

**Attitudes towards Organ Donor Advocacy  
among Swedish Intensive and  
Critical Care Nurses**

**Anne Flodén**



**UNIVERSITY OF GOTHENBURG**

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*“The range of what we think and do is limited by what we fail to notice. And because we fail to notice that we fail to notice, there is little we can do to change; until we notice how failing to notice shapes our thoughts and deeds.”*

R. D. Laing

To Leif, Maria, Malin, and Simon



## 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 Twenty-five percent of the respondents indicated that mechanical ventilation was withdrawn in order to reduce suffering for a presumably dead person and that the issue of OD was never mentioned.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

## ORIGINAL PAPERS

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

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

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## ABBREVIATIONS AND DEFINITIONS

### Abbreviations

ATODA	Attitudes towards organ donor advocacy
ATODAS	Attitudes towards organ donor advocacy scale
BD	Brain death
EU	European Union
ICU	Intensive care unit
ICU nurse	Intensive and critical care nurse
NICU	Neuro intensive care unit
OD	Organ donation
PICU	Paediatric intensive care unit
POD	Potential organ donors
SAHP	Swedish association of health professionals
TICU	Thoracic intensive care unit
TRA	Theory of reasoned action

### Definitions

The concept of ‘potential organ donor’ is used to denote a patient who is declared dead due to brain death, treated by means of a ventilator in an ICU and are considered medically suitable to become an organ donor, but where the decision about OD has not yet been made (The Swedish Council for organ and tissue donation, 2010).

*In this thesis:*

The concepts next of kin, relative and family/family members were employed synonymously.

The term nursing will refer to the discipline, unless otherwise stated.

The term loved one will refer to the deceased persons’ relationship to his/her next of kin.

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## PREFACE

My interest in the research field in this thesis is due to my work experience. The first occasion on which I participated in organ donation was in 1980 during my education to become a specialist nurse in anaesthesia and intensive care. At that time Sweden still had heart-related death criteria. During the following 19 years as a clinical nurse, I had the opportunity to care for both potential and actual donors in the intensive care unit and during organ donation in the surgical ward. Trying to offer the family members the best possible support and assistance during their time in the ICU has always been an area that I considered important, in order to provide them with the best conditions for healthy mourning. These situations have given rise to many experiences and reflections that have had a profound impact on me.

Since I started to work as a transplant coordinator almost 13 years ago and had the opportunity to meet and talk to ICU staff in different hospitals across the country, the question as to what ICU staff need to know, in order to feel secure in their role and do a good work when the possibility of organ donation arises, has become even more urgent. This particularly applies to the question about why organ donation does not take place, despite the wish of the deceased person, as it is important to respect the individual's right to decide.

A literature review was performed in 2004 to explore whether it would be possible to find answers to these questions. The results revealed that the most important factor for ensuring that organ donation takes place was the attitude of ICU staff to organ donation. This places great responsibility on ICU staff. My thoughts continued concerning what influences an individual's attitudes and actions in general and in the organ donation situation in particular. The result of these reflections led me to write this thesis.

## INTRODUCTION

In Sweden, approximately 95,000 persons die every year. Of these, 250-300 die in circumstances that enable organ donation (OD), which mean that these situations are a rare event in healthcare. In 2009, 208 persons were considered potential organ donors (POD). The number of actual donors that same year was 128 persons (The Swedish Council for organ and tissue donation, 2010; The Swedish Transplantation Society, 2011). These figures indicate that more donations would be possible in Sweden. However, there seem to be barriers preventing OD from actually taking place. At a national conference arranged by the National Board of Health and Welfare in 2002, an experienced senior physician with extensive knowledge of OD expressed that it *"might be unethical not to approach the question of organ donation"* with the relatives. He argued that it is also important to inform the relatives when OD is impossible, since some relatives ask about it at a later stage. The mother of a deceased 21-year old girl later confirmed this line of argument at the conference. She was upset by the fact that no one at the hospital had raised the question about OD. Since childhood her daughter had been pro OD. The mother asked the hospital management as well as the media: *"Why didn't you let Alexandra become an organ donor?"* (The National Board of Health and Welfare, 2002). The question remained unanswered, whether a person who has expressed the wish to donate his or her organs after brain death (BD) will actually have this wish fulfilled. Will the health care professionals carry out this last wish?

The prerequisite for a person to become an organ donor is that the event of BD takes place within the highly technological environment of an intensive care unit (ICU), during mechanical ventilator treatment. Organ donation occurs within a field of ethical tension and is often debated at national level. The whole OD-process is restricted by laws and regulations. Since OD is a prerequisite for organ transplantation, it is of the utmost importance to identify and understand the causes behind barriers to OD. Barriers might exist at various levels, among the members of society, within the health care organisation and among health care professionals.

One demanding and challenging task in the intensive care unit (ICU) is the caring for a person after the brain has ceased to function and the patient is actually dead. Understanding the concept of death, BD and its consequences is very difficult for most people, as it challenges all our previous beliefs about death and dying. Historically, we associate death with the cessation of breathing and the absence of a pulse or heartbeat. E.g. the Bible describes the moment of death the time when man stops to breathe:

*"Abraham breathed his last and died in a ripe old age, an old man satisfied with life; and he was gathered to his people"*

(Bible, Genesis 25:8).

*"Then Jesus shouted, "Father, I entrust my spirit into your hands!" And with those words he breathed his last"*

(Bible, Luke 23:46).

Traditionally, death has been associated with peace, dignity, respect and an end to suffering and recognized as the distinct passing from one state to another (Satterthwaite, 1990), marking the conclusion of end-of-life care. Recent advances in medical and technological science have blurred the boundaries that previously differentiated the living from the dead, through their ability to artificially maintain cardiac and respiratory function for a variable period of time. A consequence is that end-of-life care continues into after-death care in order to facilitate OD. The often short and intensive period of after-death care is the focus in this thesis, which aims to investigate attitudes towards organ donor advocacy among Swedish ICU nurses, since there is a lack of scientific knowledge about these professionals as viewed from the perspective of the Swedish laws and regulations and Swedish health care organisation.

## BACKGROUND

### Perspective and viewpoints

Nursing is a discipline and profession that sustains caring. In this thesis it's assumed that nursing cannot take place without caring actions. Caring is a central and unifying concept for the discipline and it is necessary to understand the phenomenon, i.e. organ donor advocacy, in the context of care for a potential or actual organ donor. It takes a nursing perspective on OD and focuses on how nurses can facilitate nursing in the sense of organ donor advocacy when there is a POD. The primary interest is how ICU nurses perceive and understand organ donation as a situation and organ donor advocacy as a motive driven action, when caring for a potential or actual organ donor.

The meaning of the ICU-nurses' experience is possible to determine only as a relation between its content and context. What they experience occurs in a context and must be taken into consideration to be understood (Marton & Neuman, 1989). This thesis deals with the pattern of human behaviour in interaction with the environment in life-critical situations. The life-critical situation in focus is the unexpected BD of a person in an ICU, which might result in OD. Thus, the highly technological ICU environment constitutes the context in which these studies were performed.

The queries raised involve perceptions of experiences of OD among Swedish ICU nurses. In this thesis, OD as a situation is defined as; a clinical situation involving the care of a (potential) organ donor and OD as a phenomenon is defined as "*a fact or situation that is observed to exist or happen*" (Oxford reference on line, 2011). One of the research questions is whether there are supportive or non-supportive organisational structures for the ICU nurse that affect his or her professional responsibility and nursing activities in this situation. Throughout this thesis the term nursing will refer to the discipline, unless otherwise stated.

### What methods are used?

The effort to acquire scientific knowledge involved seeking the unique in each individual case (I and III) as well as group correlations (II and IV). For this reason, the data collection methods were both inductive and deductive and included interviews and questionnaires (Table 1, p. 41). The inductive approach was chosen for Papers I and III because the area had been poorly investigated and there was a lack of specific knowledge about attitudes towards organ donor advocacy. Humans differ in how they experience the world, but these differences can be described, communicated and understood by others (Sjöström & Dahlgren, 2002). In phenomenography, the research concerns the "experienced world", which means that I was interested in the ICU nurses' everyday world without adopting a phenomenological notion of the life world as a starting point. Phenomenography is said to structure the subjects' practical life world. Central concepts in phenomenography are 'what' and 'how'. The first order perspective presents 'what' the informants talk about and the second order perspective 'how' they talk about it. We can only meaningfully describe the experienced world. Therefore only ICU nurses who had cared for a POD were included in the data collection. The reason for choosing phenomenography was to describe ICU nurses'

experiences. Reality is considered to exist in the way the ICU nurse conceives it. Thus the world is thought to give itself to the ICU nurse through his or her experience of it. We cannot meaningfully discuss inexperienced reality, as reality only extends as far as our experiences (Marton & Neuman, 1989). Consequently, it is argued that people's different ways of understanding or experiencing the surrounding world are all there is. We may compare different understandings with each other, but not with reality itself. This means that it is impossible to reach the absolute truth about something, in this case ICU nurses' perceptions of experiences of organ donor advocacy, since new interpretations are continuously made both by ourselves and by every new generation (Uljens, 1993).

Phenomenographic reduction is constituted by reflection on the part of the researcher's. The empirical studies in this thesis have been guided by a specific research interest. The knowledge of interest has guided the specific studies as well as many years' experience of being an ICU nurse and later a transplant coordinator in OD. In order to ensure a good interpretation, I also familiarize myself with theoretical knowledge in the OD field. Previous knowledge was no hindrance to being open-minded, in terms of the data collection and analysis. According to Uljens (1993), we normally possess the ability to consciously suspend our personal understanding of a subject in order to comprehend somebody else's argumentation.

The epistemological assumption also involves a belief that knowledge about e.g. organ donor advocacy can be studied by observing the behaviour of professionals by means of measurement instruments. The deductive approach in Paper IV was motivated by the absence of a method for measuring the attitudes towards organ donor advocacy. In Papers II and IV, numerical data were collected to allow comparison and enable statistically significant relationships. The measurements and questionnaires were used to evaluate and map ICU nurses' attitudes towards organ donor advocacy as well as to collect descriptive data on OD as a situation from the ICU nurse's perspective. The results of the two initial papers contributed a knowledge base for the following two papers, e.g. when designing the questionnaire for the fourth paper.

In conclusion, this thesis:

- is viewed in the light of professional ethics, where one basic assumption is that being a professional nurse involves an ethical demand to respond to the pledge of human beings, alive as well as deceased, and rests on Koehn's (1994) description of and argumentation about the ground of professional ethics.
- strive to illuminate and describe the Swedish context of organ donation from the perspective of the ICU nurse, in order to understand underlying dimensions that might affect the situation of OD and might obstacle the realization of OD.
- is based on the assumption that the ICU nurse is a motive driven person who tries to make meaning out of caring for the POD.

- is built on the assumptions that OD takes place in an ethically tensed field and that advocacy plays a central role and is a crucial phenomenon in the work with a (potential) organ donor. Patient advocacy is an important aspect of current professional nursing and considered to be a fundamental value of nursing (Hanks, 2010)
- focuses on perceptions of and attitudes towards (potential) organ donor advocacy among Swedish ICU nurses.

## **Brain death**

Death is an irreversible, biological event that consists of permanent cessation of the critical functions of the organism as a whole. Brain death therefore qualifies as death, as the brain is essential for integrating critical functions of the body. An important report from Sweden by Löfstedt and von Reis (1956) described six coma patients, in whom there was no passage of contrast through the cerebral circulation. Autopsy revealed no obstruction of the cerebral arteries. The authors concluded that increased intra-cerebral pressure, possibly in combination with vasospasm, was the most probable explanation for the x-ray findings. The concept of irreversible coma or brain death was first described by Mollaret and Goulon (1959) who coined the term “coma dépassé” for an irreversible state of coma and apnoea. Although specific details of diagnostic criteria differ between countries, the fundamental definition of BD has essentially remained constant over time and across countries. One exception is that whereas some countries (e.g., the United Kingdom) use the concept of brainstem death, others (e.g., Sweden) understand brain death as “whole brain death”. Causes of BD include intracranial haemorrhage such as intra-cerebral or subarachnoid haemorrhage, head trauma, cerebral neoplasm or hypoxic brain injury following a cardiac or respiratory arrest. Any condition causing permanent widespread brain injury can lead to BD.

BD (‘brainstem’ or ‘whole brain’ death) is a medical, legal and cultural concept, constructed to fill an important need created by the evolution of medical technologies and clinical practice. It is commonly believed that the concept of BD evolved to benefit organ transplantation (Siminoff, Burant & Youngner, 2004; Youngner, 1992; Youngner, 1994). Nevertheless, a historical approach to this issue will demonstrate that BD and organ transplantation had entirely separate origins. Organ transplantation developed thanks to technical advances in surgery and immunosuppressive treatment (Pernick, 1988), while the BD concept originated in the advancement of intensive care techniques (Machado, 2003; Machado, 2005). However, the construction of the category ‘BD’ introduced the possibility of procuring organs from heart beating donors and successfully transplanting them into critically ill patients. While there is international variation, BD is generally defined by the absence of clinical functions of the brain. The determination of BD is mainly limited to the context of organ procurement for transplantation, where the BD diagnosis ensures that the act of organ procurement is not the legal cause of death. The number of patients waiting for transplants worldwide continues to increase. In Sweden on January 1, 2011, approximately 600 persons were

on the transplantation waiting list. According to Council of Europe (2010) statistics, 3,819 persons within EU died during 2009 while on the transplantation waiting list (out of 64,723 in total). Increasing OD rates is a key goal for many national health care and political organizations. In the efforts to increase OD rates, organ donation is often presented as an opportunity for a bereaved family to provide the 'gift of life' by 'donating' the organs of a loved one to assist a critically ill stranger. The transfer of an organ from one body to another helps to create positive meaning out of otherwise meaningless deaths for surviving family members as well as clinicians. However, cultural beliefs and practices do not always keep pace with clinical and advocacy discourses.

### **Brain death criteria**

The first law in Sweden that regulated when a person is dead was introduced in 1988 (SFS 1987:269). An intense discourse over a period of 20 years preceded the adoption of the new theory of death in Sweden. The debate started after an event in 1964 at the Karolinska University Hospital in Stockholm, when a dying woman was used as a donor to a man with kidney disease (Brante & Hallberg, 1989). Sweden was one of the last countries in Europe to adopt the concept of BD. The first motion to introduce the BD concept was tabled in The Swedish Parliament in 1980 but it took another eight years before the law was adopted in 1988 (The Swedish Parliament, 1982). The current legislation (SFS 1987:269) states that a human being is dead after the brain function has ceased completely and irrevocably. In cases where a person dies after cardiac arrest, health care professionals traditionally still consider the time at which the heart stopped as the moment of death (which covers the majority of deaths). Declaration of death is established by indirect criteria based on a clinical examination and demonstrates permanent cardiac and respiratory arrest resulting in BD.

In some cases the brain stops functioning without cardiac arrest, which means that the person dies as a result of BD. Clinical neurological examination is the gold standard in Sweden for performing BD diagnostics. The diagnostics is realised with direct criteria by performing two clinical neurological examinations. In certain specific cases, it is required that the clinical neurological examinations are confirmed by cerebral angiography (which must also be carried out twice) before death can be declared. Guidelines for declaration of death are regulated by the National Board of Health and Welfare (SOSFS 2005:10).

All drugs that might influence the patient's neurological status, such as muscle relaxants or sedatives, must be stopped and Hypothermia  $<33^{\circ}\text{C}$ , metabolic disturbances and/or hemodynamic instability must be corrected. Once these preconditions have been met, the BD tests are carried out twice by a physician with specialist competence. The period that must elapse between the two sets of tests is a minimum of two hours. The BD tests involve examining the integrity of the brainstem reflexes to ensure that there is no residual or returning function. In accordance with SOSFS 2005:10, the following tests are performed:



1. Coma without response to speech, touch or pain in the cranial nerve innervated area (spinal reflexes excluded).
2. The absence of spontaneous eye movements or movements in jaws, face, tongue and/or pharynx.
3. Light-rigid, usually dilated, pupils.
4. Loss of corneal, twinkle- and pharyngeal reflexes and reflexive eye movements during turning of the head (the so-called Doll's-eye movements).
5. Unchanged pulse rate, when putting pressure on the chamber of the eye or when performing massaging the sinus carotid.
6. Absence of spontaneous breathing – verified by the apnoea test.

If these tests demonstrate that all brainstem reflexes are missing, the person is legally declared dead. The time of death is recorded as the time of completion of the second examination.

It is essential that nurses working in the ICU are aware of these criteria in order to care for these persons and their relatives with knowledge and sensitivity (Sharp, 2009; Smith, 1992). Another reason ICU nurses need this awareness is the fact that they assist during the diagnostics of BD. A majority of the donations for organ transplantation take place in the context of BD, which creates a possibility to save the lives of other individuals awaiting transplantation. At this time it is crucial to respect the so-called 'dead donor rule', i.e. that persons must be dead before their organs are retrieved. This is a vital part of the moral framework underlying organ procurement (Koppelman, 2003).

### **Participants in the OD process**

When OD is a possibility, there are a number of persons involved. The actors who are most involved are presented below:

- The donor
- The donor's next of kin
- The intensivist
- The nurse specialist in intensive care

In most cases a donor is a human being in the midst of life, but a donor can also be newly born or over 80 years old. Death is invariably sudden and unexpected for the family and can be described as a 'crisis event'. Important and demanding tasks for the intensivist and the ICU nurse are taking care of the bereaved next of kin while caring for the deceased person's body with dignity and respect and at the same time investi-

gating the deceased person's wish in terms of organ donation. All those involved are affected and engaged during this process, which embraces the extremes of life and death.

