Factors affecting the relatives' decision regarding organ donation in interaction with intensive care nurses: a meta-synthesis

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TITTEL PÅ MASTEROPPGAVE:

Norsk tittel: Faktorer som påvirker pårørendes samtykke angående organdonasjon i interaksjon med intensivsykepleierne: en meta-syntese.

Engelsk tittel: Factors affecting the relatives' decision regarding organ donation in interaction with the intensive care nurses: a meta-synthesis.

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Foreword

We would like to give a big thank you to our supervisor, Kristin Akerjordet, for her patience and highly skilled guidance throughout the writing process.

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SAMMENDRAG

Bakgrunn. Studier og statistikk viser et økt behov for organer på internasjonal basis i forhold til tilgangen. Vurderer hvordan intensivsykepleierens interaksjon med pårørende kan ha noe å si for denne statistikken.

Hensikt. Utforske og identifisere faktorer som kan påvirke pårørendes avgjørelse angående organ donasjon i møte med intensivsykepleieren.

Metode. En systematisk kunnskapsoppsummering av kvalitativ forskning ved bruk av meta-etnografi. Søket inkluderte forskning fra 2005-2015. Ti artikler ble inkludert og analysert.

Resultat. Fire hoved faktorer ble identifiserte som relevante for de pårørendes avgjørelse; forståelse av hjernedød, avdødes ønsker, organisatoriske faktorer, og oppfattelser og holdninger. En bakenforliggende faktor bak dette så ut til å være manglende utdanning, regelmessig kursing og erfaring med donor prosessen.

Konklusjon. Kunnskapsoppsummeringen gav et konkret bilde av hovedfaktorene som påvirket pårørendes avgjørelse. I tillegg ble behovet for økt kunnskap om organdonasjon hos intensivsykepleierne som en profesjon, og pårørende identifisert.

Implikasjoner for praksis. Identifiseringen av de gjennomgående faktorene som påvirker pårørendes avgjørelse, kan få betydning for videre organisering, forskning, utdanning, og jevnlig kursing av intensivsykepleiernes kommunikasjonsferdigheter. Det kan også rette fokus på behovet og utviklingen av offentlige donor kampanjer for å øke den allmenne kunnskapen om donasjon.

SUMMARY

Background. Studies and statistics worldwide have shown that the demand for organs is greater than the supply. Evaluates how the intensive care nurses' interaction with relatives can affect the statistics on organ donation.

Aim. To explore and identify factors potentially affecting relatives' decision regarding organ donation in interaction with the intensive care nurses.

Method. A systematic review of qualitative research using meta-ethnography. It included research from 2005-2015. Ten research articles were included and synthesised.

Results. Four main factors were identified as affecting organ donation decision-making: Comprehension of Brain Death, Decedents Wishes, Organisational Factors and Perceptions and Attitudes.

A major contributing factor appeared to be intensive care nurses lack of education, continuous training and exposure to donor patients.

Conclusion. The meta-synthesis gave a clear picture of the main factors affecting relatives' decision. In addition, the educational needs of intensive care nurses as a profession and the public in general were identified.

Implications for practice. The identification of the factors, affecting the relatives' decision, can be essential for further research and development of educational and in hospital continuous training of intensive care nurses' communication skills. It can also direct focus towards the need and development of targeted organ donor campaigns for the general.

DEFINITIONS & ABBREVIATIONS

Brain death	**(BD)**	Cessation of all neurological functions in the brainstem and cerebral cortex due to ceased electrical activity, and no intracranial blood-flow (Lov om donasjon og transplantasjon av organer, celler og vev, 2015).
Deceased Organ Donor	**(DOD)**	A person who is declared dead using criteria for brain death, se above, and who is going to donate organs and tissue (Lov om donasjon og transplantasjon av organer, celler og vev, 2015).
Intensive Care Nurse	**(ICN)**	An authorized nurse with a master degree or a postgraduate degree in intensive care nursing (Stubberud, 2010, p. 32).
Informed Consent		Process of reaching an agreement based on full disclosure and full understanding of what will take place (Urden, Stacy & Lough, 2006, p.1078).
Opting in	**(Opt-in)**	Explicit given consent to organ donation (Wikipedia 2016)
Opting Out	**(Opt-out)**	Only those who has not refused, is a donor (Wikipedia 2016).
Potential Organ Donor	**(POD)**	A patient is only considered a potential organ donor after being declared brain dead (Lov om donasjon og transplantasjon av organer, celler og vev, 2015).
Presumed Consent		Based on the decedents' presumed will regarding organ donation (Lov om donasjon og transplantasjon av organer, celler og vev, 2015).

Relatives	Used when referring to the PODs' next of kin or family. Norwegian legislation define relatives as; the one stated by the patient as a relative in their medical records (Stubberud, 2010, p. 77).
Western Countries	Western European countries, Australia, Canada and USA. These countries have similar views and practises regarding organ donation.

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PART 1:

MASTER THESIS

"Potential organ donors are slipping away, & with them, slip away the hopes of countless people and families…"

-James Redford-

1.0 INTRODUCTION

1.1 Structure of thesis

The master thesis consists of two parts. *Part 1* presents the master thesis, and consists of introduction, background, aim, theoretical framework, methodology, results, discussion and finally conclusion.
Part 2 presents the article written in accordance with author guidelines from Journal of Advanced Nursing (attachment 5).

1.2 Background

In a thankyou letter published in Critical Care Nurse, Alspach (2013, p. 11), a grandmother and former trauma nurse, wrote, "Thank you for never just walking away and letting us fend for ourselves, but remaining with us to ensure that not just some, but all of our needs were met to the fullest extent possible." As both a relative and a nurse, Alspachs' heartfelt letter provides unique insight into the world of organ donation. In it, Alspach describes how well the relatives of a donor patient were taken care of by health care providers at a trauma centre. Letters like hers reveal the impact high quality care can have during the complex experience of donating the organs of a loved one.

