

## Original Article

# Intensive Care Nurses' Experiences of Caring during the Organ Donor Process in Sweden – a Qualitative Study

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## Abstract

**Background:** The organ donor process is challenging, not at least for intensive care nurses. The situation changes radically, from intensively working to save the patient's life to instead caring for the donor patient's organs so that those, in turn, can save another patient's life. The donation process challenges nurses' view on what dignified caring at end-of-life entails. The inner core of caring comprises love, mercy and compassion. Dignified caring is related to treating the patient as a unique human being and respecting human value, rooted in the theory of caritative caring that is the framework for this study.

**Aim:** The aim was to illuminate intensive care nurses' experiences of caring during the organ donor process, from a caring science perspective.

**Methodology:** A descriptive research design including inductive qualitative content analysis of interviews with twelve intensive care nurses in Sweden about their experiences of caring during the donor process.

**Results:** The theme *The complexity of caring during the organ donor process* with two categories and five subcategories was generated. Intensive care nurses experienced caring during the donor process as being complex in relation to the potential donor patient and patient's family as well as communication, teamwork and organization. Caring affects not only the patient and families, but also the nurses and receivers of the donated organs. Intensive care nurses perceive the other's life situation as if it were their own and recognize the importance of shared humanity.

**Conclusion:** The present study can increase knowledge from intensive care nurses and the caring team, in order to provide better conditions such as the development of effective intervention strategies in the process of organ donor care as well as caring for the families and members of the team.

**Key words:** Brain Death, Caring, Experiences, Intensive Care Nurses, Organ Donor Process

## Introduction

Organ donation is an established method of treatment whereby patients with fatal organ dysfunction may experience extended life. Through organ donation, organ recipients' possibilities for survival and quality of life improve. Organ donation and organ transplantation even have a major beneficial impact on public health regarding socio-economic aspects (Vanholder, 2021). There are noticeably different transplantation rates between the European Union (EU) member states. While the number of transplantations has increased in recent years, there is still an overwhelming need for organs worldwide (Lewis et al., 2021). It is therefore important to enable more organ donations, both for each unique patient and on a societal level.

The organ donor process is challenging because it is a non-daily task with an extreme limit of time (Meyer et al., 2012). A successful donation process presupposes effective organizational management and interprofessional support (cf. Simonsson, 2020; YazdiMoghaddam et al., 2020). Unfortunately, nurses experience lack of support during the donor process, seen as shortcoming in effective organizational management as well as an inefficient and non-targeted care system (Moghaddam et al., 2018). Doubts and conflicts between physicians and nurses can arise regarding the understanding of treatment and care during the donor process (YazdiMoghaddam et al., 2020). The presence of nurses when families are informed about the donation process may ease families' grief and thus facilitate the donor process (Kerstis & Widarsson, 2020).

Caring for a potential donor patient can be described as the most complicated task that intensive care nurses undertake (Moghaddam et al., 2018). The situation changes radically, from intensively working to save the patient's life to instead caring for the donor patient's organs so that those organs, in turn, can save another patient's life. Nurses are influenced in the donor process by medical- and technical challenges as well as ethical challenges and processing of their feelings, thoughts and values (Moghaddam et al., 2018). An important part of nurses' work is raising discussion about possible donations with both physicians and patients' families while simultaneously continuing to care for and support donor patients as well as the donor patients' families (Meyer et al., 2012).

The donation process can challenge nurses' views on what dignified care entails (Smith et al., 2019). Nurses strive to provide dignified and respectful

care, encompassing not only the donor patient but even the donor patient's family and other care team members (Forsberg et al., 2014). However, nurses have experienced that both the family and donor do not receive adequate caring (Hurst & Ricou, 2015). The aim of this study was to illuminate intensive care nurses' experiences of caring during the organ donor process, emanating from a caring science perspective. The theory of caritative caring forms the basis for the study's theoretical framework (Lindström et al., 2018). In the theory of caritative caring, the inner core of caring is comprised of love, mercy and compassion. Caritas is an expression of love and compassion. Caring is also healing and sharing, which presupposes fellowship and relationship (Bergbom et al., 2021). Dignified caring, moreover, entails treating each patient as a unique human being and thus respecting the value of each individual (Nyholm, 2017).

**Methodology:** A descriptive research design was chosen, including inductive qualitative content analysis of interviews with intensive care nurses in Sweden about their experiences of caring during the donor process.

**Participants:** In Sweden, intensive care nurses are clinical nurse specialists who hold a postgraduate degree (180 + 60 ECTS). Twelve intensive care nurses from six randomly selected intensive care units (ICUs) throughout Sweden were selected by the head nurse for each included unit: seven females and five males aged 24-59 years with between five months to 20 years of ICU experience. All participants had experience of caring for a potential donor patient. Exclusion criteria were ICUs specializing in neurologic intensive care and/or pediatric intensive care.