### ***The donor***

In situations of OD from a deceased person in the ICU, the major ethical area surrounds the event of death. Issues include the identification and diagnosis of BD as well as the responsibility for investigating the wish of the deceased in relation to organ donation. Additional issues concern attitudes and beliefs surrounding death itself (Smith, 1992). The real focus for ICU nurses is the deceased person, not the brain-dead organ donor (Sadala & Mendes, 2000)

The concept of 'potential organ donor' is used to denote a patient who is declared dead due to BD, treated by means of a ventilator in an ICU and considered medically suitable to become an organ donor, but where the decision about OD has not yet been made (The Swedish Council for organ and tissue donation, 2010). Once the medical suitability of a donor is established, consent to OD needs to be explored.

According to the Swedish Transplantation Act, the attitude of the deceased to OD is paramount. The wish to donate can be expressed through the Donor registry, a donor card or verbally. The last expressed wish is valid. Consent is presumed in cases where the attitude of the deceased is unknown. In such cases, families are asked to interpret the wish of the deceased. Next of kin have the right of veto only in cases where the wish of the deceased is not known, (SFS 1995:831; SOSFS 2009:30 (M)). Failure to raise the question of OD means that the ICU staff have decided against OD without investigating the matter. If the deceased wanted to donate his or her organs after death, he or she is deprived of this opportunity, despite the fact that The Health and Medical Services Act requires an ethical approach in nursing and caring, where respect for the deceased's autonomy is crucial (SFS 1982:763). A survey carried out in 2005 revealed that while 86% of Swedish people were willing to donate their organs after death, less than 50% had made this intention clear (Life as a gift, 2005). The relationship and encounter between health care staff and family are an important part of such care situations.

### ***The donor's next of kin***

Wright (1996) described sudden death as a highly traumatic crisis event. The death in BD is often sudden and unexpected, leaving the relatives overwhelmed by shock and grief. They first have to grasp the fact that their loved one will not survive. In addition, they are faced with the responsibility of expressing or interpreting their loved one's wish to donate organs or not (Tymstra, Heyink, Pruijm & Slooff, 1992). The family members have a long way to go and will face many difficulties due to the circumstances of the donation (Sadala & Mendes, 2000). Relatives must be given time to ensure that they fully understand the implications of BD and OD (Sharp, 2009). To care for and meet the family's needs is important for all ICU nurses (Ingram, Buckner & Rayburn, 2002; Pearson, Robertson-Malt, Walsh & Fitzgerald, 2001; Sadala & Mendes, 2000).

A study by Pearson et al. (2001) described the perception that caring for the family involves caring for the brain dead person, to show them that their loved one [the patient] is not only seen as an object. Jacoby and Jaccard (2010) who presented specific elements associated with consent to OD found that donor and non-donor families had different perceptions of the quality of care provided to themselves and their next of kin. The strongest predictor of consent was receiving understandable information about OD. One of the most important needs of relatives is to continually obtain information. How it is provided is therefore crucial. Organized meetings to inform the family should preferably take place in a secluded, peaceful environment, where both physicians and nurses are involved. The role of the nurse is to later repeat and maybe further clarify the information (Beaulieu, 1999; Robb, 1998).

Approaching the relatives often appears to be the most difficult aspect of OD (Sadala & Mendes, 2000; Sharp, 2009; Smith, 1992). One important ethical issue is talking with the family to investigate whether the deceased had a wish for or was against donating his or her organs. According to SOSFS 2009:30, the director is responsible for the management of the donation process and the establishment of suitable routines and a clear division of responsibility. The statute also includes guidelines for who should provide the information and how it should be done: *“information shall be formulated and provided, taking account of the grief experienced by next of kin and the support they may require”* (SOSFS 2009:30).

### **The intensivist**

In the ICU, the intensivist [i.e. ICU physician] is the authority governing the organization of care and has specific responsibility for the highly specialized medical treatment administered. This responsibility is supported by an organizational structure consisting of schedules, instructions and guidelines. The physicians are responsible for medical treatment and the ICU guidelines that nurses must follow (Cronqvist, Theorell, Burns & Lütznén, 2004). According to Sadala, Lorençon, Cercal and Schelp (2006), the role of the ICU physician during the OD process involves:

- identifying a POD
- consulting with the transplant coordinator/transplant unit regarding the medical suitability for transplantation
- medical treatment of the POD, to keep the organs transplantable
- performing the diagnostic tests to declare BD
- informing and communicating with the family, e.g. that their loved one has died, as well as asking about the deceased's wish regarding organ donation

The role of the ICU physician is crucial during the OD process. However, few studies describe the ICU physicians' role when caring for brain dead PODs. Sadala et al. (2006), reported that the ICU physicians' role when providing care to potential donors is similar to that when caring for regular ICU patients. Although medical techniques and speedy interventions are essential, there are some differences when caring for a

(potential) organ donor. It is important to understand that family participation is decisive in the donation process. Interactions between family members and the physician were described by Sadala et al. (2006), as difficult because of the sensitive nature of the situation and the fact that physicians often felt ill prepared to openly discuss the topic of BD and organ donation. Many years of experience was described as being helpful for positioning physicians more positively in this complex situation. Sanner, (2007) found that pro-donation intensivists regarded preventing a hasty 'No' as their most important duty. They also considered it their duty, to help next of kin to make a carefully considered decision without persuasion (Sanner, 2007).

The ICU physician plays a major role in the different stages of the donation process. His or her main objectives are to keep life going and make people healthy. To find a meaning for these actions in the context of OD, the ICU physician focuses on the possible benefits for a recipient (Sadala et al., 2006). Several studies indicated that the knowledge and attitude of the intensivist has a major impact on the donation rate (Bartucci, 1987; Federal Centre for Health Education, 2001; Sanner, 1991, 2007; Siminoff, Arnold, Caplan, Virnig & Seltzer, 1995).

Both nurses and physicians are expected to work together for *each* patient, although they have different responsibilities and perspectives. Collaboration between nurses and physicians is often intense and it is necessary for them to maintain a good working relationship. Physicians are responsible for many patients while nurses have responsibility for one or a few patients. The nurses are also at the bedside, closely monitoring the patient's condition, sometimes for many hours (Cronqvist et al., 2004). Sadala et al. (2006) stated that it is clear that a team approach is required when caring for a brain dead organ donor. Each member of the different teams plays an important role, and all members must be educated regarding the process and diagnostics of BD.

### ***The specialist nurse in intensive care***

ICU nurses are the health care professionals most closely involved in the bedside care of the POD and his or her relatives. They spend a considerable amount of time in close contact with the patients and their families. Therefore, they have the opportunity to develop relationships that give them insight into the values, beliefs and understanding of patients and relatives (Bertolini, 1994). Nurses are at the centre of patient care, as they have access to medical, nursing and patient information. They relay information and actions between the physician and patient. According to Craig (1989), the nurse is in a unique position to appreciate the dynamics of the entire caring situation.

A specialist nurse has a post graduate level education and a research base firmly embedded in nursing care science. The educational programs in which they participate, aim at preparing them to function in expanded roles as comprehensive caregivers (International Council of Nurses, 2009; The Higher Education Ordinance, 2011). Handling the needs of families who have experienced clinical BD in a loved one requires advanced nursing knowledge, skill and expertise (Coyle, 2000). Andrew (1998) argued that it is possible to optimize the human experience of the families whose next of kin has died in an ICU. This might be achieved through triangulation of the roles of the nurse:

- as a person
- as a practitioner
- as a colleague

The nurse defines key elements through merging these roles by; being there, sharing, supporting, involving, interpreting and advocating. Nurses' essential characteristics are cited as critical components in their ability to act as nursing advocates (Hanks, 2010; Penticuff, 1989; Sellin, 1995). Factors that influence nurses' ability to advocate are the main characteristics of their self-concept, personal values and confidence as nurses as well as their personal beliefs (Chafey, Rhea, Shannon & Spencer, 1998; Foley, Minick & Kee, 2002; Perry, 1984). Forces have been identified that oblige nurses to advocate, including emotional and moral distress (Perry, 1984; Sudin-Huard, Fahy, 1998), moral obligation (McGrath & Walker, 1999) and vulnerable clients with unmet needs (Hanks, 2008; Mallik, 1998; O'Connor & Kelly, 2005; Segesten, 1993).

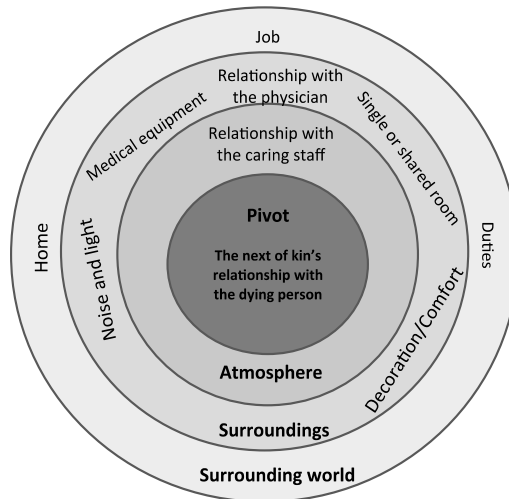
### **How the various actors in the organ donation process are related to each other**

In order to position the relationships between the different actors in the organ donation process, I applied a model describing the end-of-life care in the ICU. The model is presented in a recently published dissertation by Fridh (2009c) covered end-of-life care in the ICU. The critically ill patient was described as being the main target of the ICU nurses' care and concern, but most important was the certainty that the family should receive the best possible care and treatment. To illustrate this Fridh used a modified model of the caring environment developed by Ylikangas (2007) containing four layers (the *Pivot*; the *Atmosphere*; the *Surroundings*, the *Surrounding world*), to describe the relatives' experiences related to the death of their loved one in the intensive care environment (Figure 1).

1. The patient was always in the *Pivot* while next of kin physically moved between all levels, despite the fact that the surrounding world became smaller when their relative was dying. The Centre for the relatives was their relation to and concerns about their loved one's condition.
2. The next layer was the relationship with the caregivers/nurses. The relatives were decisive for how the *Atmosphere* was experienced. If the nurses invited them into a relationship and showed concern and empathy towards the patient as well as the family members, it generated a high degree of trust and confidence. When the caregivers were perceived as professional, the family felt trust and security so that they sometimes physically dared to leave their loved one.
3. The third level contains the *Surroundings*, where the relationship to the physicians was found. Their role was described as informative and explanatory, more objective towards the patient's condition and with a greater distance to the family than the caregivers/nurses. The environment also included technology, other patients and their next of kin. The waiting room for the relatives was also included in the environment area.

4. The *Surrounding world* was found in the fourth and outermost layer and included the relatives' home, work and other duties.

When the relatives were in the Surroundings or in the Surrounding world, they were still mentally in the Pivot with their loved one (Figure 1).



**Figure 1.** The relatives' experience of the death of a close family member in an intensive care environment as described in the thesis by Fridh (2009c, p. 45) and modified from a model by Ylikangas (2007). Interpreted for this context by Flodén and published with permission of I Fridh.

Doing one's utmost, which involves ensuring dignity and comfort for the dying patient, was described by Fridh, Forsberg and Bergbom (2009b) as the essential caring actions when relatives were present in the ICU. The role of the ICU nurse in these situations was characterized by the effort to provide dignified end-of-life care and to give the family members an enduring memory of their loved one's death. The central role of the nurse comprised providing comfort for the patient as well as offering presence, trust and support for relatives. It was essential for the nurses to establish a caring relationship with next of kin. The nurses' endeavour to 'Do one's utmost' comprised: assuring relatives that the patient is not suffering; communicating with relatives; encouraging family presence; being present; providing support and creating trust; adjusting the 'high tech' environment; direct the time of death; arranging a dignified goodbye and offering and conducting a follow-up meeting (Fridh et al., 2009b).

### **The role of the specialist nurse in relation to brain death**

Nurses working in an ICU might face the situation of caring for brain dead persons, some of whom may become organ donors. The nurses' role in such situations is multifaceted. In addition to mastering the medical treatment, he or she must care for the relatives and support them during their time in the ICU, e.g. when they receive news

of the death, when the issue of OD is raised, when saying a final farewell after surgery and occasionally at the follow-up meetings a time after the OD (McCoy & Argue, 1999). By their presence at the bedside, the nurses have an opportunity to create a closer relationship with the relatives (Johnson, 1992).

The ICU nurse specialist plays a role in BD as, along with physicians and other health-care professionals, he or she faces the daunting task of supporting the family through the emotional crisis as they attempt to come to terms with the diagnosis of clinical BD (Coyle, 2000). It has been suggested that the shock and disbelief experienced by relatives may be minimized if they are aware of the process that leads to the confirmation of BD (Bisnarie, Burden & Monik, 1988; Johnson, 1992). In addition, it is essential that nurses are aware of the regional, national and local policies and protocols that govern BD testing, thus enabling them to support and inform families. If nurses appear uncomfortable when relaying or explaining information, the family may question or fail to accept the diagnosis of BD (Coyle, 2000).

The whole concept of OD is surrounded by an increasing variety of ethical issues and considerations. In order to illustrate the complexity of the situation, a scenario of a POD in the ICU is provided below. Let us imagine a young ICU nurse caring for a person of about the same age who suffered a fatal head injury.

*“The young patient is going to donate her organs today and her body is going to die quickly without the support of artificial ventilation, fluid and drug therapy. The nurse is charged with caring for this dying body, this young dead person and their bereft family. This example announces the extreme aloneness and shocking finitude of the other. The nurse is already faced with the irrevocable transition of an alive human body, who looks as if she is comfortably sleeping, to a lifeless corps, there on the bed. This person, yesterday embodied a full aliveness, carried a personal story, a unique life’s journey that he, her nurse today, knows nothing of. By nightfall she will be a cadaver for him to make ready for removal to the mortuary. His only sense of the remembered aliveness of this person is through her family members who are waiting to say a final goodbye to their loved one. He can feel the family’s distress, he can feel the wretchedness of the situation, he identifies with it, but he is not the other. There is a boundary between him and her vulnerable body, but he is still shocked deep down. This person is dead. Cut down. He senses his own vulnerability and he feels from somewhere deep inside a bodily recognition of the desperateness of this situation. This could be him or his loved one. It is not the details that are important but how they announce a felt sense of being in a vulnerable and marginal space. He feels a tightening in his gut. In caring, the nurse whose task is to be present is to care for this already dead person, whose body lives. In caring, he has to sensitively straddle this most fundamental disconnect, an alive body on the one hand with, ‘she is already gone’, ‘this is final’, on the other, for the family’s sake. This dilemma announces a fundamental ambiguity about this situation: is this person dead or not?” (Galvin, 2010, p. 172)*

The above scenario implies the ethical dimension in the particular situation of OD and raises queries about what kind of knowledge is needed to guide caring practices. Although certain facts are accepted and compromises reached, there often appears to be no definitive right or wrong answer to the various ethical questions. Ethical situations arise when the moral decision of one person conflicts with the moral decision of another (Fries, 1989). People come to their own conclusions and decisions according to their personal opinions, feelings and philosophical views.



# FRAMEWORK

## The Profession

Christoffersen (2007) asks what a profession really is and argues that the term is often used synonymously with occupation. The National Encyclopaedia (2011) defines profession as “an occupation whose authority and status are based on high levels of formal education, often university-based”. According to Bentling (2009), a profession can be characterized by the fact that its members are covered by a particular paradigm based on a worldview and strategy. A profession can also be described as a culture where people, in a field of rules, are taught what they need to know and how to be.

This thesis is inspired by a model by Bentling (2009) describing professional competence, which is a unitized concept that can be illustrated by four different areas:

- the given
- the intended
- the tacit
- the possible

*The given* concerns a public and a social level, reflected in legislation and affecting the educational content on which the professional role and competence are based. It is governed by laws and government documents and can therefore not be questioned without strong arguments or political pressure.

*The intended* refers to a different social level that includes developments in research and thus provides a scientific basis for education, training and skills development. Scientific documents are used to regulate the formal education. By using research in this way, scientific knowledge will be publicly acknowledged. As an individual, it is required to be informed and have a critical approach based on scientific research.

*The tacit* belongs to the organization and the working group’s common skills and values. In the tacit field, individual interpretations of the two previous levels are used and communicated. This field also comprises the notion of the working group in terms of the work of individuals in a specific organization and how different workplaces interpret and apply law and new research. The unspoken culture at a work place is about the hands-on work, regulations and routines, reflected or unreflecting acts, common ideals and working methods.

*The possible* illustrates an individual dimension in which each human being becomes the final filter through which the professional competence will pass according to his or her own ability and ambitions. It deals with how to interpret one’s mission, how to use and develop one’s skills and whether one can, will and dare to stand up for one’s actions. Life and the professional paradigm integrate and emerge via the ideal, visions and ambitions, where theory and practice interact with each other. Reflecting upon ideologies, skills, values and working methods contribute to achieving the goals of the four different fields.

The first two levels, *the given* and *the intended*, are probably the easiest to understand and use, while the latter two may be viewed as more difficult to grasp. As a professional it is a major challenge to clarify, exploit and develop what lurks in *the quiet* and *the possible*, in order to apply *the given* and *the intended*. The differences between professions imply that every profession has its own professional ethics.

## **Professional ethics**

The results in this thesis is viewed in the light of professional ethics, where one basic assumption is that being a professional nurse involves an ethical demand to respond to the pledge of human beings alive as well as deceased. Using Koehn's (1994) description and argumentation regarding professional ethics, one might say that the unilateral, unqualified pledge of professionals to serve a specific group of vulnerable human beings, e.g. PODs, is the basis of professional's authority and legitimises their power to initiate and perform or authoring life-altering actions on the client's behalf. The pledge functions as a foundation, as it meets the objective requirements for a trusting relationship between professional and client. It binds only the pledger and legitimates only the authority of those making the vow, as opposed to all human authority. In addition, the pledge can be said to be the ground of professional authority because, like all grounds, it reveals in whose eyes professionals have authority. Those making the pledge have the authority to do what they promised to do, both in their own eyes and in those of their actual or potential clients.

