidelines in the organization. There were also a need for a local organisation chart and a check list regarding the organ donation process, especially in the early phase. It was perceived that identification of potential organ donors did not take place due to the lack of structure and guidelines.

It was also considered that the manager and director of the ICU had no expectations in terms of organ donation. The ICU nurses expressed that they wanted him or her to take a stand in favour of organ donation. The absence of leadership resulted in ambiguity and the feeling of being abandoned when caring for a potential organ donor. However, 80 percent of the nurses reported that there was a physician or nurse responsible for organ donation in their unit.

Caring for an organ donor was considered to be a teamwork, despite the fact that the physician was in charge. The presence of the physician throughout the donation process was per-
ceived as essential, in terms of the care provided and the contact with family members. Situations in which this was not the case for various reasons had left the nurse feeling abandoned and exposed.

Ambiguity and various perceptions of the brain death 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 organization also appears to be a limitation. Both of these aspects are essential for the ICU nurse's to fulfill his or her professional responsibility towards the deceased, the next of kin, colleagues and organ recipients.

The thesis Attitudes towards organ donor advocacy among Swedish intensive and critical care nurses, Sahlgrenska Academy, Gothenburg 2011 can be read in full at: http://hdl.handle.net/2077/24632

Including papers


Anne Flodén, RN, PhD
Sahlgrenska Academy, Gothenburg University and
The Unit for Organ Donation
Gothenburg, Sweden
anne.floden@vgregion.se