**Data collection and analysis:** The first author (NN) conducted the participant interviews in 2018. The interviews emanated from a 14 question, semi-structured interview guide, pilot-tested for the current study. The interview guide encompassed questions about the experiences and feelings that could arise when caring for potential organ donor patients as well as organizational items. The questions facilitated open discussion about feelings, thoughts and experiences during all stages of the donor process. Four of the interviews were conducted as face-to-face meetings at included ICU settings while eight interviews were conducted by web-link. Each interview lasted 45-75 minutes.

The analysis process followed Graneheim and Lundman's (2004) steps in a qualitative content analysis. Each interview was transcribed verbatim and in the first step read several times to develop a

grasp of the whole. In the second step, meaning units were identified in the text. In the third step, the condensed text was sorted into two categories and five subcategories. Differing interpretations were settled through negotiated consensus among all authors. As the present content analysis was latent, an interpretation was made in the final step of the analysis, during which a theme was established. This process enabled underlying meaning to be made visible (Table 1).

**Ethical considerations:** The ethics board for the local university and the heads of the units where the nurse participants worked granted permission for the study. The act concerning the Ethical Review of Research Involving Humans (2003:460) and the Declaration of Helsinki (World Medical Association, 2013) were followed throughout the entire course of the project. The participants were not in a position of dependence in relation to the researcher. Prior to interviews, the participants received written and verbal information about the study and were informed of their right to withdraw without any explanation. The participants provided written informed consent.

**Results**

The theme: *The complexity of caring during the organ donor process* was prominent in all interviews. Two categories and five subcategories were generated (Table 1).

**Striving to provide multi-dimensional care:** The first category, *Striving to provide multidimensional care*, includes two subcategories. Subcategory I, *Caring for a potential donor patient - Grieving for the life lost, the life found and one’s own life*, encompassed caring for a dying patient and at the same time performing lifesaving work for someone else. Caring was described as multidimensional, where the grief for one life simultaneous with gratitude for the donated organs and a possibility for someone else’s further life were in focus:

*It is a special switch when care changes direction. It causes a strange feeling. In the beginning, it was difficult. When you are in tragedy, to see the positive. But just before the diagnosis is made, you stand a bit with one leg on each side, you know where you are going but you are not quite there yet. Here you care for someone who will not survive – you care for someone else.* (Nurse K)

The nurses highlighted the emotional aspect from two perspectives, from the caring perspective as professionals but also from a “me” perspective, where the nurses relate to themselves.

*You carry the donor patient with you. Lovingly! Both as a person and as a professional. It takes a lot of energy, but it’s so interesting when you understand and are able to connect the whole chain* (Nurse K).

Table 1. Intensive care nurses’ experiences of caring during the organ donor process.

Categories	Striving to provide multi-dimensional care	Striving to provide care through multi-professional teamwork
Subcategory I	Caring for a potential donor patient - Grieving for the life lost, the life found and one’s own life.	Team communication – Caring through respectful communication without risking a loss of time and resources
Subcategory II	Caring for the potential donor’s family - To provide compassionate care and at the same time work quickly and be honest	Teamwork: Caring as well-functioning interprofessional cooperation.
Subcategory III		Organizational prerequisites - Caring in a demanding situation - and at the same time a need for support

It was impossible to care for the potential donor patients, without at the same time feeling grateful for their own family. The nurses also had thoughts about their own possible future donation needs and own death. A need to manage and reflect on these existential emotions became paramount.

Subcategory II, *Caring for the potential donor’s family - To provide compassionate care and at the same time work quickly and be honest*, encompassed that caring for the potential donor patient’s family was challenging. The situation was described as a shock-

phase for the family and a situation where the nurses relate to the family and becomes deeply involved:

*When you speak to the family you speak just as much to yourself* (Nurse C).

The nurses experienced becoming that they became closer to donor patients' families than other ICU patients' families. Each encounter with the families was described as unique. It is an ambivalent situation where the nurse on the one hand provides compassionate care to families in their grief, and on the other hand must work quickly and systematically to take care of the donor patient's organs for someone unknown. One nurse described this complexity:

*As a person, I feel sorry for the family. You work so close and bond with them. The relationship is gripping. It is easy for us to become so focused on caring for the organs that we forget about the family, we forget that we care for a person who the family has just lost. It is complex.* (Nurse B)

The nurses emphasized the importance of honest communication with families and not withholding information.

*It is very straightforward information here from the very beginning. There's never a lot [of] I don't know, we do not know or that you try to hide something. It is like very straightforward* (Nurse L).