According to Koehn (1994), adherence to the pledge meets the requirements for client trust. The pledge itself can be considered as embodying these requirements. The origin of the structure does not affect its ability to serve as a legitimizing foundation for professional practice. The question of legitimacy arises in every interaction with each client because in order to continue to merit a client's trust, the professional must repeatedly demonstrate that he or she is acting in that client's best interests.

In conclusion, professionals must have some way of establishing that they are worthy of the clients' continuing trust. Adherence to the professional pledge in each and every interaction with the client constitutes a solution to this problem. Koehn list seven conditions (see below) for professional authority. Applying these general conditions to the situation of caring for the brain dead POD reveals the following picture:

*Condition 1:* To be trustworthy, the ICU nurse must have the POD's interest at heart, including that of his or her relatives. Trust is simply the trustor's expectation that the trusted person will act in his or her best interest. Since the ICU nurse is the one who is trusted, and the POD and his or her relatives are the trustors, it follows that the nurse must do his or her utmost for the patient's good, to be worthy of the relatives' trust.

*Condition 2:* The best evidence of professional nurses doing their utmost, for the client's good, is taking action on behalf of the POD and his or her relatives. Demonstrating willingness to act is therefore necessary for trust in this situation.

*Condition 3:* The willingness must be sustained, since the POD and his or her relatives expect the nurse's good will to be forthcoming, not only for the next minute or hour, but also for as long as it takes for the decision to be made about whether or not OD will take place.

*Condition 4:* Even sustained willingness to help will not make a professional trustworthy unless he or she is actually competently determined of the POD's and his or her relatives condition, and to until then, do what will in fact tend to help them. The judgment of the profession and individual practitioner constitutes a standard of practice defining what it means to act for the benefit of the POD. To be trustworthy, the ICU nurse must conform to this standard or provide compelling reasons for deviating from it. In short, to be trustworthy, ICU nurses must be competent.

*Condition 5:* Is not applicable to a deceased POD since the professional must be able to demand that the client exhibits the degree of accountability and discipline necessary for treatment to proceed. However, it might be applicable to the relatives.

*Condition 6:* The trustworthy ICU nurse must have the freedom to act in the best interest of each individual POD and his or her relatives. Revising prior commitments and previous allocations of time and energy might result in a better service for the clientele as a whole.

*Condition 7:* Finally, ICU nurses must have a highly internalized sense of responsibility. No one can supervise professionals all the time, so the professional him or herself must monitor his or her own behaviour (Koehn, 1994, p. 54-56).

## **Values and attitudes**

Value is an extensive concept. It can be defined as something that we are interested in, that we value and that is essential for a human being. Our values are revealed by our words and actions. When important values are achieved, basic needs are covered at the same time.

What is understood as basic needs are to some extent relative, as they are associated with specific situations and living conditions (e.g. food, clothes, democracy and freedom). There are both conscious and unconscious (hidden) values. Both affect our way of behaving, for instance in the interaction with other people. The hidden values are usually concealed even to ourselves and affect our behaviour without being aware of it. In the same way as our values help us to focus on what we value, they can also make us blind to everything but that which occupies us (Tranöy, 1976). As described above, our values are expressed in our attitudes and way of being and acting. These attitudes can be evaluated as positive or negative, meaning that we have "taken a stand" (Breckler, 1984). The tripartite model of attitude structure is composed of three

components; cognitive (knowledge), affective (emotional) and intentional (the trend in our actions). Attitudes based on imperfect knowledge are often referred to as pre-conceptions (Breckler, 1984). According to Ajzen and Fishbein (1980), individuals' attitudes towards behaviours are a significant predictor of their behavioural intention and actual performance of the behaviour.

It is especially important that nurses are aware of their own attitudes and pre-conceptions. This awareness is the first and necessary step towards positive change and development. Seeking self-knowledge is particularly important for the professional caregiver. Changing attitudes is a time-consuming process. The cognitive component is central to being able to achieve change in the affective component and hence a change in the trend how to act in a particular situation. There is also a hierarchy within the values, where some are more important to us than others. This hierarchy is highly personal and is continually under development and change. Our inter-mutual order of the values determines how we make our priorities. When different core values stand against each other, a dilemma or conflict will arise. To avoid these negative consequences, it is important to try to make well-aware choices. However, being aware of one's own values and the different options available requires knowledge (Breckler, 1984; Tranöy, 1976). Values have a central position in the nurses' ability to function and in their professional identity. Therefore, it is essential that the nurse makes consciously choices when caring for the POD, in order to be able to safeguard the will and wishes of the deceased person.

## **Advocacy**

Nursing has designated the advocate role as a central role of nursing practice, even though other health professionals also advocate for their patients (Hanks, 2010). This thesis was built on the assumptions that OD takes place in an ethically tense field and that advocacy is a crucial phenomenon that plays a central role in the work with an organ donor. Hanks (2010) argue that patient advocacy is an important aspect of current professional nursing and is considered to be a fundamental value of nursing. Also the codes of nursing ethics reflect the on-going significance of advocacy (American Nurses Association, 2001; International Council of Nurses, 2006). The concept of advocacy involves the activity of advocating, which is synonymous with to support, uphold, champion, back, defend, justify and promote. Advocacy is also described as being the patient's voice, protecting patients and acting as a guide (McSteen & Peden-McAlpine, 2006; Sellin, 1995). According to Vaartio, Leino-Kilpi, Salanterä and Suominen (2006), advocacy is a part of excellent nursing and performed by the nurse due to personal or professional involvement. One form of advocacy is so called whistle blowing, where the nurse highlights the patient's rights and needs.

The concept most frequently cited as a component of nursing advocacy research involves acting on behalf of patients, including intervening on their behalf within a system, resulting in nursing actions of speaking, fighting and standing up for patients (Chafey et al., 1998; Foley, Minick & Kee, 2000; Hanks, 2008). The role of advocacy has also been described within the ICU by Lindahl and Sandman, (1998). According to them the meaning of the role of advocacy in the ICU lies in a moral and existential

response to another human being, an expression of caring. They argued that when a patient needs advocacy, the nurse responds to this need in order to create dignity and comfort for the patient and his or her relatives. Lindahl and Sandman (1998) described the role of advocacy in the ICU, arguing that advocacy implies building a caring relationship that involves encountering the private person and sharing a part of his or her life history. It also includes commitment and empowerment. In terms of patients' next of kin, it concerns making room for interconnectedness, involving providing and explaining information as well as communication and collaboration with the family members. The nurse acts together with the next of kin in the patient's best interest; guiding, assisting and involving the relatives. The role of advocacy in relation to colleagues meant being a risk-taker and a moral agent.

In conclusion, previous studies have defined advocacy as using expert knowledge to advocate effectively, challenge traditional health care power structures, empower patients and bridge the perceived communication gap among patients, other professional categories and the health care system (Chafey et al., 1998; Hellwig, Yam & Di Giulio, 2003; Lindahl & Sandman, 1998; Mallik, 1997; O'Connor & Kelly, 2005; Vaartio et al., 2006).

### **Patient advocacy as a theoretical construct**

Bu and Jezewski (2007) developed a mid-range theory of patient advocacy, arguing that advocacy is linked to the context and that nurses advocate differently depending on the situation. In this theory, patient advocacy is viewed as a process or strategy consisting of a series of specific actions for preserving, representing, and/or safeguarding patients' rights, best interests and values. Patient advocacy includes three broad core attributes:

- *safeguarding patient autonomy* – which involves a series of specific actions aimed at respecting and promoting the patient's self-determination in situations where he or she is competent and willing to participate in self-care activities.
- *acting on behalf of patients* – constitutes a series of specific actions that safeguard and represent patients' values, best interests and rights in situations where they are incapable of representing themselves, e.g. due to unconsciousness.
- *championing social justice* – refers to actively striving for change on behalf of individuals, communities and society as a whole, aimed at identifying inequalities and inconsistencies in the provision of health care.

The first two core attributes relate to different types of clinical situation. They are complementary, do not conflict with each other and represent the advocacy role at a micro social level. The third core attribute represents the advocacy role at the macro social level.

## Organ donor advocacy

Snowball (1996) described advocacy activities as respecting patients' rights, speaking up for patients' point of view in the decision-making process if they are unable or unwilling to speak for themselves, ensuring that patients make informed decisions, protecting patients' dignity and privacy as well as shielding them from interventions that might cause them distress. Applying this description to OD as a situation, participation in the OD process and caring for the potential or actual organ donor can be viewed as advocacy activities in line with the following description:

*Respecting the potential or actual organ donor's rights, representing or speaking up for his/her wishes and the relatives' points of view in the decision-making process regarding organ donation. Protecting the potential or actual donor's dignity and the relatives' privacy and defending them from interventions that might cause them distress (Flodén et al., Paper IV).*

The theoretical definition of attitude towards organ donor advocacy in this thesis was developed from Ajzen and Fishbein's (1980) definition of attitude in their Theory of Reasoned Action (TRA) and by applying Bu and Jezewski's (2007) theory of patient advocacy. According to TRA, a person's attitude towards performing a given behaviour refers to the degree to which he or she has a positive or negative evaluation thereof.

In Paper IV the construct of attitude towards organ donor advocacy is defined as follows:

*It is an ICU nurse's judgement whether he/she is in favour of or against participating in OD and caring for the potential or actual donor, for preserving, representing and safeguarding the donor's and his/her relatives' rights, best interests and values after death (Flodén et al., Paper IV).*

This includes three dimensions:

- Safeguarding the potential donor's will and wishes
- Safeguarding the will and wishes of the relatives of the potential donor
- Championing social justice.

The ICU nurse's actions in terms of organ donor advocacy when caring for a POD will be governed by the will and wishes of the potential donor and his/her next of kin.

## **Summary of research during the first 17 years of brain death legislation (1988 - 2005)**

In summary, research during the first 17 years since the new legislation regulating BD was adopted primarily focused on four domains; the donor, the relatives, the health care professionals and ethical considerations.

### ***The donor***

Early identification of a potential donor, a quick and correct diagnosis of death, maintenance of bodily functions and collaboration with the transplant coordinator are regarded as important aspects in the management of care of an organ donor (Darby, Stein, Grenvik & Stuart, 1989). Late identification of a potential donor can result in a significant loss of organs for transplantation. Consequently, early identification is crucial in order to enable supportive treatment aimed at preventing multi organ failure and other complications.

### ***The relatives***

The sudden and unexpected death of a close relative can create feelings of mistrust, guilt, helplessness, anger and emotional pain. Sudden and unexpected death is described as a highly traumatic situation for the relatives (Wright, 1996), who may find it difficult to distinguish between total cerebral infarction and coma (DeJong et al., 1998; Tymstra, Heyink, Pruim & Slooff, 1992).

Andrew (1998) stated that, in the encounter with the deceased person and his or her next of kin, the most important functions of the nurse were to be present, provide support, demonstrate commitment and interpret and safeguard their interests. As the nurse's role implies being constantly present and involved in the care provided in the ICU, he or she has a unique opportunity to function both as a listener and as an impartial informant (Andrew, 1998). However, Benner, Tanner & Chesla (1996) stressed that there is a difference between experienced and inexperienced nurses in terms of their ability to listen and take part in the suffering process of the close relatives. It may be advisable that only clinically experienced nurses, who have had time to develop this knowledge and competence, should perform these tasks. Individuals who succeeded in finding some sort of meaning in an apparently senseless loss found it easier to bear their grief. Relatives have described how continued support from ICU staff was valuable. On the other hand, lack of interest has sometimes led to bitterness and criticism of the health care system (Schulman & Håkansson, 1994).

The main reason why a donation did not take place after identification, was that the next of kin refused consent (Federal Centre for Health Education, 2001). When it was known that the deceased person wanted to donate his or her organs the will was to a large extent followed. When the deceased person had been against OD, relatives gave their consent in 22% of the cases. Next of kin who had been satisfied with the emotional support and medical care provided in the ICU consented to donation in 90% of the cases, while families who were dissatisfied only did so in 50% of the cases.

Previous research on relatives' experiences of the question about OD suggests that it may actually bring relief while mourning (Pelletier, 1992). On the other hand, Binett, Gäbel, Rencrona and Hagberg (1993) described how some relatives faced with the question of OD felt that they had no choice and considered it the most stressful issue during the whole illness trajectory. In interviews conducted one to six years after the death of their loved one, 80% of relatives stated that the decision to donate had been obvious, while others had felt some doubt afterwards and questioned whether or not

the decision had been the right one. Several of the relatives commented that they found it positive and extenuating that the organs could help others. Bartucci (1987) reported that 85% of donor families perceived that the OD was a positive aspect during the mourning period and that 91% did not regret the decision to donate their loved one's organs. Frid et al. (2001) depicted next of kin's needs as an inner journey that started with a secure life that had been taken for granted and suddenly ended without warning, when they were forced into an insecure life and the unknown. They had to face and deal with their own feelings and anxiety, but at the same time encounters with health care staff, relatives and friends were crucial for how their inner journey would develop. Of their physical and mental needs, the greatest was the need for a speaking partner, someone who could listen.

In order to lead to a sense of contentment and no regrets, it is important that the family's decision about OD is genuine and taken of their own free will. Irrespective of their decision, the family must be supported and reassured that the care of their relative will not be affected. Douglass and Daly (1995) as well as Painter, Langlands and Walker (1995) revealed that the majority of relatives did not find the situation stressful if the information was provided in a satisfactory way and if the deceased's wish to donate was known.

In an other study, Pelletier (1993) concluded that health care professionals lack knowledge about the relatives' grieving process and coping after OD. Cleiren and Van Zoelen (2002) illustrated the inconsistency between the relatives' and professionals' perspectives regarding the question of OD. The staff avoided posing the question out of respect for the relatives, since they feared it would increase the latter's suffering. However, Cleiren and Van Zoelen (2002) proved them wrong, since it was the total experience of the professionals' approach that mattered in the grieving process and not only the question about OD. According to Fulton, Fulton and Simmons (1977), the total experience of a caring and supportive approach in the ICU positively affected the relatives' perceptions of OD. Not being asked about OD seemed to be more stressful than being asked (Bartucci, 1987; Pelletier, 1993). Previous studies are conclusive regarding the importance of an empathetic and professional approach to relatives.

Providing comfort, listening actively and time as well as being sensitive and caring towards the grieving family are vital. The relatives remember how they were treated in the ICU (Maroudy, 2008), which affects their experience of how the question of OD was raised (Binett et al., 1993; Flodén, Kelvered, Frid & Backman, 2006). Frid, Haljamäe, Öhlén and Bergbom (2007) reported that relatives use imagery or metaphorical language in this situation, which might form the basis for a caring conversation. Unfortunately Frid, Bergbom-Engberg and Haljamäe (1998) also reported that a heavy workload and psychological strain might affect the care of the POD and his or her relatives.

There is a need for support during the whole OD process as well as follow-up afterwards (Burroughs, Hong, Kappel & Freedman, 1998). Holtkamp and Nickolls (1993) as well as Sadala and Mendes (2000) emphasized the importance of supporting the relatives' self-esteem, which will help them to move on and have confidence in their



decision to allow OD. Pearson, Bazeley, Spencer-Plane, Chapman and Robertson (1995) reported that most families viewed the experience of OD positively and considered it helpful in their grieving process. Most people who are given an opportunity to save someone's life want to do so (House, Durham & Joyner, 1993). Douglass and Daly (1995) confirmed this fact by studying an Australian population of donor relatives, among whom the actual death rather than the question of OD constituted the burden and 71% considered OD a consolation. The importance of seeing the dead person and saying goodbye after OD had been performed was also emphasized. Finally, the authors stressed the necessity for a follow-up meeting in the ICU after some time had passed. The hospital should provide an opportunity to pose questions and reflect on what has happened (Binett et al., 1993; Pelletier, 1992). Sque, Long and Payne (2005) also presented similar results from interviews with families who had experienced OD. The relatives needed time to grasp what had actually happened and they needed support from the professionals.

### ***The health care professionals***

Studies focusing on the perspective of care staff, deal with attitudes to OD and how the situation of caring for a potential donor is experienced. In a report by the Federal Centre for Health Education (2001) it is stated that the attitude of ICU physicians and nurses may influence whether or not consent to OD is granted. The report described that physicians experienced a great deal of anxiety in approaching the donor family and that the attitude of the senior physicians in the clinic had a considerable influence on staff members. The more positive they were, the more likely it was that the conversation with the relatives would be probing and leads to consent more frequently. Physicians who often obtained consent to OD also perceived these conversations as stressful. In her thesis, Sanner (1991) outlines nine different barriers among staff that explain why so few organs are retrieved: The physician's reluctance/uneasiness at asking the relatives to consent to OD; Relatives' negative attitude to donation; The attitudes of the ICU staff; Role conflicts among staff; Lack of time; Insufficient knowledge about medical issues; Inadequate knowledge of rules and routines; Organisational difficulties; Legal factors; and Financial considerations.

Other circumstances discussed were the complicated care of the donor. The most burdensome aspects described in Sanner's thesis (1991) were the ambiguity of the patient being perceived as both dead and alive, the confrontation with the relatives and the hectic conditions surrounding the operation. Both nurses and physicians stated that there were limits to the activities and what was regarded as macabre, inhuman or unethical but the exact position of these limits varied for each individual (Sanner, 1991). It was also usual for ICU staff to feel uncomfortable taking care of bereaved families and finding it difficult to discuss OD with them (Bartucci, 1987).