The demand for organs has become a concern worldwide (Berntzen & Bjørk, 2014). Organ donation rates are described as per million of population (pmp). Rudge, Matesanz, Delmonico & Chapman (2012, p. i49) presents statistics showing that Spain, with the highest rate in the world, has had a donor rate over 30 pmp, followed by Portugal, who is the only country who has achieved a rate above 30 pmp for the first time in 2009. Norway had in 2014 a rate of 22.6 pmp, the United Kingdom, on the other hand, had a rate of 16.4 pmp (NOROD, 2015). Expression of the donor rate in pmp does not, however, measure the differences of the effectiveness of the organ donation system (Rudge, Matesanz, Delmonico & Chapman 2012, p. i49). In the United Kingdom, an article was presented by the BBC News, stating that the UK had one of the biggest drops in over a decade in organ donations, and the consequence was a decline of 12% in heart and lung transplantation (BBC News, 20th July, 2015).

Through their employment in an intensive care ward, both authors have experienced to be involved in situations with organ donation and the involved relatives. As well as the personal experiences, it was interesting to observe colleagues' uncertainty regarding expertise and knowledge surrounding the organ donation process. Especially challenging to the authors and colleagues was the interaction with relatives in the decision-making process, the emotional strain, and the stages of providing adequate information. This was the personal inspiration behind conducting this study, to create awareness amongst intensive care nurses regarding organ donation. There has already been done several papers on the field, however, they have a somewhat different focus.

1.3 Aim

The aim of the qualitative meta-synthesis, was to explore and identify factors potentially affecting relatives' decision regarding organ donation in interaction with the intensive care nurses.

Review questions are defined as specific queries of researchers, to help answer the formulated problems, and guide what data the researcher should collect (Polit & Beck, 2012, p. 73). The following review questions guided the review process:

1. What factors affect a relatives' decision regarding organ donation in interaction with the intensive care nurses?

2. What role does the intensive care nurse have in the decision making process of potential organ donors' relatives?

3. How do intensive care nurses perceive their ability to provide quality support to potential donors' relatives?

1.4 Clarification of concept

The thesis is about factors influencing the relatives' decision making process regarding organ donation. Organ donation is defined as transferring an organ from one person to another (Meyer, 2010, p. 259). Organ donation consider both living and deceased patients, however, the main focus in this thesis will be on the potential organ donor patient.

2.0 THEORETICAL FRAMEWORK

The theoretical framework of this master thesis is presented in this section. Based on the identification of the major findings from the synthesis, relevant ethical theories and principles were investigated. In addition, to get a deeper understanding of the interpersonal aspects of an intensive care nurses role, renowned strategies for communication, and a closer look at the stages of crisis were examined in relation to the donor process. The chosen theoretical framework also made the authors more conscious of how nurses and relatives' personal attitudes and knowledge affected the interaction and consequently the outcome of their decision-making.

2.1 Ethical perspectives in organ donation

Deontology

Immanuel Kant is regarded as one of the most influential philosophers within the deontological way of thinking. From his view, deontology posits that people are obliged to "do good deeds" to others. The term *deontology* derived from the Greek *deon*, "duty," and *logos*, "science" (Brinchmann, 2008, p. 56). Deontology also supports that a person in general should act regardless of the consequences and judgment of the actions should be based on the motives behind the action. Moreover, deontology states that there is a difference between the inner and outer duties. Inner

duties, for example, are motivated by common sense and free will, while outer duties can be motivated by factors like legislations and religion (ibid, p. 57).

The deontological perspective is essential to the organ donation process, because it deals with both the principle of autonomy and the inner duties. Taking the deontological perspective into consideration, when working with people in crisis, an ICN has to act ethically on the subject of organ donation. The ethical dilemma, forces the ICN to promote the positives regarding organ donation; motivated by the inner duty of common sense and personal attitudes. On the other hand, from a utilitarianism perspective, the ICN have to act in a way that maximizes the potential positive consequences for all involved (Beauchamp & Childress, 2001).

Utilitarianism

Utilitarianism, a form of consequence ethics, first considers the benefits of the action (Sneltvedt, 2008, p. 68). Organ donation, from a utilitarian perspective, is morally right, as donations would benefit many. One organ donor can potentially save several lives (ibid, p. 73). Consequently, it would be morally and ethically justifiable to donate (Groot, Hoek, Hoedemaekers, Hoitsma, Smeets, Vernooji-Dassen & Leeuwen, 2015, p. 9).

2.1.1Four ethical principles

In the organ donation processes, one has to deal with many ethical issues. From a relatives' point of view, the main concern would be the dilemma of what would be the right or wrong decision. It would be especially challenging if the decedent had not registered as a donor, or expressed their wish. The ICNs' would have to carefully consider how they interact and what information they provide the family to aid or support them in the process. If applying Beauchamp & Childress (2001) view on biomedical ethics, one can say finding a balance between ethical principles would be somewhat morally expected, and also ingrained in the medical professions.

Autonomy Principle

The concept of autonomy originates from the Greek words "*autos*", meaning "*self*", and "*nomos*", meaning "*rule*", "*governance*" or "*law*". Autonomy represents a persons' independence or "self-rule" (Beauchamp & Childress, 2001, p. 57). Among the different theories of autonomy, all fundamentally agree on two essential conditions, *liberty* and *agency*. Liberty and agency refer to the independence of controlling influences and capacity for intentional action (ibid, p. 58). A common perception of morality is that a person must respect the autonomous choices of another person and their decision-making process. A persons' autonomy is supposed to be free from any interference (ibid, p. 58). Applying this principle, the ICNs' must make sure to equip the relatives with enough information to possible give an informed consent.

Non-maleficence principle

The essence of this principle is to "not inflict harm" on people, which is considered the maxim in biomedical ethics, *Primum non nocere: "Above all, do no harm"* (Beauchamp & Childress, 2001, p. 113). In some respects, one can say that this principle inspired the developing of framework for policies and procedures within the health care industry, in particular pertaining to the seriously ill, and questions relating to life-sustaining treatments (ibid, p, 113). In some respects, this can be tied to both the ICNs' and relatives understanding of BD. If the relatives perceive that donating would do harm to the POD, it would affect their decision and cause harm in form of extra inflicted strain.