Still, a small amount of concise information could mitigate the family's grief. The nurses tried not to communicate verbally with the patient who was declared dead, even though it was difficult.

*When they are declared dead, to perceive the patient as dead, it doesn't go into the head. Not until they come back from the [organ transplant] operation. It is to be sure [like that] for all...impossible to not talk to them* (Nurse C).

Verbally communicating with the deceased patient might confuse the family and lead to the belief that their loved one was still alive. Previous encounters in similar situations facilitated caring for the families and gave the nurses assurance about what information the families' could bear in their grief. Through continuous information and by inviting the families into the care of the patient, the nurses' experiences were that the families were more receptive once the decision about the donation was taken.

**Striving to provide care through multi-professional teamwork:** The second category, *Striving to provide care through multi-professional teamwork*, includes three subcategories. Subcategory I, *Team communication – Caring through respectful communication without risking a loss of time and resources*, encompassed that informative interprofessional communication within the team was essential. Through clear information within the team, nurses began work in a structured and timely manner

throughout the donation process, without risking inefficient use of time. The nurses described that respectful communication was about having an open climate within the interprofessional team. Everyone in the team, regardless of profession, could share thoughts and opinions. In this way, a potential donor could be noticed at an earlier stage, which has led to significantly more donations in Nurse B's ward in recent years. The nurses also described the importance of informative communication with the responsible physicians, which could help ensure that straightforward information could be provided correctly to families, without complicating the caring relationship. Being able to read families' thank-you letters from the Organization for Organ Donation was meaningful for the whole team. One nurse described the situation:

*The physician-in-charge [organizes] a meeting when the thank you letter arrives. The donor patients' family as well as the [professional] team that cared for the patient are at that meeting. It is a good way to let go and move on. Both for family and personnel. Lovely to hear that the organs [have] been put into use.* (Nurse K)

Subcategory II, *Teamwork: Caring as well-functioning interprofessional cooperation*, encompassed that everyone in the interdisciplinary care team during the donation process had an important task. The nurses' experiences were positive when the care team had one nurse exclusively for the donor patient and families. Caring for a potential donor patient was considered both more time-consuming and energy-intensive than for other patients.

*Most often with an extra nurse with donor patients, it feels nice to have support. You get help checking everything through so it's right. You want it to be right* (Nurse H).

Having knowledge and support from the transplant coordinator only a phone call away was described by nurses as providing a sense of security during the donor care process. A well-functioning team emerged as being of the utmost importance to being able to provide good care. In-house training with interdisciplinary simulations and routines created a sense of security about the donation process. Uncertainty sometimes could occur as to what was prioritized: the donor patient or the patient/patients that should receive the organs. Interprofessional simulations and/or workshops on donation process were desirable to create experiences and a sense of security.

The importance of the physician's involvement and that the care team is well versed in the donation process were also essential for the teamwork. The nurses described that a lack of interest from the

physician could result in a sense of insecurity in the caring team, and the nurses were aware of cultural differences and discussions about physicians' lack of interest in organ donation. Some nurses also described difficulties with some physicians:

*Can imagine raising the question of donation...with some physicians...some I would shy away from. It is dependent on the physician whether there will be a donation or not* (Nurse B).

An open climate where everyone's knowledge and opinions were considered was described as favorable for interdisciplinary teamwork.

*The donations I've been on have worked well. There is a great sense of openness in our unit.*

*At our unit, we are really allowed to 'speak our mind'* (Nurse I).

Subcategory III, *Organizational prerequisites - Caring in a demanding situation - and at the same time a need for support*, encompassed that caring for a donor patient was found to be both mentally and physically challenging. Long experience in donation processes facilitated the nurses' working situation. The nurses described the donation process as being interesting and unusual and as honing skills in identifying further potential donor patients. Most of the included units also implemented in-house routines during the donor process. In units with clear guidelines for donation, nurses expressed greater security in the donor process. Nevertheless, some nurses described a feeling of loneliness and lack of support during the donor process:

*I have been offered no support. None. It is difficult with colleagues' lack of understanding; many do not understand at all, they have never been involved in donation. You feel a bit solo, not many others understand what you have been through and what you carry with you afterwards.* (Nurse G)

Education was a prerequisite for the donation process. It was important that less experienced nurses were also included in the care of potential donors, to prevent the same nurses from always being responsible for potential donor patients. Reflection and debriefing about organ donation were considered rare but useful. There was a demand for more time for debriefing during and after the donation process. Some nurses described experiencing tension when working during the donation process, depending on resources such as the number of team members and their working experience with donor patients. As one nurse described:

*It is an event that does not happen every day; it is a non-daily task outside the regular ICU schedule.*

*We receive no external help. The workload is tremendous. It is a lot and it is difficult* (Nurse J).