Thus, some studies suggest that ICU staff attitudes and approaches to OD affect whether or not a POD becomes an organ donor, and attitudes have been found to constitute the single most decisive factor (Bartucci, 1987; Federal Centre for Health Education, 2001; Sanner, 1991). There remains a great deal of confusion and ambivalence in both lay and medical populations regarding both OD and BD (Childress,

1996; Dorr, 1997; Edwards and Forbes, 2003; Siminoff et al., 2004; Streat, 2004; Youngner and Arnold, 2001). Research indicates that families are often not well informed about BD and OD (Franz et al., 1997; Oliver, Sturtevant, Scheetz & Fallat, 2001), that many clinicians have difficulty defining and applying the concept of BD (Harrison and Botkin, 1999; Youngner, Landefeld, Coulton, Juknialis & Leary, 1989) and that BD declaration practices vary greatly (Chang, McBride & Ferguson, 2003). It has also been reported that health care professionals working in ICUs experience the OD process as demanding, especially investigating the wishes of the potential donor regarding OD by raising the issue with the family. The studies highlight the ICU staff's need for follow-up and support to enable them to see the donation activities in context. (Bartucci, 1987; Federal Centre for Health Education, 2001; Flodén et al., 2006; Sanner, 1991; Schulman & Håkansson, 1994). They requested deeper knowledge about the development and outcome of transplantation surgery as well as information about different practices and traditions surrounding death. The ICU staff also wanted more information about the need for organs and on transplantation activities. There was a great need for feedback, to know the outcome of the organs and the anonymous transplant recipients (Sanner, 1991). Education and training are also necessary to be able to provide relatives afflicted by sudden and unexpected death with adequate psychological support (Schulman & Håkansson, 1994).

In conclusion, both Swedish and international studies have shown that the attitude of the person posing the question about OD to the relatives affects the outcome and whether or not OD will take place. According to Riley and Coolican (1999), the most important factor behind the relatives' consent to OD was the nurse's approach to the grieving family. These authors even argued that one of the main reasons for refusal to consent to OD was the physician's and ICU nurse's approach when posing the question about OD.

### ***Ethical aspects***

An ethical conflict can arise when a deceased person has been identified as a potential donor, which may be linked to a necessary shift of perspective, from having cared for the patient for his or her own sake to caring for him or her for the sake of another. This represents a shift of ethical perspective from deontological ethics, where the patient is regarded as a goal in him or herself and not as a means for another, to consequentialism where the maximum utility is central. It is this deviation from the accepted norm within health care that may give rise to emotional tensions, leading to the perception that the duties are more burdensome (Sanner, 1991). A question posed way back in 1979 (Osborne & Gruneberg, 1979) focused on the transition from life-saving care to care of the organs as a dilemma itself. Failure to save the life of a patient would lessen the mental preparedness to identify the deceased person as a POD. According to Sanner (1991), this conflict could not be verified from the perspective of physicians, who instead expressed the clear view that everything possible was done for the patient and that death was inevitable.

Nurses and physicians have different ways of reasoning about ethical problems in intensive care. While physicians focus on difficulties in decision-making regarding

the level of care, nurses have a relationship perspective that focuses on the suffering of patients and families (Söderberg & Norberg, 1993, Söderberg, Gilje & Norberg 1999). This type of caring relationship is not only limited to the patient-nurse dyad, but also includes the relationship between the nurse and other nurses, physicians and co-workers. Söderberg et al. (1999) referred to virtue ethics and claimed that “*doing the right and good thing calls for being the right person rather than following a particular set of rules*”. These findings were later supported by Gavrin (2007). Shogan (1988) introduced the concept of ‘care about – care for’ as a pedagogical perspective on moral motivation. The concept of ‘caring about’ rests on moral grounds, as moral obligation is inherent in the concept and assumes a personal ability to know which actions are morally good in a caring situation. ‘Caring about’ also implies a genuine concern for the well-being of the other. The participants’ examples of ethical situations in Shogan’s study (1988) were communicated with a genuine concern for patients in terms of beliefs, feelings and insight into patients’ vulnerability. ‘Caring for’ is task-oriented nursing care assigned and controlled by ‘others’ (employers, superiors, physicians) and can be considered a moral obligation to fulfil work responsibilities. It rests on what organizations set out as guidelines for practical, technical and medical assessments.

The concepts of ‘caring about’ and ‘caring for’ might be useful for understanding and interpreting ICU nurses’ caring actions for a potential donor. In a study by Cronqvist et al. (2004) the same interrelated concepts were found to be a relevant conceptualization for explaining intensive care nurses’ experiences. They described a tension between the professional dimensions of ‘caring about’ and ‘caring for’ and nurses’ concerns about the care provided. The tension occurred when ‘caring about’ and ‘caring for’ a patient could not be achieved at the same time. Another example of distress was when the nurses realised that they did not agree with the physicians. The feeling that ‘something was wrong’ was an essential part of the process of becoming ‘aware’, followed by a cognitive ability to grasp that the situations can be viewed from different perspectives.

### **Summary of the research performed after 2005**

More recent studies have also focused on attitudes towards organ donation among health care professionals. Jacoby and Jaccard (2010) support previous results by stating that specific supportive behaviours by ICU staff were significantly associated with consent to OD. Sharp (2009) highlights the importance of ICU nurses as critical links to the family during the OD process, since they are close to PODs and their relatives while continually working bedside in the ICU. She also claims that it has been demonstrated that nurses often take the lead in initiating dialogues with the relatives, resulting in organ donation.

Pellerlaux, McBride and Ferguson (2008) showed that lack of knowledge and confidence in OD issues contributed to make the ICU staff feel uncomfortable in conversations with the family, resulting in an avoidance behaviour, which contributed to the question of OD was not raised by ICU staff. An American study by Cohen, Ami, Ashkenazi and Singer (2008) revealed a similar finding. When hospital staff, i.e. a

physician or nurse, posed the question about OD, 54% consented. When a person specialized in OD issues, e.g. a transplant coordinator, was present, 81% of relatives gave their consent. Sanner, (2007) argued that it is not sufficient to be neutral when posing the question about OD, since this might be interpreted by relatives to mean that the physician is negative towards OD. Physicians who were reported to be neutral were also more hesitant regarding their own wish to donate than those who were positive (Sanner, 2007). In conclusion, recent research also suggests that attitudes among ICU staff can constitute a barrier to OD.

In spite of the shock and grief, the relatives were able to consider donation since it was not the question about OD that caused the most distress but the fact that they had lost their loved one (Sanner, 2007). The relatives remembered very well how they were treated in the ICU (Maroudy, 2008). Receiving understandable information about OD was the strongest predictor of consent. The emotional support to the family, including having someone there to listen to them, giving hope, showing understanding and being there in case of need, were factors identified as important when caring for the next of kin (Jacoby & Jaccard, 2010). Family also required time in cases where they were not familiar with the deceased's will and wishes regarding OD. Dodd-McCue, Cowherd, Iveson and Myer (2006) reported that 75% of relatives experienced security when they knew the potential donor's wish and 79% had discussed the issue before death. Fridh, Forsberg and Bergbom (2009a) also stated that every relative who lost someone in the ICU should be invited to a follow-up conversation.

The hospital must provide an opportunity to pose questions and reflect on what has happened (Binett et al., 1993; Pelletier, 1992). Sque et al. (2005) presented similar results from interviews with families that had experienced OD. The relatives needed time to grasp what had actually happened as well as professional support. Ensuring dignity and comfort for the dying patient was described by Fridh et al. (2009b) as the essential caring actions of the ICU nurse. Patient advocacy is an important aspect of professional nursing and considered fundamental nursing value (Hanks, 2008, 2010) and is performed by the nurse due to personal or professional involvement as part of excellent nursing (Vaartio et al., 2006). Daly (2006) stated that the complexity of the issues and factors associated with end-of-life care is also applicable to all phases of OD. She holds that education is the simplest and most obvious way to improve the ability of ICU nurses throughout the OD process.

Several studies are available that measure knowledge and attitudes to OD among ICU staff (Alghanim, 2010; Kim, Fisher & Elliot, 2006a; Kim, Fisher & Elliot, 2006b; Lima et al., 2010; Lin LM, Lin CC, Lam & Chen, 2010; Pelleriaux et al., 2008; Roels, Spaight, Smits & Cohen, 2010). Many of these were carried out in non-European contexts (e.g. the Republic of Korea, Taiwan, Saudi Arabia and Brazil) and the results can therefore be difficult to transfer to a western context. However, a common feature is their focus on educational issues. Kim et al. (2006a; 2006b) identified knowledge gaps related to the care of PODs among Korean ICU nurses, maintaining that effective education was necessary in order to increase the number of organ donors. Roels et al. (2010) investigated the impact of ICU staff attitudes towards OD, acceptance of the concept of BD, self-reported skills and educational needs and presented data from eleven countries. Sharp (2009) stated that there is a lack of research identi-

fying nurses' knowledge and educational requirements in relation to OD. A study demonstrated that the implementation of an education program six years earlier had a positive impact on staff working within critical care. The findings revealed a positive impact on staff knowledge and attitudes towards OD and reflected a change in culture within the trust.

Macdonald, Liben, Carnevale & Cohen (2008) revealed that managing life and death in accordance with BD criteria is associated with controversy, stating that much confusion and ambivalence remains regarding both organ donation and BD diagnostics. According to Cohen et al. (2008), understanding and acceptance of BD, as valid to determinate death, had a significantly positive impact on the level of comfort of health care professionals when performing donation-related tasks.

Ethical dilemmas surround death. Effective functioning in the ICU also involves understanding the behaviours that surround mortality. Human behaviour is not solely based on rules. Central to health care is to respect the patient dignity. Achieving a dignified and tolerable death is of great significance. End-of-life issues in the ICU do not require a technological solution, but a social and philosophical one (Gavrin, 2007).

Overall, previous research has identified a number of factors that explain why OD does not take place despite the wish of the deceased. The single most important factor was ICU staff members' attitude to OD, which was demonstrated to be important for whether or not consent to OD was granted. The more positive the attitude of ICU staff members, the greater their efforts to ascertain whether consent to OD was forthcoming. These studies mainly focused on physicians or ICU staff and provided no answers in relation to how ICU nurses' attitudes influence the OD process.

Previous studies also seem conclusive that the question about OD itself does not cause the most distress and suffering to the donor family. It is the actual death that is the main concern, causing grief, pain and a tremendous sense of loss. The question about OD can provide consolation and hope. It has also been found that support and follow-up of the relatives is an essential part of the OD process and routines need to be developed to ensure this vital intervention. Finally, the professional task of caring for a POD involves ethical demands and aspects of care associated with professional ethics as well as a tension between the professional dimensions of 'caring about' – 'caring for' and nurses' concerns about the care provided.

Since organ donation is regulated by the laws and circumstances in each country, some previous research is not easily transferrable to a Swedish context. Studies regarding attitudes mainly focus on physicians or staff in general, despite the fact that ICU nurses provide bed-side care of the POD. No previous studies aimed to obtain an in-depth understanding of ICU nurses' perception of brain death or the organisational structure surrounding organ donation. The codes of nursing ethics reflect the ongoing significance of advocacy. However, advocacy has never been investigated in relation to the care of a POD during the period of after-death care, nor has it been defined as a theoretical construct and applied to ICU nurses' attitudes towards advocating actions.

## RATIONALE

The European Union (EU) promotes donation and transplantation by its efforts to develop a common directive of standards related to the quality and safety of human organs intended for transplantation and by the formulation of an action plan for OD and transplantation covering the period 2009 to 2015. The need for greater cooperation between the member states was agreed by the Commission on 8<sup>th</sup> December, 2008 (EU, 2008). The Directive was proposed to the Commission in February 2009. The EU (2008) called for effective national quality control programs in the entire donation/transplantation process. The Swedish Council for organ and tissue donation (2011) therefore requested the health services to create better routines for identifying potential donors, which was also recommended in the Istanbul Declaration (The Transplantation Society & International Society of Nephrology, 2008).

*“Each country should strive both to ensure that programs to prevent organ failure are implemented and to provide organs to meet the transplant needs of its residents from donors within its own population or through regional cooperation. The therapeutic potential of deceased organ donation should be maximized not only for kidneys but also for other organs, appropriate to the transplantation needs of each country”* (The Transplantation Society & International Society of Nephrology, 2008).

As stated above, the EU encourages each country to assume responsibility for creating a directive of standards and formulating an action plan for OD. Research from a Swedish context is therefore necessary to be able to adjust the required interventions to Swedish circumstances. This thesis strives to illuminate and describe the Swedish context of OD for one of the professionals involved, the ICU nurse, in an attempt to understand underlying dimensions that might affect and hinder the realisation of OD.

The rationale behind this thesis was to describe ICU nurses' perceptions of experiences of caring for the POD and to answer the question of how experienced ICU nurses perceive OD as a phenomenon. It is important to approach attitudes to brain death and organ donation from a national perspective due to the differences in legislation between countries. However, existing instruments were not applicable and therefore an additional rationale was to present data on Swedish ICU nurses' attitudes to BD and OD and to test a questionnaire designed to explore these issues in terms of validity and reliability.

To our knowledge, no studies have aimed at investigating the importance of and need for an organisational structure. Therefore an additional purpose was to illuminate ICU nurses' perceptions of the organisational issues involved in OD and to investigate perceptions of BD in a more in-depth manner.

The concept of advocacy is critical for nurses faced with the challenge of caring for a POD in order to facilitate OD and respect the last wish of the deceased. In spite of the importance of advocacy in nursing, there is a notable lack of instruments for measuring it. No specific instrument was available to measure attitudes towards organ donor advocacy. The different characteristics of advocacy are fairly well described, but not in relation to OD and the care of the potential donor in the ICU environment. It is vital to be able to measure attitudes towards organ donor advocacy in order to create a stable knowledge base for organizational and educational interventions aimed at optimizing the different phases of the donation process. The absence of systematic and structured measurement instruments also hampers the possibility of making comparisons between groups of ICU nurses and evaluating the effects of various interventions. In addition to developing a context-specific instrument for self-assessment of attitudes towards organ donor advocacy, there is a need to expand the existing understanding of the advocacy experience and deepen our insight into the attitudes involved in the care of a potential donor in the ICU.

The foremost rationale for this thesis is to increase our knowledge from the ICU nurses' perspective in order to improve the care of the POD including safeguarding his or her will and wishes regarding OD. This knowledge will also be useful for the education of ICU staff in general and ICU nurses in particular as well as serving as a basis for future longitudinal and interventional studies.

## **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.

### **Specific aims**

- I To describe ICU nurses' perceptions of experiences in the area of OD from the perspective of caring for potential organ donors
- II To present data on Swedish ICU nurses' attitudes to BD and OD and test a questionnaire designed to explore these issues in terms of validity and reliability
- III To study ICU nurses' perceptions of their experiences of professional responsibilities and organisational aspects in relation to OD and how they understand and perceive BD
- IV To develop and psychometrically evaluate an instrument for measuring ICU nurses' attitudes towards organ donor advocacy



## METHODS

It has been found that the main explanation as to why a potential donor does not become an actual donor is the attitude of the ICU staff towards organ donation (Flodén et al., 2006; Jacoby & Jaccard, 2010; Sharp, 2009). I therefore began inductively by interviews to study ICU nurses' perceptions of organ donation, as a phenomenon and as a situation, and subsequently to explore the distribution of different attitudes and perceptions among Swedish ICU nurses, which led to a broad survey. The results of the survey indicated that organizational aspects are important as well as trust in BD diagnostics. To gain an understanding of how these two aspects are viewed by Swedish ICU nurses as well as their perceptions of their professional responsibility, interview data from different geographic regions were analysed. It became increasingly clear that actions aimed at safeguarding the will and wishes of the deceased person are of importance for the care of a potential donor, thus the meaning of the concept of organ donor advocacy emerged more clearly. This led to the need for an instrument to measure organ donor advocacy aiming to developing knowledge of organ donor advocacy actions while performing after-death care.

**Table 1.** Research design overview

Paper	Aim	Data collection	Participants	Analysis
I	To describe ICU nurses' perceptions of experiences in the area of OD from the perspective of caring for potential organ donors.	Interviews	9 ICU nurses, all female, 36-53 years old, 3-27 years ICU work experience, 3 different hospitals	Phenomenography
II	To present data on Swedish ICU nurses' attitudes to BD and OD and test a questionnaire designed to explore these issues in terms of validity and reliability	Questionnaires	702 Swedish ICU nurses	Principal component analysis, Multi-trait analysis, Cronbach's Alpha and Descriptive statistics
III	To study ICU nurses' perceptions of their experiences of professional responsibilities and organisational aspects in relation to OD and how they understand and perceive BD	Interviews	15 ICU nurses, 1 male, 14 female, 36-65 years old, 3-32 years ICU work experience, 6 different hospitals	Phenomenography
IV	To develop and psychometrically evaluate an instrument for measuring ICU nurses' attitudes towards organ donor advocacy.	Questionnaire The ATODAS instrument	502 Swedish ICU nurses	Principal component analysis, Multi-trait analysis, Cronbach's Alpha

OD = organ donation, BD = brain death, ATODAS = attitudes towards organ donor advocacy scale

## **Papers I and III**

### ***Inclusion criterion and selection procedure in Papers I and III***

ICU nurses who had experience of caring for PODs that did or not did result in OD were considered eligible for the study. Although not inclusion criteria, the informants were of different sexes, ages and ICU work experience.

A letter was sent to the director of the respective ICU with a request for permission to interview the nurses. When permission was granted, the ICU manager was asked to select nurses on the basis of the above criterion. The selection was left to the respective care unit and thus took various forms. In two of the units, nurses who wished to participate registered their interest, after which the ICU manager selected three participants based on the above criterion. In the third ICU, the manager herself invited persons whom she considered suitable and who met the study criterion (Paper I). The informants in Paper III included the nine participants from Paper I. Selection of informants in the ICUs at the additional three hospitals in Paper III differed. In one of the units, nurses who wished to participate registered their interest, after which the ICU manager selected two or three informants based on the above criterion. In the other two ICUs, the manager herself invited persons whom she considered suitable and who met the study criterion.

### ***Participants in Papers I and III***

In the first paper, nine nurses from three different ICUs at three Swedish hospitals were selected for inclusion. The participants were aged from 36-53 years. Length of work experience in an ICU ranged from 3-27 years. The intention was to include both men and women in the study, but as no male nurses were employed in these units at the time of the study, all participants were female.