Beneficence principle

In addition to "not do harm", this principle focus on treating the person autonomously and to "do good". In practical terms, to act on behalf of vulnerable patients, to protect their rights, to improve their quality of life (Beauchamp & Childress, 2001, p. 165-170). The challenge for ICNs' in the context of the organ donation process, is how to prioritize the principle. Should it benefit the POD, the relatives in their state of crisis, or the society as a whole, in form of securing a donor, and improve the lives of many. The overall aim should be to balance the care to "do good" to all.

Justice principle

To treat people equally, to act fairly, and in a non-prejudicial or discriminatory way. This refers to respecting peoples' rights, as well as showing respect for the law. Linking this to the utilitarian aspect, it demands that the overall good needs to be maximized to benefit all (Beauchamp & Childress, 2001, p.225-231). This could be crucial for how the ICNs' approach the subject of donation and the care delivered in the process.

2.2Communicating effectively in the donor process

Effective communication is challenging and complex, but imperative for the interaction between intensive care nurses and relatives in the organ donation process. ICNs' are the health care professionals interacting the most with the relatives' in the hospital setting (Fox, 2014, p 1). ICNs' approach when establishing an interpersonal relationship with relatives', can affect the donor decision and ultimately aid their grieving process (Moesmand, 2007, p. 186). Regardless of the relatives' final decision, or the ICNs' personal or professional view, they must be supportive (ibid, 186-187). According to Joyce Travelbee, communication is viewed as a process and enables the nurse to establish a human-to-human relationship (Travelbee, 1971, p.91). Travelbee also stated that communication is the instrument were changes can be made, were nurses wish to influence others and may use communication as a way of inducing change (ibid, p. 95).

Relevant to this process is also the nonverbal communication, which can express inner attitudes and feelings. ICNs therefore need to be highly aware of their own attitudes and body language when. In addition, non-verbal communication can reveal something about people's relation to each other, or express relatives understanding of information provided communicating (Eide & Eide, 2010, p. 198).

Empathy & conveying information

Empathy is the ability to understand, and accept another person's reality, to accurately perceive feelings, and to communicate this understanding to the other. Empathy

statements are neutral and non-judgemental. They can be used to establish trust in difficult situations, such as in a donor process. Affective empathy is absolutely fundamental to understand and confirm another person's feelings, but can also be misinterpreted, or mixed with own feelings (Potter and Perry, 459-460).

Naturally, conveying bad news can be daunting. Such news can be shocking and trigger strong reaction, and can interfere with the cognitive processing of information. The provider has to be prepared, explain the situation as best as possible, giving emotional support to relatives, practical help and then summarize the information. (Gay, Pronovost, Bassett, & Nelson, 2009, p.1). The relatives have the need for continuous information during the whole process, and environmental surroundings and settings should be appropriate (Moesmand, 2007, p. 184).

The organ donor situations are very critical and usually very unexpected, caused by acute illness or a severe incident. These events can trigger a crisis reaction in the relatives that have an emotional impact affecting their usual coping skills (Cane & Ter-Bagdasarian, 2003, p. 59,65). ICNs' equipped with the knowledge of techniques such as proactive communication skills in end of life phases, aid the relatives' process of coping (Fox, 2014, p. 1).

A study conducted in the USA found that effective and timely performance of interdisciplinary meetings with relatives of a critically ill patient have been found to improve relatives comprehension of information. Making this standard of quality care would also make the ICNs' more involved and skilled in the role of conveying information (Krimshtein, Luhrs, Puntillo, Cortez, Livote, Penrod & Nelson, 2011, p, 1325).

3.0 METHODOLOGY

In this chapter the methodological considerations are presented. A description of systematic review and meta-synthesis will be presented along with researchers' perspective, search methods and outcome, and finally, synthesis.

3.1Meta-synthesis

The authors chose to conduct a meta-synthesis because there is limited literature that focuses on what factors affecting relatives' decision regarding organ donation. Meta-synthesis is the systematic integration of qualitative findings (Polit & Beck, 2012, p. 666). Walsh & Downe (2004, p. 204) highlight that the technique of meta-synthesis of inter-related qualitative studies is interpretive in its approach, in contrast to the aggregating meta-analysis method of quantitative literature.

For the thematic extraction phase of this meta-synthesis, Noblit and Hare's 7 steps meta-ethnography approach was adapted (Polit & Beck, p. 670, & Flemming, McCaughan, Angus & Graham, 2014, p. 1213). These steps were: 1 Deciding on the phenomenon, 2 deciding on relevant studies, 3 reading and re-reading studies, 4 identifying relevance between the studies, 5 translating studies into another, 6 synthesizing translations, and finally, 7 writing the synthesis (ibid, 2012, p. 670). This approach was chosen to provide a systematic way of analysing and extracting the data (table 1).

Table 1. *Phases of meta-ethnography inspired by Flemming, McCaughan, Angus & Graham 2014, p. 1212, adapted version from Noblit & Hare 1998.*

Phase of meta-etnography	***Involved process***
Phase 3 – reading the studies	Developing an understanding of each study's context and findings
Phase 4 – determining relations	Comparing contexts and findings across and between studies, including looking for refutations
Phase 5 – translation studies	Mapping similarities and differences in findings, and translating them into one another
Phase 6 – synthesizing translations	Identifying translations that encompass each other and can be further synthesized; expressed as "lines of argument"

A systematic review is defined as "a rigorous synthesis of research findings on a particular research question, using systematic sampling and data collection procedures and a formal protocol" (Polit & Beck, 2012, p. 744). The reviewers used procedures that could be reproduced, and verified by a third part. Total subjectivity cannot be carried out in a systematic review, however, the review process is transparent and disciplined so that readers can assess the conclusions (ibid, p. 653).

3.2 Researchers perspective

The authors' different backgrounds and experiences would affect the analysing of the literature and their extraction and interpretation of findings. Both authors are registered nurses, finalising their Master of Intensive Care Nursing.

Author 1 (ME) has an educational and work experience from Australia, were evidence based practice is highly integrated in the nursing profession. Working in both Norway and Australia has influenced her cultural view and approach when working and

communicating. Author 2 (CH) has an educational and employment background from Norway, working within the palliative and acute care settings, which has formed her interaction skills with relatives in their parting with loved ones' end of life phase.

