Intensive and Critical Care Nursing (2014) 30, 275—282

Available online at www.sciencedirect.com

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The core of after death care in relation to organ donation — A grounded theory study

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Accepted 12 June 2014

KEYWORDS
After death care;
Brain death;
Grounded theory;
Intensive care nurses;
Organ donation

Summary
Objectives: The aim of this study was to investigate how intensive and critical care nurses experience and deal with after death care i.e. the period from notification of a possible brain dead person, and thereby a possible organ donor, to the time of post-mortem farewell.
Research methodology: Grounded theory, based on Charmaz' framework, was used to explore what characterises the ICU-nurses concerns during the process of after death and how they handle it. Data was collected from open-ended interviews.
Findings: The core category: *achieving a basis for organ donation through dignified and respectful care of the deceased person and the close relatives* highlights the main concern of the 29 informants. This concern is categorised into four main areas: safeguarding the dignity of the deceased person, respecting the relatives, dignified and respectful care, enabling a dignified farewell.
Conclusion: After death care requires the provision of intense, technical, medical and nursing interventions to enable organ donation from a deceased person. It is achieved by extensive nursing efforts to preserve and safeguard the dignity of and respect for the deceased person and the close relatives, within an atmosphere of peace and tranquillity.

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http://dx.doi.org/10.1016/j.iccn.2014.06.002
0964-3397/

Implications for Clinical Practice

- A supportive ICU-environment and a well-organised hospital structure developed for organ donation facilitate intensive care nurses' work when performing after death care.
- To create awareness and include all clinical staff involved in the homage of the dead person means respecting the donor and brings dignity in the situation.
- Facilitate the family members grieving process by enable a farewell to their loved one before the donation and a last farewell when the body is cold.
- Invite the family members to a follow-up meeting with the clinical staff involved in the patients care.

Introduction

The aim of this study was to investigate how intensive and critical care nurses experience and deal with after death care i.e. the period from notification of a possible brain dead person and thereby a possible organ donor to the time of post-mortem farewell. An increasing number of people are in need of a transplant for their survival. Great efforts are made in European Member States to increase the number of donated organs (Commission of the European Communities, 2008).

Organs for transplantation are mainly retrieved from ventilated patients declared dead by brain death criteria. These patients are cared for in the intensive care unit (ICU) where nurses have an extremely important role to play in the management of the procedure around organ donation.

Whilst the media has drawn the public's attention to the lack of organs and to the plight of the potential recipient, the tragedy and the circumstances behind the death of the potential organ donor are seldom given much attention in this publicity. However, this is precisely the scenario facing ICU-nurses when taking care of potential organ donors and their families (Flodén and Forsberg, 2009; Pearson et al., 2001). The care of dying patients forms a part of the nursing profession, irrespective of the caring context and is thus included in intensive care nursing (Efstathiou and Clifford, 2011). Although the percentage of ICU deaths varies between countries and settings, the number of patients declared dead using brain death criteria forms only a minority of the number of patients who end their lives in the ICU. Consequently, the care of these patients is rarely a routine matter for nurses in most ICUs.

The goal of intensive care is to save lives. When, in spite of the very best medical efforts a life cannot be saved, nurses do everything possible to ensure that the patient is given a dignified death (Fridh et al., 2009a; Hawley and Jensen, 2007). When a patient dies, care of the body becomes a normal part of nursing care (Hadders, 2007). When a patient is on a ventilator and suffers from cessation of brain circulation, the course of death takes another trajectory and death is diagnosed by brain death criteria. If the patient is identified as a potential organ donor, the body is kept on the ventilator until the donation operation is performed. This unique form of ''after death care'' appears solely in intensive care settings and is mainly performed by nurses (Monforte-Royo and Roque, 2012).

Except for unexpected and sudden deaths, we normally consider end-of-life care and dying as a process. When the heart stops beating, death is the expected final result of this process. When it comes to cessation of brain stem circulation, death notification itself can be considered as a process. When caring for a patient on a ventilator, physical signs such as a sudden drop in the heart rate and a drastically increased blood pressure can be signs that the patient has probably had a herniation and that death is close. However, these signs are not always obvious due to the use of various vasoactive drugs and the transition from dying to death can be invisible to the eye. Death must therefore be established after the event and by other methods, i.e. clinical neurological examination, cerebral angiography and/or computer tomography.

Even if nurses may find these situations burdensome, there is also a growing clinical but tacit acceptance that experienced nurses handle this type of care in a very professional way. It is important to explore and explain how nurses deal with and describe the nursing care process during these events, in order to expand clinical as well as theoretical knowledge in this field.

Methods

Design

We utilised grounded theory (GT) according to Charmaz (2010). This is because after death care and the donation process involve a great deal of social interactions. In this study the focus was on how intensive and critical care nurses experience and deal with after death care, i.e. the period from notification of a possible brain dead person and thereby a possible organ donor, to the time of a post-mortem farewell.

Context

In Sweden, almost all critical care nurses have a diploma in intensive care nursing which is acquired by a one year post graduate university education. During this course nurses receive in-depth training in end-of-life care within the ICU as well as in nursing ethics and nursing sciences. According to Swedish legislation, every hospital should have a Donor Responsible Physician and a Donor Responsible Nurse who support the ICU-staff when a possible organ donor is identified, as well as distinct guidelines covering the practical performance of organ donation in order to support the organ donor process. The ICU-staff members are also offered the