In the third paper, fifteen ICU nurses (one male and 14 female, which is representative of the gender distribution of Swedish ICU nurses) were selected from six different hospitals, geographically spread throughout Sweden. Their ages ranged from 36-65 years and their length of work experience in an ICU from 3-32 years. Nine of the fifteen participants were included in 2006 in order to study their perceptions of OD as a phenomenon and as a situation (Paper I). Since the data were rich and very extensive, those pertaining to professional responsibilities and organisational structures in the hospital were not included in the analysis of Paper I. Deeper analyses of these areas would have been required to obtain a comprehensive understanding of the whole material. One basic assumption was that OD might be organised differently in various parts of Sweden. Therefore, further data were collected in 2010, covering different geographic areas.

### ***Data collection in Papers I and III***

Data were collected by semi-structured interviews that were audio-taped and transcribed verbatim. The interviews were conducted by me during 2006 and 2010, at the different hospitals and at a time decided by the informants. The participants were

first asked to describe their background and experience as an ICU nurse as well as their experience of caring for a potential or actual organ donor. They were also asked why they wished to participate in the study. Then the actual interview began with the question “*What associations occur to you when I say the words ‘organ donation’?*” The questions were open-ended and in order to elucidate and deepen the answers, short follow-up questions were employed that were formulated on the basis of the participant’s previous responses. The interviews lasted 50-70 minutes.

### ***Data analyses in Papers I and III***

In Paper I, all transcripts were read individually by the authors including steps 1-3. In Paper III, all transcripts were initially analysed separately by two of the authors (Flodén & Forsberg) and then compared. All three authors participated in the subsequent steps.

Analysis of the interview data followed the seven steps described by Sjöström and Dahlgren (2002):

1. *Familiarisation*: the interviews were read through in order to obtain an overview
2. *Compilation*: the most important parts of the informants’ responses were identified
3. *Condensation*: the individual responses were shortened in order to identify the central parts of longer responses or dialogues
4. *Grouping*: similar responses were tentatively grouped or classified
5. *Comparison*: a preliminary comparison of the categories was made to find associations between them, after which the preliminary groups were revised
6. *Naming*: the categories were labelled in order to highlight their essence
7. *Contrastive comparison*: the unique character or essence of each category and the linkage between them were described

Central conceptions in phenomenography are ‘what’ and ‘how’. The first order perspective, presented as domains, is formed by ‘what’ the informants’ talk about (steps 1-2). The second order perspective presents ‘how’ the participants talk about the ‘what’ and comprises the qualitatively different variations in perceptions (steps 3-4). The categories are formed by descriptions at a more integrated level (steps 5-6). Finally, the essence constitutes a description of the unique phenomenological character of each category (step 7).

### **Papers II and IV**

#### ***Inclusion criterion and selection procedure in Papers II and IV***

The inclusion criterion was; being a nurse employed in an ICU. The participants were identified from an existing register administered by the Swedish Association of Health

Professionals (SAHP), which is a trade union and professional organisation for registered nurses, midwives, biomedical scientists and radiographers. The SAHP register provided a random sample of 50% of the ICU nurses included in their member registry.

### **Participants in Papers II and IV**

The participants in Paper II comprised 702 ICU nurses representing different levels of hospital. The majority worked at a general ICU. Nine out of ten were female, had a mean age of 45 years and mean ICU work experience of 14 years. Participants in Paper IV were 502 ICU nurses representing different levels of hospital and the majority worked at a general ICU. In total, 445 were female, had a mean age of 47 years and 16 years of ICU work experience. Demographics of the study participants are presented in Table 2.

**Table 2.** Demographics of the Swedish ICU nurses in Paper II (n=702) and in Paper IV (n=502)

<b>Demographics of the Swedish ICU nurses</b>	<b>Paper II (n=702)</b>	<b>Paper IV (n=502)</b>
Mean age (range)	45 years (26-65 years)	47 years (24-66 years)
Mean work experience in the ICU	14 years (0.3-41 years)	16 years (0.5-40 years)
Female	91% (n=639)	88.5% (n=445)
Male	8.6% (n=60)	9.5% (n=48)
Missing responses	0.4% (n=3)	2% (n=9)
Local hospital	26% (n=184)	26.5% (n=133)
Regional hospital	31% (n=219)	33.5% (n=169)
University hospital	38% (n=265)	37% (n=185)
Missing responses	5% (n=34)	3% (n=15)
General intensive care unit (ICU)	82% (n=575)	74% (n=373)
Neurosurgical intensive care unit (NICU)	8% (n=54)	7% (n=34)
Thoracic intensive care unit (TICU)	9% (n=63)	8% (n=40)
Paediatric intensive care unit (PICU)	1% (n=10)	2% (n=11)
Other ICU		7.5% (n=37)
Missing responses		1.5% (n=7)

### **Data collection in Paper II**

In December 2006, questionnaires were sent to half of all ICU nurses working in general intensive care units (ICU), neuro intensive care units (NICU), thoracic intensive care units (TICU) and paediatric intensive care units (PICU) in Sweden. The questionnaire was developed from an earlier instrument aimed at exploring the attitudes of ICU physicians and neurosurgeons in order to identify obstacles to OD in Swedish ICUs (Sanner, Nydahl, Desatnik & Rizell, 2006). The physician questionnaire was based on the experiences of the authors as well as questions identified in an interview study by one of the authors (Sanner, 2007). Five questions were identical to those in the Hospital Attitude Survey (Wight, Cohen, Roels & Miranda, 2000). The instrument was tested on a small cohort of physicians, but not validated before use. The validity of the original instrument was tested by an exploratory factor analysis of the

22 questions. The validity of the questionnaire was established by the consistency of the answers (Sanner et al., 2006). The best way of fulfilling the aim of Paper II was to modify the physician questionnaire and adjust it to ICU nurses. The modification was guided by an analysis of the physician questionnaire, an extensive literature review (Flodén et al., 2006) and experiences of the authors (Juniper, Guyatt & Jaeschke, 1996). The item pool (a total of 34 statements relevant to the OD process) was divided into three parts. The first concerned organisational aspects such as staffing, number of ICU beds and the role of the transplant coordinator (15 items), e.g. *“Do you believe that additional staff resources for the care of potential donors would lead to more donors?”* The second dealt with the approach to the relatives and included twelve items, e.g. *“What approach do you generally try to adopt towards the relatives in a conversation about donation?”* The third group comprised seven items about personal beliefs, e.g. *“Would you consider donating organs and tissue for transplantation after your death?”* Some items were rated on a five-point Likert scale in terms of their relevance to the respondent. The response alternatives ranged from ‘strongly disagree’ (1) to ‘strongly agree’ (5). Other items were answered using the alternatives; Yes, Occasionally, No and Don’t know. The choice of response alternative was guided by the physician questionnaire.

A letter containing information about the study was sent to the nurses together with the questionnaire. Demographic data were collected in the questionnaire and included age, sex, ICU work experience, type of hospital (i.e. local, regional or university) and type of ICU. After the first mailing and reminder, 601 participants (59%) responded. A second reminder was sent, increasing the number of responders by n=101, thus the final response rate was 69% (702 out of 1013). We were unable to analyse the external dropout rate of 31% (n=311), as the questionnaires were sent anonymously, which made it impossible to determine the reasons for declining participation. Of these 311 questionnaires, 64 were returned without being completed and without comment. Despite the two reminders, 247 questionnaires were not returned. The SAHP handled the random sample, distribution and collection of the questionnaires. They also destroyed the serial numbers when the questionnaires were returned, prior to their distribution to the researchers. This procedure made it possible to protect the nurses’ privacy and confidentiality.

#### **Data collection in Paper IV**

In November 2010 the Attitudes Towards Organ Donor Advocacy Scale (ATODAS) questionnaire was sent to half of all ICU nurses working at ICU, NICU, TICU and PICU units in Sweden. The ATODAS questionnaire was theoretically anchored in the framework of patient advocacy. Snowball (1996) described advocacy activities as respecting patients’ rights, representing or speaking up for the patients’ points of view in the decision-making process if patients were unable or unwilling to do so themselves, protecting patients’ dignity and privacy and guarding them from interventions that might cause them distress.

Applying this description to OD as a situation, participation in the donation process and the care for the potential or actual organ donor can be viewed as advocacy activities in line with the following description:

*Respecting the potential or actual organ donor's rights, representing or speaking up for his or her wishes and the relatives' points of view in the decision-making process regarding organ donation. Protecting the potential or actual donor's dignity and the relatives' privacy and defending them from interventions that might cause them distress. (Flodén et al., Paper IV)*

The initial item pool of 55 items was reduced to 47 after being scrutinized by a panel of seven content experts established to assess content validity. A six-point Likert-type scale was used, ranging from very negative to very positive Attitudes towards organ donor advocacy. Responses were scored on a six-point scale ranging from *strongly disagree (1)* to *strongly agree (6)*. Scoring was reversed for one negatively worded item so that a high score reflected strong support for advocacy. There were 15 items aimed at measuring Attitudes towards *safeguarding the potential donors*, 15 items aimed at Attitudes towards *acting on behalf of the potential or actual donor as well as his or her relatives* and 17 items covering Attitudes towards *championing social justice*.

Also in Paper IV, a letter containing information about the study was sent to the nurses together with the questionnaire. Demographic data included age, sex, ICU work experience, educational level, type of hospital (i.e. local, regional or university hospital) and type of ICU. After the first mailing and reminder, 445 participants (38%) responded. A second reminder was sent, increasing the number of responders by n=57, thus the final response rate was 42.5% (502 out of 1180). We were unable to analyse the external dropout rate of 57.5% (n=678), as the questionnaires were sent anonymously, which made it impossible to determine the reasons for declining participation. The SAHP handled the random sample, distribution and collection of the questionnaires prior to handing them over to the researchers. This procedure made it possible to protect the nurses' privacy and confidentiality.

### **Statistical methods in Papers II and IV**

In Papers II and IV, data were analysed by means of the SPSS version 15.0 (Paper II) and SPSS version 18.0 (Paper IV) and the Multi-trait Analysis Program – version 2 (Hays, Hayashi, Carson & Ware, 1988). In order to explore validity and reliability, the expected scale dimensionality of the questionnaire was examined both by explorative principal component analysis (with oblique, varimax rotation) and by confirmatory multi-trait analysis. In the explorative principal component analysis, three strategies; Cattell's scree plot, absorption of variance and meaningfulness of factors, were used interactively to determine the number of tentative factors to retain (Gorsuch, 1983). These factors were then tested by multi-trait analysis. Here the hypothesized internal item-scale structure was examined, i.e. convergent and discriminatory validity. Convergent validity refers to the consistency of the items expected to measure a scale (factor). It was tested by computing the item correlations with their expected factor, corrected for overlap. A common criterion is item-scale correlations of at least 0.40

(Hays et al., 1988). Discriminatory validity was tested by computing the proportion of items that had a higher or significantly higher correlation with their expected (hypothesized) scale compared with the other scales (success rate). The item-scale structure that was the best compromise between the results of the multi-trait analysis and the explorative factor analysis was thus retained. Scale reliability was further estimated using Cronbach's alpha. According to a conventional rule, this coefficient should at least exceed .70 (Nunnally & Bernstein, 1994). In addition to the psychometric evaluation, Paper II also provided descriptive data obtained by the Chi square test in order to compare proportions. If nothing else was reported, the significance level of  $p=0.05$  was used. Pearson correlations were calculated to investigate relationships between each of the four verified factors and the single items, with a significance level of  $p=0.01$  (Paper II).

### **Rigour and trustworthiness in qualitative research**

Lincoln and Guba (1985) suggested four criteria for developing the trustworthiness in a qualitative inquiry: credibility, dependability, confirmability and transferability. These four criteria represent parallels to the positivists' criteria of internal validity, reliability, objectivity and external validity. How these four criteria have been applied to demonstrate trustworthiness in Papers I and III is presented in Table 3.

### **Validity and reliability in quantitative research**

Validity is a quality criterion that refers to whether an instrument measures what it is intended to measure. The key construct validity question with regard to measurement is: What is this instrument really measuring and does it validly measure the abstract concept of interest? Internal validity relates to the degree to which it can be inferred that the independent variable, rather than uncontrolled, confounding factors, caused the observed effects. Reliability refers to the degree of consistency or dependability with which an instrument measures an attribute. Objectivity of the data refers to the extent to which two independent researchers would arrive at similar judgments or conclusions not biased by personal values or beliefs, while external validity represents the degree to which study results can be generalized to settings or samples other than those studied.

Other forms of validity relevant in these studies exist, including content validity, which is the degree to which the items in the ATODAS instrument adequately represent the universe of content for the concept being measured, i.e. here the attitudes towards organ donation. The extent to which the ATODAS instrument measures what it purports to measure is termed face validity (Table 3). Exploratory factor analysis is a factor analysis undertaken to explore the underlying dimensionality of a set of variables, while internal consistency is the degree to which the subparts of an instrument measure the same attribute of dimension, in order to establish the instrument's reliability (Polit & Beck, 2010).

**Table 3.** Efforts to establish rigour and validity in Papers I-IV

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<b>Papers I and III</b>	<b>Papers II and IV</b>
<p><b>Credibility</b></p> <p>To enhance the credibility of these studies and prevent retrospective distortion or misinterpretation, the participants' statements were followed-up by new questions. The interviewer was familiar with the context and could therefore enter deeply into the participants' descriptions and experiences. Quotations were used in order to illustrate the participants' perceptions, thus allowing the reader to decide whether our descriptions and interpretations are reasonable as well as to reflect on the meaning of their statements.</p>	<p><b>Internal validity</b></p> <p>When paper II was tested for internal validity, only 11 out of 34 items actually fitted a structure. From the perspective of the questionnaire as an instrument, it is a problem that we could not verify more factors to retain.</p> <p>Content validity of the ATODAS was enhanced by using the results from the qualitative studies reported in Papers I and III as items on the scale. Secondly, a new panel of seven content experts was established to assess content validity. Thirdly, a pilot study was performed which resulted in minor revisions.</p> <p>Construct validity was established by administering the ATODAS to a sample of 1180 Swedish ICU nurses. The item pool in the primary version of the ATODAS consisted of fifty-five authentic statements covering the components defined in the construct of attitude towards organ donor advocacy. This version of the ATODAS was subjected to factor analyses. In the explorative principal component analysis, three strategies were used interactively to determine the number of tentative factors to be retained - Cattell's scree plot, absorption of variance and meaningfulness of factors (Gorsuch, 1983) The item-scale structure that was the best compromise between the results of the multi-trait analysis and the explorative factor analysis was finally retained.</p>
<p><b>Dependability</b></p> <p>With regard to dependability the data collection was performed in the informants' regular ICU setting and did not involve any "set up" settings or environmental conditions that would prevent replication.</p>	<p><b>Reliability</b></p> <p>In Papers II and IV scale reliability was estimated using Cronbach's alpha, resulting in values of .68-.73 for Paper II, and .59-.90 for the ATODAS (Paper IV), which indicate good scale reliability. Further tests regarding reliability is needed.</p>
<p><b>Confirmability</b></p> <p>With regard to conformability, the full text of the interviews was read and considered by all authors and only statements relevant to the aim of the studies were included in the final analysis.</p>	<p><b>Objectivity of the data</b></p> <p>Due to the standard procedure for psychometric testing and development of the instrument in Paper II as well as in the ATODAS, the analysis process was prevented from being affected by personal values or beliefs.</p>
<p><b>Transferability</b></p> <p>The transferability to ICU nurses outside these study groups is considered to be good since the main focus of the studies is perceptions of and attitudes towards organ donor advocacy, which is a familiar phenomenon in the mind of every ICU nurse educated at advanced level. The participants were also of various ages, both sexes and had extensive experience from working in the ICU.</p>	<p><b>External validity</b></p> <p>Since the item pool behind the ATODAS was selected both from interviews with ICU nurses and from a theoretical construct, and the sample chosen for the psychometric testing was representative of the target population, the results of this study can be generalized to other settings or samples, although not outside the ICU nurse population.</p>

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## ETHICAL CONSIDERATIONS

According to the Swedish Act concerning the ethical review of research involving humans, permission is not required when interviewing staff members (SFS 2003:460). The studies was carried out in accordance with the requirements pertaining to research on human beings as set out in the Helsinki declaration (World Medical Association 2008), Ethical guidelines for nursing research in the Nordic countries and the HSFR (The Swedish Council for Research in the Humanities and Social Science) regulations regarding requirements on information, consent, confidentiality and utility (The Swedish Research Council, 2008). The risk of distress or violation of integrity was deemed insignificant. The ICU nurses took part voluntarily and were not in a position of dependence in relation to the researcher. There were no financial incentives. Both the respondents and the participants were informed of the aim, utility and confidentiality of the study, of their right to integrity and the voluntary nature of participation. Before the start of the interviews an oral agreement was made with all ICU managers, whereby they assumed responsibility for following up and dealing with any emotional reactions that might occur in connection with the interviews. All participants gave their written informed consent and were informed that they could withdraw at any time during the study. Organ donor advocacy, when caring for a mechanically ventilated potential OD, was seen as a great burden involving emotional strain. Everyone involved in the OD process; i.e. ICU staff and the researcher, moves within a field of ethical tension and is affected, as it raises thoughts about life and death.

## RESULTS

The main findings of these studies can be summarized as follows:

- Less than half of the ICU nurses trusted clinical diagnosis of BD without a confirmatory cerebral angiography.
- A majority of the ICU nurses were either neutral or unable to describe their approach in discussions with relatives about OD.
- Almost half of the nurses considered that caring for a mechanically ventilated potential organ donor 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 organ donation to investigating attitudes towards organ donor advocacy, defined as an ICU nurse's judgement that he or she is in favour of or against participating in OD and caring for the potential or actual donor in order to respect, represent and safeguard the donor's and his/her relatives' rights, best interests and values after death.
- It is possible to measure attitudes towards organ donor advocacy in three dimensions divided into five factors.