Hermeneutic phenomenology aligns with the empirical model behind a systematic review. Hermeneutics focus on epistemology, the "how we know", whereas phenomenology focus on ontology, "what it means to be". Heidegger developed hermeneutics, which can be described as determining the intention and meaning of the experience Husserl, on the other hand, is regarded the founder of phenomenology, which has been viewed as how a phenomenon appears to the consciousness of a person (Laverty, 2003, p. 22).

3.3 Search methods and outcome

Before the initial literature search was conducted, a strategy and development of a search tool to organise the framework was essential. For the purpose of this study and guiding the formulation of the aim, a PICO table was created (table 2). A study conducted by Methley, Campbell, Chew-Graham & McNally (2014, p.1), recommended Population, Intervention, Comparison and Outcome (PICO) for best practise when conducting a qualitative systematic review, and is also endorsed by the Higgins & Green (2011). It helped identifying relevant components of clinical evidence (ibid).

Table 2: *Population Intervention Comparison Outcome (PICO) form.*

Patient/population	Intervention	Comparison	Outcome
Nurses Relatives Organ donor	Roles Attitudes Communication Education Coordinated collaborative communication	Nil	Awareness of ICN communication with relatives Need of extended education

The first search was conducted in British Nursing Index and in the Cinahl databases 10th of December 2015. The authors used the following 3 combinations in both British Nursing Index and in Cinahl;

Search 1: experiences AND nurses AND organ donation

Search 2: relatives AND organ donation

Search 3: communication AND nurses AND organ donation

This resulted in 227 studies. For the next 2 searches conducted, in the OVID and EBSCO HOST (including CINAHL and MEDLINE databases, specialised librarians were enlisted to increase the possibility of receiving the most relevant literature. OVID retrieved additionally 103 articles, and finally the EBSCO Host search added another 30 articles. 1 study was added after recommendation by the organ-coordinator at Stavanger University Hospital, and was used in the master thesis only. This resulted in a total of 361 results (attachment 1).

All the searches were limited to the last 10 years, and included primary peer review articles. By excluding the duplicates, the total reduced to 327, and after screening these using the inclusion and exclusion criteria, 18 studies remained (table 3). The authors conducted the literature search as a team, to effectively discuss and select articles. Majority of the articles in the screening phase were excluded because of the geographical sample location.

Table 3: *Inclusion & exclusion criteria*.

Inclusion criteria	**Exclusion criteria**
Published 2005-2015	Published before 2005
Donation from a potential organ donor	Donations from living patients
Conducted in Western Europe, Scandinavia, USA, Canada & Australia	Studies conducted outside included countries
All gender & age of population	Abstracts without full text papers
Qualitative studies & mixed methods	Quantitative Articles

Critical appraisal skills program

Due to the rigorous nature of the critical appraisal skills program (CASP, 2013). CASP was used as an analysis tool to secure a thorough critical review prior to the extraction and analysis phase (attachment 2). The authors decided to exclude articles with a score below 7 to ensure the quality of the chosen articles. Six articles were excluded based on a score below 7, 1 was a quantitative article and 1 was a doctoral thesis, and it was therefore decided to use those 2 in the master thesis to secure a pure qualitative synthesis in the systematic review article. One of the included articles was a mixed method study, however, the only data used was the qualitative part. After the CASP checklist was conducted, 10 articles were finally synthesized.

3.4 Synthesizing evidence from the studies

The authors met continuously through all stages of identification, screening and eligibility. Both authors read half of the articles each and met for discussions of impressions and findings to create a common understanding of the data. Initial extraction of relevant data in terms of aim, method, sample, major findings, strengths and limitations from 18 studies, was carried out by author 2 (CH), and checked by author 1 (ME). In addition, the country of the study was recorded. This was done due to both authors personal interest in possible differences between the different countries. However, there was not found any major differences. The articles were then alphabetized (Attachment 3).

The synthesizing of qualitative research results is an important aspect of the analysis and a wide range of different methods are used to help make sense of and explain the perspectives of participants included in studies (Tong, Flemming, McInnes, Oliver & Craig, 2012, p. 1). Noblit & Hare argued that a meta-ethnography focus on constructing interpretations rather than analysis (Polit & Beck, 2012, p.670). The phases in the synthesis step consisted of phase 3-6 (table 4). Author 1 (ME) conducted the translations and synthesizing, and then discussed the findings with author 2 (CH) to ensure agreement on the identified findings. The translations were further adapted in a thematic extraction form (attachment 4).

Table 4: *Translations and lines of argument.*

Translations	Lines of argument
Nurses and relatives' comprehension of brain death Nurses ability to explain and inform about brain death to relatives	*Comprehension of brain death*
Decedents wish Express will regarding organ donation	*Decedents wish*
Information provided continuously and reinforced	*Organizational factors*
ICN perception of own knowledge and skills in relation to potential donors and relatives ICN personal attitudes towards donation and the effect on care and relative' decision Relatives perception of provided information and care	*Perceptions and attitudes*
Educational and campaign beneficial for ICN and relatives to increase awareness and competence Targeted campaigns to make people aware and express their will Training/education/organizational changes could affect donor rate	*Educational needs*

4.0 RESULTS

The 10 studies reported experiences from three perspectives regarding donation. Five of the studies explored the ICN's experiences, perceptions and attitudes. Four offered a view from relative's perspective, and one considered the understanding and experience of procurement coordinators. All the studies consider factors that would influence donor rates, based on these experiences. The factors identified were: comprehension of brain death, decedents wish, organizational factors, and finally perceptions and attitudes. The underlying contributing factors identified, was intensive care nurses lack of education and experience caring for donor patients and their relatives.

Comprehension of brain death

During the analysis process, it became apparent to the authors that the ICNs' lack of knowledge was a common finding. This affected their ability to provide relevant and timely information to relatives, whom in turn then struggled to comprehend the severity of the diagnosis.