The nurses described how experience and further education about the donor process facilitated caring

for donor patients:

*It is a strange situation. Abstract. They lay there rosy-cheeked and nice and look normal. Sometimes they have spinal reflexes. I can imagine that if you are a nurse on a unit where you don't have so many donations and you don't have so much education - then it can be a problem* (Nurse F).

## Discussion

As expressed in this study's theme, intensive care nurses experienced caring during the donor process as being complex due to several reasons: the potential donor patient and patient's family as well as communication, teamwork and organization. The organ donor process includes multiple relationships, with the potential donor patient and family as well as within the health care team (cf. Meyer et al., 2012). The results from this study illuminate that it requires a high level of competence and capacity from a nurse to create caring encounters with several human beings with different and sometimes contrasting feelings (grief, sorrow, hope and gratitude), all at the same time. A caring encounter requires a reflective way of being from the nurse, which includes openness, sensitivity, empathy, the ability to communicate confidence, courage and professionalism as well as showing respect and supporting dignity (Holopainen et al., 2019). Caring for potential donor patients and their families was complex for the nurses included in this study from two perspectives: from the professional nursing perspective, where the nurses need to manage the situation and care for the donors' organs for someone else in combination with a lack of time as well as a large workload. Complexity even arose from a "me" perspective, where the nurse relates to him/herself as a person. Even if the main substance of the caring encounter is to help family members verbalize and express their suffering, the results show that the caring encounter also influences the nurses. Nurses were touched by feelings about their own and their own families' existential life issues, human dignity and existential thoughts about death and donation. Nurses perceives the other's life situation as if it were their own (Lindström et al., 2018) and recognize the importance of shared humanity (Nyholm et al., 2017).

Caring during the donor process is also complex due to communication. Communication in ICU is not only limited to patients but also extends to families and team members where intra/inter/transpersonal communication is important (Mahvar et al., 2020). The nurses described an open climate and respectful communication within the team as being valuable but not always a matter of course. One explanation may be structures of hierarchy between different professions which, according to YazdiMoghaddam

(2020), still cause doubts and conflicts during the donor process. Good communication with the potential donor patient's family is vital in promoting participation in decision-making (Happ et al., 2004) and providing care to family members (Almansour & Abdel Razeq, 2021; Kerstis & Widarsson, 2020). However, families' considerable distress can make communication difficult (cf. Carlson, 2015). To communicate and provide caring for family members in this situation requires that the nurse receives families' world and feelings, engages in genuine sharing, and can see and witness families' suffering. The existential position of being a witness requires courage of the nurse, and this may bring a new understanding of life in the face of death and suffering (Arman, 2007). The nurses in this study stated that it is important to be honest with family members and not withhold information even though it causes grief. Truth telling and standing by the family's side is to mediate caring based on true presence and togetherness according to the nurses (cf. Karlsson & Bergbom, 2015). Caring during the donor process was further complicated by a lack of support from the organization, and the nurses' expressed feelings of loneliness and insecurity. These shortcomings threaten a successful donation process because such presupposes effective organizational management and collegial support (cf. Simonsson, 2020; YazdiMoghaddam, 2020). Walker et al. (2013) describe the importance of emotional support throughout the entire donation process. According to Bridges et al. (2013), the organization of health care is important for health care professionals' ability to create caring relationships. Patient safety and well-being are the most frequent concerns in publicized interventions, while interventions with health care professionals are more unusual (Bueno et al., 2019). From our point of view, there is a need to increase competency in multiple aspects of organ donation, including team communication and collaboration, with the goal of promoting a caring culture of donation. Caring affects not only the patient but even all involved - family, the caring team, the bedside nurses – all of whom contribute to the caring culture in organ donation care.

These findings should be interpreted with consideration of several limitations. Data were collected through interviews with intensive care nurses. The study sample group consisting of twelve intensive care nurses was rather small, but the interviews provided rich data rich with descriptions and a sufficient amount of information. Another limitation was the two different data collection methods, face-to-face meetings and web-based meetings. However, web-based interviews enable the possibility to include nurses nationwide. Credibility was attained using a semi-structured interview guide

in which, after a pilot test, some minor changes were made. Furthermore, credibility was enhanced by robustness of analysis and the researchers discussing each step.

**Conclusion:** This study increases knowledge about intensive care nurses' and caring teams' perspectives on the donor process to provide better conditions, such as the development of effective care intervention strategies during the organ donor process as well as caring for the families and organ donor caring team. Intensive care nurses experience that there is a complexity in the potential organ donor caring process. In the future, and in times of limited resources, intensive care nurses must be afforded ample organizational conditions to be able to make difference in the donor process, for the organ donor caring team, and for the donor patient's family.

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