### Trust in brain death diagnostics

Less than half of the ICU nurses (48%) trusted clinical diagnosis of BD without a confirmatory cerebral angiography (Table 4) (Paper II). In Paper I, the perception emerged that it is only logical that "*one is dead when one is brain dead*" (Paper I, P:3) but it was considered an uncertainty when nurses lacked knowledge of how to

**Table 4.** Trust in brain death diagnostics among Swedish ICU nurses (n=702)

<b>Trust in clinical neurological BD-diagnostics</b>	
Yes	48% (n=333)
Yes, but complemented by other methods	46% (n=324)
No	4% (n=28)
Missing responses	2% (n=17)

perform the tests in order to establish BD. The concept of BD was not considered generally established, while death from cardiac arrest was perceived as being conclusive. It was a question of understanding BD both intellectually and emotionally

The findings revealed four qualitatively different ways in which the participants perceived BD and had confidence in BD diagnostics (Paper III):

- A. *Trust in brain death diagnostics regardless of the method.* This perception was represented by nurses who had confidence in the reliability of BD diagnostics (regardless of method).
- B. *Confidence in the skills of the physician.* This perception was expressed by nurses who had confidence in the skills of the physician as a prerequisite for trusting the BD diagnosis (regardless of method).
- C. *Trust in brain death diagnostics if present during the diagnostic procedure.* This perception was represented by nurses who believed that in order to understand and be confident intellectually, and in particular emotionally, that the patient has died, it is necessary to attend and witness the BD diagnostic procedure with their own eyes. Participation during this procedure was crucial, regardless of the method employed.
- D. *The need for cerebral angiography to be convinced of the accuracy of brain death diagnostics.* This category represented a perception of being forced to accept the fact that, in Swedish law, clinical examination to establish BD is the gold standard. Cerebral angiography was perceived as a safe method, making it possible to look at the x-ray images and see the discontinued circulation of the brain, i.e. that the patient is dead.

In Paper III, the domain of ICU nurses' perceptions of death and the BD diagnosis comprised a striving to understand and be convinced of the BD concept and diagnostics. It was considered important for an ICU nurse to have processed the concept of BD and be clear about his or her own attitude when caring for the POD. The nurse's own attitude towards BD was considered to influence the perception of the family. If the nurse harboured doubt, it would become evident and lead to the family becoming doubtful.

### **Approaching the relatives**

Thirty percent of the nurses (n=207) claimed that raising the question about OD was an additional strain for the relatives. A total of 39% (n=275) had experienced occasions when the question was never raised, as the situation was considered so emotionally tense that it was deemed inappropriate to mention the topic (Paper II). However, the perception emerged from the interviews that the question about donation should always be asked and that it was important to fulfil the wish of the deceased, irrespective of whether the answer was positive or negative. The perception was that "neutral" colleagues were less proactive in promoting OD (Paper I). The nurses considered it important that the family members' decision about OD was genuine and taken of their own free will and that it would lead to a sense of contentment and no regrets.

The nurses felt frustrated when they perceived that the deceased had been deprived of the possibility of donation. Examples of such situations were:

- The care had not been optimal
- The physician had taken the unilateral decision that donation was not medically possible
- Diagnostics had not been carried out
- The decision had been taken not to raise the question.

Communication with family members during their time in the ICU was seen as an important task. The lack of structure and guidelines as well as clarification of who is responsible was considered inadequate. The participants expressed a wish to take part in these meetings in order to be well informed during follow-up contacts with the family (Paper III).

### **Caring for the potential organ donor**

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. There was something different in the air, but it was difficult to put one's finger on exactly what it was (Paper I). When the question of OD arose, 53% experienced that their own feelings were influenced in a positive or fairly positive way, while 9% reported negative or fairly negative feelings (Paper II). 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 (Paper III). *"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. Central to the nurse's relationship with the family was being present, humble and, at the same time, professional. A professional stance was also considered to help the nurse not to "lose him or herself" in situations experienced as difficult. The nurses regarded caring for the potential donor as an awe-inspiring task, where it was vital to ensure that nothing went wrong. The responsibility included the necessity to create a dignified situation where the nurse showed the patient and his or her family respect while at the same time taking care of the organs in the best possible way. The situation in relation to a potential donor was sometimes perceived as tense for ethical reasons, mainly due to communication problems, confusion as a result of language and lack of knowledge about other cultures. Caring for a POD was perceived as more physically and mentally demanding compared to caring for other ICU patients. The participants perceived that

their attitude/approach towards OD 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 OD 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 OD or aware that an ethical conflict could arise for a colleague who had such an attitude. It was therefore considered necessary to distinguish between reason and one's feelings and to be aware of one's own attitude and the influence it might have on the POD's family (Paper I).

Four different approaches towards OD as a clinical situation among ICU nurses were identified in Paper I.

- *Attitude 1 – “I can alleviate the suffering”* implies that it is the nurse's duty to alleviate suffering at all levels and in situations of life and death, including the donor, relatives, colleagues and organ recipients.
- *Attitude 2 – “My duty is to care for the living and not the dead”*
- *Attitude 3 – “The most important thing is to remain neutral”*
- *Attitude 4 – “The whole process is unpleasant”*

These approaches were illuminated by using the Johari window, a model by Luft and Ingham (1955), and quotations from the participants to describe the content of the different approaches (Figure 2). The Johari window is used in, among other things, social psychology as an instrument to describe different modes of communication. The Johari window is also termed “the model that discloses self-knowledge” (Luft & Ingham 1955). The concept of value is here central. Our values are revealed in our words and actions and will be perceived by those around us (other people, e.g. ICU colleagues).

	<b>What I know</b>	<b>What I do not know</b>
<b>What other people know</b>	A1 <i>“I can alleviate the suffering”</i> Known to me Known to other people	A3 <i>“The most important thing is to remain neutral”</i> Hidden from me Known to other people
<b>What other people do not know</b>	A2 <i>“My duty is to care for the living and not the dead”</i> Known to me Hidden from other people	A4 <i>“The whole process is unpleasant”</i> Hidden from me Hidden from other people

**Figure 2.** Approaches to organ donation among ICU nurses (n=9). The model was developed from the so-called “Johari window” (Luft & Ingham, 1955) by Flodén and Forsberg (2009, p. 311) in Paper I.

It is likely that the various approaches exert an influence on the decision about OD. However, on the basis of our findings it is not possible to draw any conclusion as to the extent to which the different attitudes are represented.

### **The professional responsibility**

The motivation for working as an ICU nurse was a general interest in and affection for human beings. Being a spokesperson for the patient and working within an interpersonal relationship was viewed as very exciting and important. The nurses expressed a wish to do their best as well as mediate hope and positive experiences to patients and relatives. There was also a perception of that it was their duty as an ICU nurse to take responsibility (Paper III).

The perceptions of ICU nurses' responsibility for after-death care varied. One perception stated that the duty was to care for the living, while other perceptions involved a change of focus from the deceased patient to the POD and the possible organ recipients (Paper I). In Paper III, OD was perceived as being a part of the work of an ICU nurse as well as a part of the ICU culture. The informants described their responsibility to make efforts to enable OD, which was motivated by respect for the deceased and the overall situation. When the possibility of OD arose, the informants perceived a responsibility to care for the donor with absolute dignity. Caring for an organ donor demanded extraordinary commitment and required more emotional engagement compared with care of a regular ICU patient. Taking on the so-called 'role' was a tool used to avoid losing oneself.

Respecting the wish of the deceased was viewed as crucial, even if it meant that OD would not take place. Establishing good contact with the family was described as central. Awareness of one's own perceptions of BD and OD was considered paramount, due to the belief that the nurse, consciously or unconsciously, acts in accordance with it. The perception was that the nurse's own opinion could influence the family. The nurses described the sudden loss of a loved one as traumatic for the family members, a situation that became even more difficult when the question about donation arose. They were concerned that the relationship with the family might go wrong, leading to mistrust. A situation perceived as a potential ethical conflict was when the nurse had taken measures to promote donation before the family had been informed about the death. Feelings of a guilty conscience, shortcoming and dishonesty arose. Nevertheless, the sense of duty to undertake these medical measures was rooted in the wish to save lives; when the patient's life could no longer be saved, their thoughts focused on the lives of potential recipients. When it became clear that OD was a possibility, the nurses felt the need to provide care characterised by absolute dignity. Dignity was considered a foundation as well as an important part of the work. Their efforts were motivated by respect for the deceased and the overall situation. They deemed it important for family members that everything was performed in a harmonious way, which was the feeling the nurses wanted the family to remember (Paper I).

The findings indicate that the ICU nurse who is positive to and promotes OD strives to perform organ donor advocacy. He or she preserves dignity at all times, fulfils the wishes of the potential donor and takes responsibility for "*nothing must go wrong*".

This translates into the following nursing actions:

- Taking professional responsibility
- Showing respect
- Fulfilling the last wish of the potential organ donor

### **Perceived lack of organisation**

In the first three papers, the necessity of a clear organisation regarding OD was raised. The data from the interviews and item responses revealed disappointment due to the lack of structure and guidelines. There was a need for a local organisation chart and check list regarding the OD process, especially in the early phase. It was perceived that identification of PODs did not take place due to the lack of structure and guidelines. However, the Organ Donation Manual (distributed by the OD/transplantation units in Sweden) was perceived as helpful in caring for a POD. Only one informant described a clear and structured organisation in relation to OD. The ICU was perceived as isolated, and there was a need to develop cooperation with other departments or units, e.g. radiology. Finally, the informants were not aware of the existence of a national organisation dealing with OD issues.

It was considered that the manager and director of the ICU had no expectations in terms of OD. The ICU nurses expressed that they wanted him or her to take a stand in favour of OD. The absence of leadership resulted in ambiguity and the feeling of being abandoned when caring for a POD. It was considered important to keep knowledge of OD updated by means of discussions and continuous education (locally and nationally). The importance of someone in charge (preferably an intensivist) keeping the issue of OD alive was described as crucial (Paper III). However, in Paper II, four fifths (n=550) of the nurses reported that there was a physician or nurse responsible for OD in their unit. Caring for an organ donor was considered teamwork, despite the fact that the physician was in charge (Paper III). The presence of the physician throughout the donation process was perceived 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 (Paper I).

The analysis in the fourth paper showed that it might be possible to measure Attitudes towards organ donor advocacy by five homogeneous components linked to the theoretical construct of the ATODAS. A five-factor solution rather than the originally hypothesized three-factor solution emerged from the principal component analysis. In the five-factor solution, all factors had eigenvalues greater than 1.0. The rotated five-factor solution revealed the presence of a simple structure, with each factor showing a number of strong loadings and most variables loading substantially ( $>.35$ ) on only one factor, with a difference in loading on the other factors of at least  $.20$ . The total scale variance explained by the five factors was 41.9%.

Applying a loading criterion of  $.40$ , ten items loading  $.40$  or above uniquely for factor one, were categorized in sub scale one and labelled *Attitudes towards championing organ donation at a structural hospital level* (10 items). In addition, items originally

classified into the dimension of Championing social justice were categorized in sub scale two and labelled *Attitudes towards championing organ donation at a political and research level* (4 items). Fifteen items were originally classified to measure *safeguarding the potential donor's will and wishes* and were now re-classified into two factors labelled *Attitudes towards actively and personally safeguarding the will and wishes of the POD* (5 items) and *Attitudes to safeguarding the potential donor's will and wishes by a professional approach* (6 items). The remainder of the fifteen items originally classified to measure acting on behalf of the potential or actual donor's relatives, were sorted under the label *Attitudes towards safeguarding the will and wishes of the relatives* (7 items). In conclusion, the exploratory principal component analysis resulted in five factors, including 32 relevant items for measuring ATODA. Cronbach's alpha values varied from .62-.90, indicating satisfactory homogeneity of the scale.



## DISCUSSION

### Methodological considerations

Phenomenography was considered the obvious choice since it is the empirical study of the different ways in which people experience, perceive, apprehend, understand and conceptualize the various phenomena in and aspects of the world around them. Strategic selection was employed in order to capture as many perceptions as possible of different care levels in the hospitals involved to cover a wide geographic area. The Papers I and III included nine and 15 participants respectively, which is acceptable in phenomenographic research. Transferability to other ICU nurses and ICU settings is considered good, since the main focus of the studies is a highly relevant but rare phenomenon in the mind of every ICU nurse. The participants represented various age groups comprising both men and women who worked in the ICU and taken care of potential or actual organ donors. However, further quantitative research is required to enable generalization of these findings. It is possible that participants with a predominantly positive attitude towards OD were chosen, as the selection was made by the respective ICU managers. However, this was not reflected in the findings. According to Sjöström and Dahlgren (2002), there are at least two problems associated with the phenomenographic interview method. The first concerns the participants' reasons for participating. In these two Papers (I & III) all informants stated that they had chosen to participate as they regarded the question to be of major importance. The second problem involves the researcher's understanding of what the participants are trying to communicate. He or she has to interpret their statements during the interview and formulate follow-up questions in order to obtain clarification and avoid misunderstanding. The interviewer is very familiar with the entire donation process, which is necessary in order to pose relevant follow-up questions, but was not personally engaged in the care or in any way involved with the participants. During the data collection there were no changes in national guidelines, although there may have been some changes in local ICU guidelines.

One weakness of this initial data collection was that it was not sufficiently explained to the respondents whether the actual phenomenon under investigation was OD in general or actual organ donor advocacy. Analysis to define the first and second order perspectives therefore resulted in a large number of variations in ICU nurses' perceptions of experiences of OD as a situation as well as OD as a phenomenon that only implicitly involved aspects of organ donor advocacy.

Another aspect that needs to be addressed is our decision to explore the essence of each category, which might be viewed as being too much inspired by the phenomenological tradition. Phenomenology searches for the essence or the most invariant meaning of a phenomenon, while the aim of phenomenography is to discern and describe ways of experiencing phenomena in the surrounding world. I actually moved from maximum variation to invariance in the same data analysis process and motivate this performance by step 5-7 in the analysis suggested by Sjöström and Dahlgren (2002). I have interpreted that comparing categories in order to try to establish borders between them and naming their essence can result in a description of the unique character of

each category. I argue that our interpretation of steps 5-7 has contributed to a deeper understanding of the variations in perceptions and the presumed deeper meaning behind them. Furthermore, the core objective of Sjöström and Dahlgren's method is to explore *perceptions of experiences* of something and not merely perceptions. This implies that the respondents' various perceptions stem from experiences of the phenomenon, in this case OD and the care of the potential donor, and that the respondents presumably endow these experiences with some form of meaning that in turn shapes the perceptions. Others might argue that the method has been distorted and not fruitfully developed to fit an educational and nursing perspective. I believe the opposite, as the chosen method was applied to fit nursing research by Sjöström and Dahlgren (2002). Secondly, the first and second order perspectives were correctly revealed. There may still be disagreement regarding whether or not the categories reflect the variations in perceptions in a correct way and whether or not steps 5-7 in the analysis should be interpreted to reflect a phenomenological direction.

The instrument used in Paper II was not developed to fit the nurses' perspective but originally intended to focus on physicians' attitudes towards OD (Sanner et al., 2006). However, I believed that the best way to achieve the aim was to modify the physician questionnaire (Sanner et al., 2006) to fit the group of ICU nurses and therefore the items were adjusted. A strength of this approach was that the persons involved, i.e. ICU nurses, performed the measurement by means of self-rating scales, which are suitable due to the subjective nature of the data. A disadvantage was the fact that the instrument was new to this target population and not tested for validity or reliability in this group of professionals. However, the scale reliabilities computed in this population were acceptable. During the analysis, the physician questionnaire was found to have several limitations, i.e. the items covered a wide range of aspects, leading to uncertainty about what was being measured, the diversity of the scales and response alternatives as well as the many items pertaining to resources as opposed to personal beliefs. When the questionnaire was tested for internal validity and reliability, only eleven out of 34 items actually fitted a structure. In terms of the questionnaire as an instrument, it is problematic that we were unable to verify and retain more factors. However, each of the remaining 23 single items provided valuable descriptive information that demonstrated a lack of knowledge and trust. For instance, the lack of trust in the clinical diagnosis of BD without a confirmatory cerebral angiography indicates a need for education. I also consider that the response rate was acceptable (69%), as it is reasonable to believe that the responses are a representative sample comprising half of all Swedish ICU nurses from various parts of the country, due to the use of a random sample from the SAHP member registry. Despite the limitations of the questionnaire described above, I believe that we have explored the broad spectrum of nursing in relation to OD from brain dead persons in Sweden.

In Paper IV we aimed to develop and psychometrically test an instrument to capture attitudes towards organ donor advocacy at a level that is possible to generalize. This resulted in the Attitude Towards Organ Donor Advocacy Scale (ATODAS) instrument. In order to increase the use of questionnaires designed to assess health care outcomes, attributes of instrument properties need to be considered when evaluating

their quality and applicability in clinical use. The ATODAS does not measure health care outcomes; however, the attributes defined by the Scientific Advisory Committee involved in the work of The Medical Outcomes Trust (2002) are considered applicable to this instrument. These eight attributes of importance for instrument assessments are; conceptual and measurement model, reliability, validity, responsiveness to change, interpretability, respondent and administrative burden, alternative forms of administration and cultural and language adaptations (translations). There are similar but less comprehensive quality criteria defined by other researchers (Andresen, 2000; Fitzpatrick, Davey, Buxton & Jones, 1998). Although definitions of quality criteria for the properties of health status questionnaires differ, a common feature is that apart from evaluation of validity and reliability, they should include a clear description of the concept of interest, item selection, item reduction and the workload required from respondents to complete the questionnaire. When scrutinizing the quality of the ATODAS, it should be noted that evaluation of validity and reliability has been performed, that the theoretical framework has been elaborated on and the item selection reasonably described. However, one limitation might be that the workload is considered high since the items concern sensitive and ethically demanding aspects of ICU care and the instrument contains a fairly large number of items. This may also explain the much lower response rate compared to Paper II, despite the fact that the same data collection method was applied.