Berntzen & Bjørk (2014) sited the daughter of a donor they interviewed during their study, who made the following statement: "We were told she had passed away and I called my children, telling them grandma had died. Then we got into her room at the ICU and saw her with all the machines… I remember calling them again telling them she was not dead after all" (Berntzen & Bjørk, 2014, p. 270). This statement highlights how difficult it is to comprehend a brain death diagnosis, or how information given or possible lack thereof has been received and interpreted by relatives. In the same study, several relatives expressed problems with understanding both brain death, the characteristics and criteria to state such a diagnosis (ibid, p. 270). Collins (2005, p. 230). findings confirmed that only 67% of the nurses felt they could adequately explain BD. Naturally; this would create insecurity from both sides that could potentially affect relatives' decision to donate negatively.

Decedents wishes'

Anker & Feeley (2010, p. 241) found that if the decedent had expressed a decline to donate, the relatives would not donate, and if the decedent had expressed a positive attitude, the relatives would most likely give consent to donate. However, if the wish was not known, the relatives would in most cases decline (ibid, sp. 241). Berntzen & Bjørk (2014, p. 270) found that the donation situation was usually eased, when relatives knew the decedents wishes, but in some cases, it also seemed to be a burden when the decedent had a positive attitude towards donation. Many expressed a sense of ambivalence. Some perceived consenting to donation would prolong the suffering of the decedent (Sque, Long, Payne & Allardyce, 2007, p.140)

Organizational factors

According to the study conducted in the Netherlands, relatives experienced the donating process as too long, although this time span was not the main reason why some relatives declined donation. A few expressed they experienced the extra time as an advantage (Groot, Hoek, Hoedemaekers, Hoitsma, Smeets, Vernooji-Dassen & Leeuwen, 2015, p. 8).

Orøy, Strømskag & Gjengedal (2013, p. 205-206) found in their study that identifying the best possible time to deliver the bad news and addressing the question regarding donation was of crucial importance, but this was challenging. It could potentially create the impression that health care personnel were only "after the organs". Relatives had mixed experiences of ICNs', varying from supportive to being insensitive and avoiding the situations (Manuel, Solberg & MacDonald, 2012, p. 232). Another limiting factor, identified by Floden and Forsberg (2009, p. 312), was the lack of structured teams to conduct the organ donation procedures.

Perception and attitudes

Anker & Feeley (2010, p. 239-241) described that a common misperception was the idea of unfair organ allocation, abuse of donated organs. Speaking of donation could be seen as superstitious. In the study conducted in the USA, some relatives stated that they agreed to donation to buy time with the decedent (Manuel, Solberg & MacDonald, 2010, p. 231).

The relatives' feelings ranged from utilitarian to the total opposite where they rejected based on disfigurement of the deceased (Groot, Hoek, Hoedemaekers, Hoitsma, Smeets, Vernooji-Dassen & Leeuwen, 2015, p.7, and Anker & Feeley, 2010, p. 244). Other relatives stated they felt guilty they had declined donation, as it was the decedents wish, and that it could have improved someone else's life (Sque, Long, Payne & Allardyce, 2007, p. 141). From a health care personnel point of view, those negative towards organ donation did not raise the issue or ask for consent, or remained neutral, and "the opportunity for donation would eventually fade away" (Floden & Forsberg, 2009, p. 311).

Educational needs

The underlying contributing factor emerging through most of the included studies were ICNs' lack of experience and thereof lack of knowledge and developed skills caring for the organ donor patients and relatives'. Both Collins (2005) and Floden & Forsberg (2009) studies revealed that nurses lack knowledge about tests to establish brain death, and were not aware of the legal criteria for BD. In fact, one of the findings were that the ICNs' perceived that being sure of this criteria and awareness about one's attitude was a precondition for being able to compare (Floden & Forsberg 2009, p. 309). Most nurses found that the time between identifying the potential donor, the transition between life and death, and making the request as very challenging (Meyer, Bjørk & Eide 2011, p. 107). Educational input would enhance the ICNs' knowledge and expertise, and could benefit the donor process (ibid, p. 113).

5.0 DISCUSSION

The overall aim was to find factors affecting the relatives' decision regarding organ donation in interaction with the intensive care nurses. Judging from the synthesis of the 10 articles, the same identified factors were found throughout all the studies. Three different perspectives were included, procurement coordinators, intensive care nurses, and previous relatives of donors, which could be an argument for the validity and reliability of these results (attachment 4). The discussion is presented in order of the review questions.

What factors affect a relatives' decision regarding organ donation in interaction with the intensive care nurses?

The main factors that emerged from this synthesis as affecting the relatives' decision were their ability to comprehend the diagnosis of brain death, with many thinking the POD would recover or was not deceased. This could also be connected to the sudden crisis they were in, making it hard for them to understand the information provided. From a theoretical perspective one could argue that their normal coping skills were impaired, affecting their cognitive ability. Applying the ethical perspective, one could

argue that it is natural to have an ambivalent view, as relatives would struggle with the thought of someone inflicting harm to their loved ones. Morally they would want to do what is right, and beneficial to others. The decedents wish would also affect their decision, especially if it was not known.

An additional factor was the organisational setting and timing, and who made the request. Sometimes this was affected by the structure or lack thereof in the ICU. Inexperienced staff would negatively affect the situation, as that would be perceived as a lack of knowledge, which would create insecurity, and doubt. A common perception and attitude among relatives, were that if they consented, the potential organ donor would not receive optimal treatment.

Human interaction and communication can be challenging at the best of times, but especially challenging in an acute care setting, but this interaction between the ICN and the relatives is imperative in the process.

What role does the intensive care nurse have in the decision making process of the potential organ donors relatives?

A pioneer within nursing theories, Joyce Travelbee, talked about the human to human relationship between the nurse and patients (1971, p. 91), and she also emphasised that communication is a tool used by nurses to influence others and induce change (ibid, p. 95). Part of the ICNs' role, and arguable the most important aspect of their role in the relatives decision-making process is therefore to establish this interpersonal relationship, as it can affect the decision and aid relatives in their grieving process (Moesmand, 2007, p. 186). Regardless of the relatives' final decision, or the ICNs' personal or professional view, they must be supportive (ibid, 186-187).