## **Reflections of the findings**

Both earlier and more recent research has stressed the important role played by the ICU staff members' attitude to OD (Flodén et al., 2006; Jacoby & Jaccard, 2010; Sharp, 2009). This thesis contributes with new knowledge of ICU nurses' perspective on caring for potential organ donors and their approach to OD in the light of Swedish legislation.

### ***Trust in brain death***

The findings raise a crucial question. Is the ICU nurse's trust or lack of trust in BD a decisive factor in the care of a POD that might affect whether or not donation will actually take place? The data do not provide an answer to this question, but highlight various considerations and implications. Less than half of the ICU nurses (48%) trusted in the clinical diagnosis of BD without a confirmatory cerebral angiography while 4% did not trust in the concept of BD at all (Paper II). This finding is serious, as the gold standard for declaration of BD in Sweden is clinical diagnostics. It must be considered problematic that such a large number of professionally active ICU nurses are not convinced that it is possible to determine beyond doubt that someone has died by using the methods laid down by the National Swedish Board of Health and Welfare (SOSFS 2005:10). This uncertainty may explain why almost half of the nurses considered that caring for a mechanically ventilated POD was a great burden involving emotional strain, and 25% of the respondents indicated that mechanical ventilation was withdrawn in order to reduce suffering for a presumably dead person without the issue of OD being raised (Paper II).

In an attempt to understand what lay behind this result, the informants in Paper III were asked what was required in order for them to have confidence in the BD concept and that BD had been correctly diagnosed. The results revealed four qualitatively different ways in which the nurse can gain confidence and feel certain that the patient has died due to BD. These are new findings, not described in previous research. One way to trust or not trust in death having been established in the right way was to assess the competence of the physician performing the tests. Another was to be present during the tests, to see with one's own eyes. There seems to be a difference between theoretically understanding that someone has died due to BD and comprehending it on an emotional level. This difference can perhaps be explained by the Theory of cognitive dissonance, first defined by Festinger (1957). Because the experience of dissonance is unpleasant, the person will strive to reduce it (Clark, McCann, Rowe & Lazenbatt, 2004). It is possible that understanding the physiological death of the brain dead person can be in dissonance with his or her appearance, i.e. warm body and beating heart. Cognitive dissonance is well described in previous research (Hibbert, 1995; Pearson et al., 2001; Pelletier-Hibbert, 1998; Watkinson, 1995).

Pearson et al. (2001) suggested that nurses try to minimise this great source of stress by behaving in a manner that is consistent with the patient's appearance, i.e. as if he or she is still alive (Pelletier-Hibbert, 1998). It can be assumed that being involved in the OD process can be filled with anxiety for a nurse who experiences doubt that the patient is dead. In this caring situation, the nurse's wish to act as an advocate (Andrew, 1998; Hanks, 2010; Penticuff, 1989; Sellin, 1995) will probably lead to him or her responding to the pledge to the deceased (Koehn, 1994), as a means of finding meaning in his or her conscious and/or unconscious decisions. Feeling secure in one's professional role is fundamental for the ability to do a good job. It was considered important to keep knowledge of OD at an up-to-date level by means of discussions and continuous education (locally and nationally) (Paper III). Pellerlaux et al. (2008) highlighted the importance of knowledge and feeling secure in the OD situation, as if not, the consequence would be avoidance behaviour and failure on the part of ICU staff to raise the question about OD due to feeling uncomfortable in the conversations with the family members. One way of improving the ICU nurse's trust in BD diagnostics might be a supportive organisation in combination with BD diagnostics education. These measures might have the potential to support nursing staff in the field of 'The possible' in Bentling's model (2009), which illustrates how the individual dimension deals with how we interpret our mission, use and develop our skills and whether or not we can, will and dare to stand up for our actions.

What are the potential consequences of so many nurses experiencing uncertainty about whether or not the patient is dead after death has been established by means of clinical diagnostics? A literature study by Flodén et al. (2006) revealed how the attitude to donation influenced ICU staff members' actions when the possibility of OD arose. The ability to identify a POD and to perform adequate medical actions in time was affected as well as how the relatives were encountered and how the question of OD was raised, if at all. The more positive the attitude to OD, the more eager was the ICU staff to ascertain the will of the deceased person and to perform the necessary measures. One hypothesis is that conscious or unconscious doubt about BD diagnostics, possibly

caused by cognitive dissonance, is decisive for a nurse's way of acting when caring for a POD. The challenge associated with improving knowledge and trust in BD diagnostics is linked to several areas. First, the right of an ICU nurse to feel secure and familiar with the duties he or she is expected to carry out. Second, the potential donor's right to receive correct medical care and having his or her wish to donate ascertained. Moreover, those conditions for optimal care of the relatives are created. Systematic piloting of the relatives, as described by Fridh et al., (2009a), can allow them to mourn in a healthy way. The training for nurses within the specialist intensive care education may require adaptation to meet the need for knowledge related to the concept of BD. It is also likely that other specialist nursing programs, e.g. surgery nurse and nurse anaesthetist, could benefit from this knowledge. The results of this thesis have given rise to the question of whether the Swedish statutory instrument for determination of death (SOSFS 2005:10) in itself constitutes a hindrance to OD. However, there are no concrete data available to support this idea and, most likely, many different factors for or against the performance of OD that interact in a complex way. One such factor can be the perception that there is a structure and support in the organisation for the care of a potential donor, which may lead to OD being carried out.

### ***The importance of organisation***

The results indicate the possibility that the organization of the local ICU is important in order to support the ICU nurse in his or her work with a POD. In the first three papers the issue was raised about the necessity of having a clear organisation regarding OD. Data from the participants' interviews as well as item responses revealed disappointment about the lack of structure and guidelines. However, in Paper II, 80% of the nurses reported that there was a physician or nurse responsible for OD in their unit. This is in accordance with the National Swedish Board of Health and Welfare (SOSFS 2009:30), which stipulates that all hospitals performing transplantations should have access to a physician and/or nurse with responsibility for OD. However, this is contradicted by our finding that the nurses perceived a lack of an existing organisation. If the ICU bedside nurse is not aware of the existence of such an organisation, it can constitute a hindrance in OD work. Whose responsibility is it? The results of this thesis indicate that the nurse wishes for a supportive organisation that will enable him or her to act as a nursing advocate (Andrew, 1998; Hanks, 2010; Penticuff, 1989; Sellin, 1995) and respond to the pledge to the POD and his or her relatives from a professional-ethical perspective (Koehn, 1994). The field of '*The tacit*' in Bentley's professional model (2009) includes, e.g. how different work places interpret and apply laws and new research. This also includes the fact that the unspoken culture of a work place is about hands-on work, regulations and routines, reflected or unreflected acts, common ideals and working methods. In the same way as laws and new research exert an influence on the tacit culture in an activity, it is likely that lack of knowledge about them in the sense of perceiving that there is no formal control can influence the way in which a profession is exercised. According to SOSFS 2009:30, the director is responsible for the donation management system by establishing appropriate routines and a clear division of responsibility. The perceived lack of leadership resulted in ambiguity and the feeling of being abandoned when caring for a POD. Whose responsibility is it and what can be done to create security and a supportive organisation when the possibility of OD arises? Does the absence of a supportive organisation have

any consequences for the identification of possible donors? It was considered that the ICU manager or director had no expectations in terms of OD. Furthermore, the nurses perceived that identification of PODs did not take place due to lack of structure and guidelines (Paper III). Caring for an OD was considered teamwork, despite the fact that the physician was in charge (Paper III). The presence of the physician throughout the donation process was perceived as essential, in terms of both the care provided and the contact with family members.

### ***Attitudes towards organ donor advocacy***

The initial plan for this thesis project was to study Swedish ICU nurses' attitudes to OD. However, at an early stage a picture emerged from the data of the ICU nurses' advocacy act while caring for a POD. In Paper I, where the perception "*nothing must go wrong*" frequently occurred, the assumption that advocacy in the sense of organ donor advocacy might be a crucial aspect in the clinical situation related to OD began to take shape. The assumption was supported by the literature, where e.g. Bu and Jezewski (2007) developed a mid-range theory of patient advocacy. The results of Papers I and III seem to be in line with Bu and Jezewski's argument that advocacy is linked to the context and that the nurse advocates in different ways, depending on the situation. Advocacy performed by the ICU nurse within the OD situation seems to vary depending on the relationship with the relatives, the cooperation with the physician, the approach of nursing colleagues and available resources. 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. The perceptions that emerged from the data analysis provided a fairly clear picture of how organ donor advocacy could be reflected in practice.

In Papers I and III the nurses described how they endeavoured to ensure that everything was done in a correct manner when caring for a POD and his or her relatives. This involved taking responsibility for the situation, showing respect, preserving dignity and exhibiting a professional stance (Paper III). Other researchers have also described these elements as necessary for the nurses' ability to act as a nursing advocate (Andrew, 1998; Hanks, 2010; Penticuff, 1989; Sellin, 1995). Nurses' self-concept, personal values, confidence as nurses and personal beliefs were described as factors that influence their ability to advocate (Chafey, Rhea, Shannon & Spencer, 1998; Foley, Minick & Kee, 2002; Perry, 1984). The participants perceived that their attitude/approach towards OD was crucial for the way in which they cared for a potential donor. The nurses' perceptions about what constituted their duties and what was right and wrong varied (Paper I). These approaches were illuminated by using the Johari window, which is an instrument for describing different modes of communication (Luft & Ingham, 1955). For example, the perception "*My duty is to care for the living and not the dead*" existed. They also pondered whether there were hidden motives within the donation activities, which may contribute to the view that caring for living persons is more meaningful. However, nurses expressing the opinion that "*I can alleviate the suffering*" instead saw an opportunity to relieve the suffering for the potential donor, relatives, colleagues and any recipient of the organs. The Johari window

reveals that the actions may be hidden from oneself but visible to those around. The informants stated that they were able to discern a colleague's attitude to OD based on his or her actions. The perception was that "neutral" colleagues were less proactive in promoting OD (Paper I). In Paper II, a majority of the ICU nurses were either neutral or unable to describe their approach.

Being aware of and taking responsibility for one's own attitude seems to be crucial in order for the nurse to make conscious choices in the care of a POD and his or her relatives. Conscious choices are also a precondition for being able to advocate and safeguard the potential donor's will and wishes. Safeguarding the will and wishes is equally important irrespective of whether it means *yes* or *no* to donation.

The differences between professional categories imply that every profession has its own professional ethics. Koehn's (1994) description of the foundation of professional ethics suggests that being a professional nurse involves an ethical demand to respond to the pledge to human beings alive as well as deceased. The pledge functions as a basis to the extent that it meets the objective requirements for a trusting relationship between the ICU nurse and next of kin. Bentling (2009) underlines the value of reasoning about the importance of taking responsibility and being aware of one's own actions using professional competence as a point of departure. Such reflection on a regular basis is probably of vital importance for being able to meet the requirement to respond to the pledge in the context of OD. Another area of professional competence described by Bentling is *The Given*, which in this context is characterized by the fact that the health care organization is required by law to identify potential donors. This includes an obligation to try to ascertain the will of the deceased person with regard to donating his/her organs after death. In cases where the will of the deceased is not known, relatives should be allowed the opportunity to place a veto (SFS 1995:831; SOSFS 2009:30). The area of professional competence labelled *The Intended* means that every individual within a professional category is required to be informed and to take a critical approach based on scientific research (Bentling, 2009). Taking a critical approach in the context of OD while performing advocacy actions, i.e. safeguarding the deceased's will and wishes regarding OD, may thus result in being both pro and contra donation, which is possible and also justifiable. Thus, it is important to bear in mind that practicing advocacy does not necessarily mean that the nurse is in favour of OD. This fact leads to the need to study attitudes to advocacy actions in relation to OD, as it is likely that it is the attitude to acting in a certain way that in the end determines whether or not the will of the potential donor will be fulfilled.

The Johari window model illuminates the difficulty involved in the demand to respond to and make conscious choices, especially in nursing situations (Paper I). Is it possible for a nurse who is not aware of his or her own perception to take responsibility for his or her own approach? In the longer term, which consequences will this have for the care of the POD, the encounter with his or her relatives and in relation to colleagues? In what way is the ICU nurse's own well-being influenced in a situation when OD becomes a possibility? This thesis does not, however, provide answers to these questions, which therefore require further investigation.

An important part of the advocacy act involved safeguarding the will and wishes of the donor's relatives. Communication with family members during their time in the ICU was seen as an important task. Coyle (2000) argues that handling the needs of families who have experienced clinical BD in a next of kin requires advanced nursing knowledge, skill and expertise. The role of the ICU nurse in these situations was characterized by the effort to provide dignified end-of-life care and to give the family members an enduring memory of their loved one's death. Approaching the relatives often appears to be the most difficult aspect of OD (Sadala & Mendes, 2000; Sharp, 2009; Smith, 1992). The lack of structure and clarification was also considered inadequate (Papers I, II, III) in terms of how to approach the relatives. According to SOSFS 2009:30, the director is responsible for the OD management system by establishing adequate routines and a clear division of responsibility. The nurses expressed a wish to take part in the conversations with the families in order to be well informed during follow-up contacts (Paper III). One important ethical issue was talking with the family to investigate the wish of the deceased, for or against OD.

Fridh et al. (2009a) stated that the caring relationship with the next of kin was vital in end-of-life care, which meant that the nurses/carers piloted the next of kin through their time at the ICU. For the next of kin it was important to be able to trust in the care of their loved one and the nurses endeavoured to meet this need by piloting them during their stay in the ICU. The demands on the nurse when dealing with the relatives were more or less similar in Papers I and III, where showing respect, preserving dignity and conducting the process in a correct manner were important factors. Applying Koehn's (1994) argumentation regarding the basis of professional ethics means responding to the pledge to human beings, alive as well as deceased, by not only sustaining a willingness to help, but also being trustworthy as a professional nurse due to exhibiting competence and determination to do what he or she believes will help both the POD and the relatives.

A particularly sensitive aspect of the relationship with the next of kin is the requirement for honesty in order to prevent mistrust, which was most evident in the first paper. The informants stated that honesty towards the next of kin was fundamental for avoiding distrust of the care. The second paper revealed that 30% of the nurses claimed that raising the question about OD was definitely an additional strain for relatives (Paper II) while others stated that this question should always be asked and that it is important to fulfil the will and wishes of the deceased, irrespective of whether the answer was positive or negative (Paper I). In Paper II, 39% reported that they had an experience that the question about OD was never raised with the relatives, and the nurses felt frustrated when they perceived that the deceased had been deprived of the possibility of donation (Papers I and III). These findings raise queries due to the fact that several studies claim that it is not the question itself that is the big issue. Douglass and Daly (1995) and Painter et al. (1995) demonstrated that when the information had been provided in a satisfactory manner and the will of the deceased with regard to OD was known, the majority of next of kin did not perceive the situation as stressful. An American study by Fulton et al. (1977) revealed that relatives' experiences of OD were more positive in cases where they perceived that staff members understood their need for help and support, compared with encounters described as less positive, with is in accordance with Sanner's (2007) conclusions. The Federal Centre for Health



Education (2001) reported that when the deceased's wishes with regard to OD were known, they were respected in most cases. The results also demonstrated that when the deceased had been negative towards donation, his or her relatives nevertheless gave their consent in 22% of cases. Analysis of the families who either gave their consent or declined OD showed that those who were satisfied with the emotional support and the medical care provided in the ICU gave their consent in most of cases, while families who were dissatisfied only gave their consent in half of cases (Federal Centre for Health Education, 2001). Bartucci (1987) found that the majority of donor families considered that the donation was something positive during the mourning period and felt no regret over the decision to donate their loved one's organ(s). Could it be a coping strategy among ICU nurses to project the supposed suffering onto the relatives due to their own doubts about BD, attitude to OD and/or experience of emotional strain in the caring situation? The efforts to alleviate the nurses' own professional suffering in this demanding situation may lead to the risk of a kind of misdirected concern about next of kin. The nurse can unconsciously try to avoid posing the question about OD or taking part in such a conversation.

The initial question posed in this thesis, namely if the individual nurse's attitude to organ donor advocacy can influence whether or not the donation will take place, is not easy to answer. However, the results have contributed to a deepening of the questions and problematisation in relation to professional competence and professional ethics. According to the results of Paper II, the nurse's own attitude to BD was considered to influence family members' perception. If the nurse harboured doubt, it became evident and led to the family becoming doubtful. This idea was also described by Flodén et al. (2006) and Jacoby and Jaccard (2010).

### ***Professional responsibility***

What is then the answer to the question about professional responsibility in the clinical situation of caring for a POD? The nursing discipline has designated the advocacy role as central to nursing practice, even if other health professionals also advocate for their patients (Hanks, 2010). But what happens if the willingness to act as a nursing advocate is restricted by other obligations? Cronqvist et al. (2004) studied moral obligations and work responsibilities in intensive care nursing. She introduced the concepts 'caring about' and 'caring for', where 'caring about' involved feeling morally responsible to do good for the other, due to a genuine consideration for the well-being of the other. On the other hand, 'caring for' implied a sense of duty to fulfil the work responsibilities required by the needs and regulations of the organization, i.e. being task-oriented. It means carrying out duties controlled by 'others' and assigned to the nurse. Support for 'caring about' is found in the key elements of advocacy when caring for the deceased POD and his or her relatives (Andrew, 1998; Hanks, 2010; Penttiff, 1989; Sellin, 1995). Koehn (1994) also supports the obligation to endeavour take care of the well-being of the other. If relating 'caring for' and 'caring about' to Bentling's professional model (2009), the framework of the nurse's professional role will be governed by legislation, *the given*, while *the intended* will provide the scientific basis. Both 'the given' and 'the intended' might support 'caring for' the POD and his or her relatives. In the field of *the tacit*, individual interpretations of the two previous levels are used. This field also comprises the concept of how different workplaces

interpret and apply law, new research as well as the unspoken culture. The individual dimension, *the possible*, deals with how each individual interprets his or her duties as an ICU nurse. Depending on the local organisation and structure as well as how the individual nurse views his or her professional responsibility, both 'caring for' and 'caring about' might be applicable in these two fields. Cronqvist et al. (2004) argues that tensions will occur when the demands on 'caring for' are balanced against 'caring about' a patient, and the two cannot be achieved at the same time. The challenge is then to find a balance between the two approaches. In a clear and well-structured organisation that is open to discussion and that every member is familiar with, nurses have the opportunity to take responsibility by being involved in the development of well-functioning routines and guidelines, which may also be a support in this ethically tense situation. Fridh et al. (2009c) developed the concept of 'piloting' the relatives of ICU patients during end-of-life care. More knowledge is required about this method of dealing with relatives of potential donors, since is not studied previously. Altun and Ersoy (2003) found that courses in nursing ethics had a positive effect on the development of the advocacy role for the nursing students. This raises the question as to whether an educational intervention might help the nurse to develop his or her advocacy role when caring for a POD and the next of kin.

### ***Development of the ATODAS instrument***

To be able to perform further studies on attitudes towards organ donor advocacy, the most natural choice was to develop and psychometrically evaluate an instrument to measure the attitudes of ICU nurses (Bu & Jezewski, 2007; Polit & Beck, 2010). We considered the theoretical construction behind the ATODAS instrument important, as it is complicated to capture the phenomenon in question within a measurable framework.

As real actions constitute a central part of an attitude and approach, we chose to construct the instrument in the form of statements on how the informants would act in a certain situation. The theoretical construction was verified by the analyses and strengthened the assumption that it might be possible to measure ATODA by five homogeneous components linked to its theoretical construct.

## CONCLUSIONS

The conclusions from these studies are:

- Fifty-two percent of ICU nurses in Sweden do not trust in clinical BD diagnostics for determining death with absolute certainty.
- There are at least four qualitatively different ways to perceive BD and the diagnostics of BD among ICU-nurses.
- Caring for a mechanically ventilated POD is perceived by ICU nurses as a great burden involving emotional strain.
- Withdrawal of mechanical ventilation in order to reduce suffering for the presumably dead person might be a common event, leading to the issue of OD is never mentioned, since every fourth of the ICU nurses had experienced such a situation.
- It might occur frequently that a POD is identified and the question about OD is never raised with his or her relatives, since 39 % of ICU nurses had experienced such a situation.
- There are at least four possible approaches among Swedish ICU nurses when a POD is identified.
- A majority of Swedish ICU nurses seem to be either neutral or unable to describe their approach in discussions with relatives about OD.
- Swedish ICU nurses perceive an overall lack of organisational structure in the area of donation activities, despite the fact that 80% report that their unit has a physician and/or nurse responsible for OD.
- It might be possible to measure attitudes towards organ donor advocacy by means of five homogeneous components linked to a theoretical construct.

## CLINICAL IMPLICATIONS

This thesis reveals that caring for a person to ensure his/her survival and then being confronted with the fact that he or she has died and become a POD is extremely demanding for the staff in charge of the care bedside, i.e. the ICU nurse. Maintaining a professional and supportive care relationship with next of kin at the same time as initiating preparations in accordance with the instructions in the Organ Donation Manual to enable organ donation, can be perceived as a conflict and give rise to ethical issues. When a POD is identified, a feasible and economically justifiable measure is therefore to recruit an extra ICU nurse to perform professional after-death care by caring for the brain dead person. This means that the nurse knows the condition, that he or she is to care for a deceased person and that the nurse who has comforted and supported the relatives can continue to do so without having to make extensive preparations prior to the organ donation surgery. The results highlight the need to define and delimit the period of after-death care in intensive care and to develop knowledge of how to perform work in this area. It is likely that the problems associated with cognitive dissonance can be alleviated and tools developed to provide support for ICU nurses in the emotionally demanding situation of OD by organising venues for ethical and professional reflection. Another possibility is to provide advanced training by means of a workshop during the specialist ICU nurse education. It is obvious that many ICU nurses do not trust clinical BD diagnostics. Thus it is important to ask the ICU bedside nurse in what way he or she wishes to take part in the diagnostic process of a presumably dead person, in order to feel safe and secure in the situation. If the physician in charge is aware of the nurse's doubt, he or she can make the nurse more involved in the diagnostics as well as in the decision process, which may also strengthen team interaction and probably also facilitate the overall work surrounding a POD.

Transparency in the organisation and guidelines are required. Furthermore, it is possible that a standardized care plan that covers the different phases of the OD process could serve as a support in the care of PODs and their next of kin. In addition, the provision of knowledge and education on a continuous basis is desirable for supporting the local OD activity.

The ability to measure the prevalence of various advocacy acts in the clinical OD situation will also make it possible to extend the analysis to include whether or not the acts occur in a way that is desirable from the point of view of current legislation. Such mapping might reveal knowledge gaps which, if identified, may be possible to decrease by means of directed educational interventions that can be scientifically evaluated.

## SVENSK SAMMANFATTNING

Vård i livets slutskede inom intensivvården (IVA) innefattar även vård av personer som har avlidit i total hjärnfarkt och som genom sin död blir potentiella organdonatorer. Detta innebär att vården kommer att förändras till vård efter livets slut, som då sker för att underlätta möjligheterna för organdonation. Att förstå begreppet total hjärnfarkt ("brain death") och dess konsekvenser är mycket svårt för de flesta personer. Det utmanar alla våra tidigare åsikter om död och döende i och med att den avlidne fortfarande har ett hjärta som slår och en kropp som är varm.

I de flesta fall är en organdonator en person mitt i livet, men kan i själva verket vara alltifrån nyfödd till över 80 år gammal. Döden kommer oväntat och plötsligt. För familjen kan det liknas vid en krissituation. En viktig och krävande uppgift för IVA-läkaren och IVA-sjuksköterskan är att ta hand om de sörjande anhöriga och samtidigt vårda den avlidne personens kropp med värdighet och respekt, medan den avlidna personens inställning till att donera sina organ efterfrågas. Det är omvårdnaden och mötet mellan IVA-personalen och de närstående som är det viktigaste i dessa situationer.

Att närma sig anhöriga med frågan om donation upplevs ofta av personalen som den svåraste aspekten vid organdonation. Enligt den svenska Transplantationslagen så är det den avlidnes vilja till donation som är avgörande. I en opinionsundersökning i Sverige 2005 framkom att 86 procent av svenska folket ville donera sina organ efter sin död men färre än 50 procent hade meddelat sin vilja på något sätt.

Denna avhandling är inspirerad av professionsetiken. Ett grundläggande antagande är att vara en professionell sjuksköterska innebär ett etiskt krav att bemöta och svara an på behoven hos såväl levande som avlidna personer. Europeiska unionen (EU) uppmanar medlemsländerna till handling avseende donation och transplantation genom att utveckla gemensamma direktiv och en aktivitetsplan över perioden 2009-2015. Denna aktivitetsplan är ett svar på uppmaningarna i Istanbuldeklarationen.

Det övergripande syftet med denna avhandling var att kvalitativt och kvantitativt studera IVA-sjuksköterskors attityder till "organ donor advocacy" genom att studera deras uppfattningar, erfarenheter och förhållningssätt samt att utveckla ett kontextspecifikt instrument för IVA-sjuksköterskors självskattning av attityder gentemot "organ donor advocacy".

Datainsamling skedde både induktivt med intervjuer och deduktivt med enkäter, för att söka det unika i varje enskilt fall samt för att kunna studera gruppkorrelationer. Studiernas deltagare bestod av yrkesverksamma IVA-sjuksköterskor: studie I n=9, studie II n=702, studie III n=15 och i studie IV n=502. Intervjuerna analyserades med hjälp av fenomenografi. De instrument som användes för att samla kvantitativa data var dels ett frågeformulär som syftade till att studera IVA-sjuksköterskors attityder till organdonation samt instrumentet Attitudes Towards Organ Donor Advocacy Scale (ATODAS), vilket utvecklades för syftet i denna avhandling.

## Tilltro till diagnostik av total hjärninfarkt

Mindre än hälften av IVA sjuksköterskorna (48%) litade på att man med säkerhet kunde fastställa att någon avlidit i total hjärninfarkt med hjälp av klinisk diagnostik (vilket är golden standard i Sverige) utan en bekräftande cerebral angiografi (studie II). I studie I framkom uppfattningen att det är bara logiskt att *"man är död när hjärnan dött"* men det ansågs vara en osäkerhet och brist, när sjuksköterskor saknade kunskap om hur undersökningen gick till för att fastställa total hjärninfarkt ("brain death"). Sjuksköterskans egen inställning till total hjärninfarkt ansågs kunna påverka familjens uppfattning. Om sjuksköterskan hyste tvivel skulle detta bli tydligt för familjen och kunde leda till osäkerhet även hos dem.

## Anhörigkontakterna

Trettio procent av sjuksköterskorna (n=207) hävdade att frågan om organdonation innebar en ytterligare påfrestning för anhöriga utöver det faktum att deras närstående hade avlidit. Totalt 39% (n=275) hade erfarenhet av att frågan om organdonation inte tagits upp eftersom situationen ansågs vara så känslomässigt laddad att det ansågs olämpligt. Dock framstod uppfattningen från intervjuerna att frågan om donation alltid bör ställas eftersom det var viktigt att uppfylla den avlidnes vilja avseende donation, oberoende om svaret blev positivt eller negativt. Uppfattningen var att "neutrala" kollegor var mindre proaktiva för att främja organdonation. Sjuksköterskorna ansåg det viktigt att det beslut familjemedlemmarna kom fram till var äkta och fattades av egen fri vilja samt att det skulle leda till en känsla av rätt beslut utan ånger.

## Vård av den potentielle organdonatorn

IVA-sjuksköterskan strävade efter att skydda och uppfylla den potentiella organdonatorns vilja och önskningsar och upplevde ett krav att ta ansvar för situationen genom att visa respekt, bevara värdighet, genomföra donationsprocessen på ett korrekt sätt samt att uppvisa ett professionellt förhållningssätt. *"Det får inte bli fel"* sågs som centralt, såväl i mötet med familjen som vid vården av den möjliga donatorn. Sjuksköterskorna uppgav att ärlighet var viktigt i mötet med de anhöriga för att undvika brist på förtroende. Även om den medicinska vården var tidskrävande så upplevde deltagarna en ännu större ansvarskänsla för familjen i dessa situationer. I studie I identifierades fyra olika sätt att förhålla sig till en möjlig donator.

## Det professionella ansvaret

Olika uppfattningar fanns bland IVA-sjuksköterskorna angående deras ansvar när en person hade avlidit i total hjärninfarkt. En uppfattning som förekom var att sjuksköterskans plikt bara var att ta hand om levande personer, medan andra hade uppfattningar som innebar ett skifte av fokus från den avlidne personen till de möjliga organmottagarna. I studie III uppfattades organdonation som en naturlig del i arbetet som sjuksköterska på IVA samt att det var en del av IVA-kulturen. Att ta hand om en organdonator krävde ett extraordinärt och känslomässigt engagemang jämfört med vård av den "vanliga" IVA-patienten. Att gå in i sin så kallade "roll" var ett verktyg för att undvika att förlora sig själv i situationen.

Att respektera den avlidnes önskan sågs självklart, oavsett om det innebar att organdonation skulle bli av eller inte. God kontakt med familjen beskrevs som central. Medvetenhet om sin egen uppfattning rörande total hjärninfarkt och organdonation ansågs ytterst viktigt på grund av att sjuksköterskan kommer att handla i enlighet med denna uppfattning, medvetet eller omedvetet.

### **Upplevd brist på organisation**

Behovet av en tydlig organisation när det gäller organdonation togs upp i de tre första delstudierna. Data från intervjuerna och enkäterna visade en besvikelse över bristen på struktur och riktlinjer. Det fanns ett behov av en lokal organisation och av riktlinjer att använda genom donationsprocessen, särskilt i den tidiga fasen. Det uppfattades som att identifiering av möjliga donatorer inte ägde rum på grund av brist på struktur och riktlinjer. Dock uppfattades Organdonationspärmen (distribuerad av donations- eller transplantationsenheter i Sverige) att vara en bra hjälp när man ska ta hand om en (potentiell) donator. Analyserna i den fjärde studien visade att det kan vara möjligt att mäta attityder till ”organ donor advocacy” (ATODA) med hjälp av fem homogena faktorer.

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## ATODAS [Swedish version]

**Sektion 1** innehåller frågor om **attityder till handlingar för att säkerställa den potentiella donatorns vilja**. Var vänlig och läs varje påstående noga och kryssa i den siffra (1-6) på skalan som bäst stämmer överens med hur du skulle agera i en situation där det finns en potentiell donator.

**1= Tar helt avstånd från; 2= Tar till stor del avstånd från; 3= Tar till viss del avstånd från; 4= Instämmer till viss del 5=Instämmer till stor del; 6= Instämmer helt**

Påståenden	Tar helt avstånd från 1	2	3	4	5	Instämmer helt 6
1. Jag kommer att agera i händelse av olämplig medicinsk behandling av den potentiella donatorn.						
2. Jag ifrågasätter bristfällig vård av en potentiell donator utförd av sjuksköterska eller läkare på min avdelning.						
3. Jag uppmärksammar den som förhindrar en korrekt och konsekvent vård av den potentiella donatorn.						
4. Jag kommer att argumentera mot alla former av oetisk behandling av en potentiell donator.						
5. Jag diskuterar med tjänstgörande anestesilog om eventuella konsekvenser av hans/hennes beslut avseende den potentiella donatorn.						
6. Jag uttrycker den potentiella donatorns vilja om den är känd för mig.						
7. Jag gör tjänstgörande anestesilog samt patientansvarig läkare (PAL) uppmärksam på den avlidnes och/eller närståendes vilja rörande organdonation.						
8. Det är mitt ansvar att företräda den potentiella donatorn genom hela donationsprocessen.						
9. Det är min plikt att respektera den potentiella donatorns vilja.						
10. Jag är lyhörd för och respekterar den potentiella donatorns vilja även om jag själv inte delar hans/hennes uppfattning.						
11. Jag gör kollegor på mitt pass uppmärksamma på den avlidnes och/eller närståendes vilja rörande organdonation.						

**Sektion 2** innehåller påståenden om **attityder till handlingar för att stödja närstående till den potentiella donatorn**. Var vänlig och läs varje påstående noga och kryssa i den siffra (1-6) på skalan som bäst stämmer överens med hur du skulle agera i en situation där det finns en potentiell donator.

1= Tar helt avstånd från; 2= Tar till stor del avstånd från; 3= Tar till viss del avstånd från; 4= Instämmer till viss del 5=Instämmer till stor del; 6= Instämmer helt

Påståenden	Tar helt avstånd från 1	2	3	4	5	Instämmer helt 6
12. Jag hjälper närstående att väga motiv för och emot organdonation.						
13. Jag diskuterar med närstående om eventuella konsekvenser av deras beslut.						
14. Jag strävar efter att närstående kommer fram till ett beslut om organdonation som de kan fortsätta leva med.						
15. När möjligheten till donation uppstår så är det är min plikt att förklara transplantationslagens innebörd för de närstående, inklusive deras rättigheter i enligt med den.						
16. Jag ger fortlöpande information till närstående om värden av den potentiella donatorn.						
17. Jag ser jag till att närstående förstår de medicinska åtgärder som vidtas efter att den avlidne har identifierats som en medicinskt lämplig donator.						
18. Jag påminner andra medarbetare som är involverade i vården av den potentiella donatorn att närstående har rätt att få fortlöpande information.						

**Sektion 3** innehåller påståenden om **attityder till handlingar för att verka för organdonation på ett organisatoriskt eller strukturellt plan**. Var vänlig och läs varje påstående noga och kryssa i den siffran (1-6) på skalan som bäst stämmer överens med hur du skulle agera i en situation där det finns en potentiell donator.

1= Tar helt avstånd från; 2= Tar till stor del avstånd från; 3= Tar till viss del avstånd från; 4= Instämmer till viss del 5=Instämmer till stor del; 6= Instämmer helt

Påståenden	Tar helt avstånd från 1	2	3	4	5	Instämmer helt 6
19. Jag hjälper till att på min IVA-avdelning utveckla riktlinjer som beaktar den potentiella donatorns situation och närståendes behov.						
20. Jag samarbetar med andra professioner även utanför min IVA-avdelning (t.ex. röntgen eller laboratorium) för att förbättra riktlinjer avseende organdonation.						
21. Vid behov agerar jag på ett strukturellt plan för att förändra policydokument om organdonation.						
22. Vid behov skulle jag vidta andra åtgärder för att uppnå goda rutiner vid organdonation t.ex. utbildning av medarbetare, reflektionsgrupp för etiska frågor etc.						
23. Vid behov deltar jag i förbättringsarbete av riktlinjer för organdonation på min IVA-avdelning.						
24. Vid behov uppmärksammar jag ledningen för min IVA-enhet på vikten av riktlinjer för organdonation.						
25. Jag använder tillgänglig vetenskaplig kunskap för att försäkra mig om att arbetssättet i samband med organdonation är evidensbaserat.						
26. Jag främjar kommunikation och samarbete mellan olika professioner i vården av en potentiell donator.						
27. Jag går utanför min ordinarie IVA-avdelning för att diskutera och främja organdonation.						
28. Jag framför problem som uppstår i relation till organdonation till den högsta ledningen i min verksamhet.						
29. Jag deltar i politiska beslut som påverkar organdonation.						
30. Jag överväger att börja arbeta politiskt för att främja organdonation.						
31. Jag deltar i forskning som påverkar organdonation.						
32. Om det var möjligt skulle jag delta i forskning som påverkar riktlinjer och policies avseende organdonation.						