From a theoretical perspective, when conveying information, the ICNs' have to be prepared, explain adequately and be prepared to repeat the provided information. The synthesis generally showed that the timing of the request and information given was crucial to the relatives' decision. A recent study conducted by Siminoff, Traino & Genderson (2015, p. 1) found that relatives' refusing consenting to organ donation at

the bedside as a major barrier. One can argue that the ICNs' are the ones closest to the relatives' as they are constantly by their side, monitoring the patient and giving emotional support as well as practical help. Based on this, one can argue that being supportive and caring to the relatives, regardless of their decision, as the biggest role of an ICN in the decision-making process. It would however require ICNs'to be confident in the role when providing information, such that the relatives would be equipped to make a well informed decision.

How do intensive care nurses perceive their ability to provide quality support to potential donors' relatives?

As the last phase of the thematic extraction show, the majority of the studies revealed that the most of the nurses perceived their ability to care for the relatives as limited, due to lack of knowledge and limited experience caring for potential donors and their relatives. Insecurity about ones' own ability to provide quality care would affect all aspects of their interaction in the setting.

Many of the nurses expressed that they would be more confident if they had more educational training, particularly pertaining to the brain death diagnosis. The occurrence of potential organ donor patients is rare, resulting in a limited exposure, and thereby lack of possibilities to develop the required skills caring for relatives. Gay, Pronovost, Bassett & Nilson (2009, p. 1) article about family meetings in the ICU discuss the different aspects of that process. They also mention that in over three decades of research, communication has always been ranked as the number one concern for families in the ICU setting (ibid, p. 2). ICNs' have also expressed that they would benefit from educational input in that respect, to enable them to effectively communicate.

6.0 LIMITATIONS AND STRENGHTS

A more extended and complex literature search in other databases could have been interesting in terms of possibly identifying other influencing factors. The authors could also have performed a more thorough check of reference lists to possibly include more adequate articles. If the articles with a low CASP score had been included, it might have affected the result. More experienced reviewers would possibly have chosen another methodological and theoretical method, possibly highlighting other themes. Factors such as the publicly debated opt-in or opt-out options, the cultural and religious effects on relatives' decision-making could have revealed other dimensions. The strength of this synthesis, is the conceding findings regarding the factors influencing the relatives decision-making. This makes the results generalizable.

7.0 CONCLUSION

In conclusion, the major identified factors that seemed to affect the relatives' decision regarding organ donation in interaction to the intensive care nurses, were comprehension of brain death, decedents wish, organizational factors and perceptions and attitudes. It also transpired a significant underlying factor; lack of education and experience within the intensive care nurses regarding comprehension of brain death, brain death criteria, the donor process, communication skills. This underlying factor influenced the ability to provide relatives with adequate information continuously in the donor process. The results also indicated that written information and adapted conditions in the intensive care unit would positively affect the relatives decision-making in a positive way along with improved communication skills among the intensive care nurses.

This synthesis would suggest the further need to develop more structural approaches to hospital based training for the ICNs', increasing their knowledge and skills. This would have to include focus on what information to provide, and how to interact in a sensitive and appropriate manner with the relatives. The findings also imply a need to

develop a culture of developing and using procedures and checklists in the process, and to help set routines. Interactive interdisciplinary teams training could be very beneficial to the interaction process overall to relatives in the organ donation process.

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Part 2:

ARTICLE

"Organ donation is not a tragedy, but it can be a beautiful light in the midst of one..."

(Unknown)

Title. Factors affecting the relatives' decision regarding organ donation in interaction with intensive care nurses: qualitative meta-synthesis.

Abstract

Aim. To explore and identify factors potentially affecting relatives' decision regarding organ donation in interaction with the intensive care nurses.

Background. Studies and statistics worldwide have shown that the demand for organs is greater than the supply. Evaluates how the intensive care nurses' interaction with relatives can affect the statistics.

Design. Meta-synthesis of qualitative studies.

Data sources. A literature search conducted for relevant articles publish during the period 2005 to December 2015.

Review method. Ten studies met the inclusion criteria and were further analysed for quality. The review used structured approach for literature search and evaluation. A meta-ethnography was conducted in the analysis process and presentation of results.

Results. Four factors were identified as affecting organ donation decision-making: Comprehension of brain death, Decedent's wishes, Organisational factors and Perceptions and Attitudes. A major factor contributing factor appeared to be intensive care nurses lack of education, continuous training and exposure to donor patients.

Conclusion. The meta-synthesis gave a clear picture of the main factors affecting relatives' decision. In addition, the educational needs of intensive care nurses as a profession and the public in general were identified

Keywords: organ donation, brain death, procurement, intensive care nurses, relatives, attitudes, perceptions, decision-making, experiences, meta-synthesis

Why is this review needed?

- The need for organs are greater than the supply.
- Knowledge of factors influencing the decision-making process regarding organ donation may increase the donation rate.

What are the key findings?

- Factors influencing the decision-making was identified; comprehension of brain death, decedent's wishes, organisational factors and perceptions and attitudes.
- More information, time and support from the intensive care nurses are crucial.
- Lack of education within the intensive care nurses was identified as an underlying factor.

How should the findings be used to influence policy/practice/research/education?

- Increased intensive care nursing education regarding organ donation process and criteria would influence the decision-making in a positive way.

Introduction

Organ donation is described as an overwhelming situation where a person is forced to evaluate their thoughts and (dis)beliefs under difficult circumstances. The experience entails accepting that a loved one has passed away and, shortly thereafter, being asked about consent to donate. Often overlooked, the pain endured by relatives can place strain on health care personnel, particularly intensive care nurses, and negatively influence the care provided to the donor and family (Berntzen & Bjørk, 2014 and Rudge *et al*. 2012).

The demand for organs has become a concern worldwide (Berntzen & Bjørk, 2014). Organ donation rates are described as per million of population (pmp). Rudge *et al.* (2012) presents statistics showing that Spain, with the highest rate in the world, has had a donor rate over 30 pmp, followed by Portugal, who is the only country who has achieved a rate above 30 pmp for the first time in 2009. Norway had in 2014 a rate of 22.6 pmp, the United Kingdom, on the other hand, had a rate of 16.4 pmp (NOROD, 2015). Expression of the donor rate in pmp does not, however, measure the differences of the effectiveness of the organ donation system (Rudge, *et al.* 2012).

Background

In a thankyou letter published in Critical Care Nurse, Alspach (2013), a grandmother and former trauma nurse, wrote;

Thank you for never just walking away and letting us fend for ourselves, but remaining with us to ensure that not just some, but all of our needs were met to the fullest extent possible.

As both a relative and a nurse, Alspachs' heartfelt letter provides unique insight into the world of organ donation. In it, Alspach describes how well the relatives of a donor patient were taken care of by health care providers at a trauma centre. Letters like hers reveal the impact high quality care can have during the complex experience of donating the organs of a loved one.

The organ donation process is challenging and requires professional competence, which may vary, due to how often intensive care nurses participate in such a situation (Meyer *et al.*2011). Not only is it challenging caring for the patient, it also requires advanced knowledge and skills to manage the relatives' needs in the given situation (Orøy *et al.* 2013). It can truly be said that the relatives are the most important resource in maintaining organ supply because consent to organ donation has to come from the relatives if the patient has not expressed his or her will regarding the subject (Sque *et al.* 2007).

The review

Aim

The aim of the qualitative meta-synthesis was to explore and identify factors potentially affecting relatives' decision regarding organ donation in interaction with the intensive care nurses.

The addressed review questions were:

- What factors affect relatives' decision regarding organ donation in interaction with the intensive care nurses?
- What role does the intensive care nurse have in the decision-making process of potential organ donors' relatives?
- How do intensive care nurses perceive their ability to provide quality support to potential donors' relatives?

Design

A meta-synthesis was conducted following the Noblit & Hare (1988) meta-ethnography approach inspired by Flemmings' adaption (Flemming *et al.* 2014) and CASP quality appraisal. The strategy consisted of several stages, including, review focus, search strategy, inclusion criteria, quality appraisal, data collection and synthesis, results and

discussion. This method was considered appropriate due to the phenomenon investigated.

Search methods

The data search was conducted in corporation with two specialized librarians at both university and university hospital to strengthen the search and identify studies that met the inclusion criteria. The authors conducted a preliminary literature search to get an impression of the existing literature on the field of organ donation and relatives' experiences regarding decision-making.

The second author (CH) conducted a search in British Nursing Index, Cinahl and Medline for the period from 1 January 2005 to 10 December 2015, using the following key words in various combinations: *communication, relatives, organ donation, experiences, nurses.*

Searches conducted by specialized librarians provided less relevant literature compared to the search performed by author 2.

The search process was carried out during the period of December 10 to 15, 2015. Duplicates were identified (by CH) and removed. This resulted in a total of 327. One additional doctoral paper was included due to a recommendation, resulting in a total of 328, 310 were excluded using the exclusion criteria. A total of 18 full text articles were read (by author ME and CH), 8 were excluded, and 10 were finally synthesised. Both authors participated in the review process and continuously met to discuss the articles and inclusion/exclusion criteria.

Insert table 1 – inclusion and exclusion criteria here

Search outcome

The search was performed at three dates due to specialised librarians' contribution. A total of 361 papers were identified through literature searches, 328 required title and abstract review. Eighteen were further searched for eligibility, 10 met the inclusion

criteria (table 1). The searches were systematised in a PRISMA flowchart to give an organised overview of the results (figure 1).

Insert figure 1 – PRISMA flowchart, overview of literature searches, here

Quality appraisal

To assess the quality of the studies selected in the review, a Critical Appraisal Skills Program (CASP), was adapted. The CASP form check was conducted to score 16 articles for quality and eligibility. It was decided to include articles with a score of 7 or above. using a total score above 7 (table 2). Both authors scored the papers individually, using CASP, and then discussed the evaluation to ensure agreement on the included papers.

Insert table 2 – critical appraisal skills program (CASP) here.

Data synthesis

The ten included articles were summarized schematically under the following headings; author(s), year, country, aim, method, sample, major findings, strength and limitations (table 3).

Insert table 3 – summary of articles about here.

A meta-ethnographic approach was conducted to organize and synthesise the findings (Flemming *et al*, 2014). This process included using the data of the included articles and identifying factors affecting the decision regarding organ donation.

The process included phases of reading the studies, determining relation between studies, translating the studies into one another, and finally synthesising the translations (table 4). The phases were inspired by Flemmings' *et. al* (2014) and adapted from the original meta-ethnography by Noblit &Hare. Translations found were further divided into lines of argument to categorise the findings. Author one (ME) conducted the translations and then discussed the findings with author two (CH) to ensure a final agreement (table 5).

Insert table 4 – phases of meta-ethnography and table 5 – translation & lines of argument

The translation of lines of argument were further categorized in a thematic extraction form, identifying the factors (table 6).

Insert table 6 – thematic extraction, about here

Results

The 10 studies reported experiences from three perspectives regarding donation. Five of the studies explored the ICN's experiences, perceptions and attitudes. Four offered a view from relative's perspective, and one considered the understanding and experience of procurement coordinators. All the studies consider factors that would influence donor rates, based on these experiences. The factors identified were: comprehension of brain death, decedents wish, organizational factors, and finally perceptions and attitudes. The underlying contributing factors identified, was intensive care nurses lack of education and experience caring for donor patients and their relatives.

Comprehension of brain death

During the analysis process, it became apparent to the authors that the ICNs' lack of knowledge was a common finding. This affected their ability to provide relevant and timely information to relatives, whom in turn then struggled to comprehend the severity of the diagnosis.

Berntzen & Bjørk (2014) sited the daughter of a donor they interviewed during their study, who made the following statement:

"We were told she had passed away and I called my children, telling them grandma had died. Then we got into her room at the ICU and saw her with all the machines… I remember calling them again telling them she was not dead after all" (Berntzen & Bjørk, 2014).

This statement highlights how difficult it is to comprehend a brain death diagnosis, or how information given or possible lack thereof has been received and interpreted by relatives. In the same study, several relatives expressed problems with understanding both brain death, the characteristics and criteria to state such a diagnosis. Collins (2005) findings confirmed that only 67% of the nurses felt they could adequately explain BD. Naturally; this would create insecurity from both sides that could potentially affect relatives' decision to donate negatively.

Decedents wishes'

Anker & Feeley (2010) found that if the decedent had expressed a decline to donate, the relatives would not donate, and if the decedent had expressed a positive attitude, the relatives would most likely give consent to donate. However, if the wish was not known, the relatives would in most cases decline. Berntzen & Bjørk (2014) found that the donation situation was usually eased, when relatives knew the decedents wishes, but in some cases, it also seemed to be a burden when the decedent had a positive attitude towards donation. Many expressed a sense of ambivalence. Some perceived consenting to donation would prolong the suffering of the decedent (Sque *et al.* 2007).

Organizational factors

According to the study conducted in the Netherlands, relatives experienced the donating process as too long, although this time span was not the main reason why some relatives declined donation. A few expressed they experienced the extra time as an advantage (Groot *et al*. 2015).

Orøy, *et al.* (2013) found in their study that identifying the best possible time to deliver the bad news and addressing the question regarding donation was of crucial importance, but this was challenging. It could potentially create the impression that health care personnel were only "after the organs". Relatives had mixed experiences of ICNs', varying from supportive to being insensitive and avoiding the situations

(Manuel *et al.* 2012). Another limiting factor, identified by Floden & Forsberg (2009), was the lack of structured teams to conduct the organ donation procedures.

Perception and attitudes

Anker & Feeley (2010) described that a common misperception was the idea of unfair organ allocation, abuse of donated organs. Speaking of donation could be seen as superstitious. In the study conducted in the USA, some relatives stated that they agreed to donation to buy time with the decedent (Manuel *et al*. 2010).

The relatives' feelings ranged from utilitarian to the total opposite where they rejected based on disfigurement of the deceased (Groot *et al.* 2015 & Anker & Feeley, 2010). Other relatives stated they felt guilty they had declined donation, as it was the decedents wish, and that it could have improved someone else's life (Sque *et al.* 2007). From a health care personnel point of view, those negative towards organ donation did not raise the issue or ask for consent, or remained neutral, and "the opportunity for donation would eventually fade away" (Floden & Forsberg, 2009).

Educational needs

The underlying contributing factor emerging through most of the included studies were ICNs' lack of experience and thereof lack of knowledge and developed skills caring for the organ donor patients and relatives'. Both Collins (2005) and Floden & Forsberg (2009) studies revealed that nurses lack knowledge about tests to establish brain death, and were not aware of the legal criteria for BD. In fact, one of the findings were that the ICNs' perceived that being sure of this criteria and awareness about one's attitude was a precondition for being able to compare (Floden & Forsberg 2009). Most nurses found that the time between identifying the potential donor, the transition between life and death, and making the request as very challenging (Meyer, Bjørk & Eide 2011). Educational input would enhance the ICNs' knowledge and expertise, and could benefit the donor process.

Discussion

The overall aim was to find factors affecting the relatives' decision regarding organ donation in interaction with the intensive care nurses. Judging from the synthesis of the 10 articles, the same identified factors were found throughout all the studies. Three different perspectives were included, procurement coordinators, intensive care nurses, and previous relatives of donors, which could be an argument for the validity and reliability of these results.

What factors affect a relatives' decision regarding organ donation in interaction with the intensive care nurses?

The main factors that emerged from this synthesis as affecting the relatives' decision were their ability to comprehend the diagnosis of brain death, with many thinking the POD would recover or was not deceased. This could also be connected to the sudden crisis they were in, making it hard for them to understand the information provided. From a theoretical perspective one could argue that their normal coping skills were impaired, affecting their cognitive ability. Applying the ethical perspective, one could argue that it is natural to have an ambivalent view, as relatives would struggle with the thought of someone inflicting harm to their loved ones. Morally they would want to do what is right, and beneficial to others. The decedents wish would also affect their decision, especially if it was not known.

An additional factor was the organisational setting and timing, and who made the request. Sometimes this was affected by the structure or lack thereof in the ICU. Inexperienced staff would negatively affect the situation, as that would be perceived as a lack of knowledge, which would create insecurity, and doubt. A common perception and attitude among relatives, were that if they consented, the potential organ donor would not receive optimal treatment.

Human interaction and communication can be challenging at the best of times, but especially challenging in an acute care setting, but this interaction between the ICN and the relatives is imperative in the process.

What role does the intensive care nurse have in the decision making process of the potential organ donors relatives?

A pioneer within nursing theories, Joyce Travelbee, talked about the human to human relationship between the nurse and patients (1971), and she also emphasised that communication is a tool used by nurses to influence others and induce change (ibid, p. 95). Part of the ICNs' role, and arguable the most important aspect of their role in the relatives decision-making process is therefore to establish this interpersonal relationship, as it can affect the decision and aid relatives in their grieving process. Regardless of the relatives' final decision, or the ICNs' personal or professional view, they must be supportive.

From a theoretical perspective, when conveying information, the ICNs' have to be prepared, explain adequately and be prepared to repeat the provided information. The synthesis generally showed that the timing of the request and information given was crucial to the relatives' decision. A recent study conducted by Siminoff *et al.* (2015, found that relatives' refusing consenting to organ donation at the bedside as a major barrier. One can argue that the ICNs' are the ones closest to the relatives' as they are constantly by their side, monitoring the patient and giving emotional support as well as practical help. Based on this, one can argue that being supportive and caring to the relatives, regardless of their decision, as the biggest role of an ICN in the decision-making process. It would however require ICNs' to be confident in the role when providing information, such that the relatives would be equipped to make a well informed decision.

How do intensive care nurses perceive their ability to provide quality support to potential donors' relatives?

As the last phase of the thematic extraction show, the majority of the studies revealed that the most of the nurses perceived their ability to care for the relatives as limited, due to lack of knowledge and limited experience caring for potential donors and their relatives. Insecurity about ones' own ability to provide quality care would affect all aspects of their interaction in the setting.

Many of the nurses expressed that they would be more confident if they had more educational training, particularly pertaining to the brain death diagnosis. The occurrence of potential organ donor patients is rare, resulting in a limited exposure, and thereby lack of possibilities to develop the required skills caring for relatives. Gay *et al.* (2009) article about family meetings in the ICU discuss the different aspects of that process. They also mention that in over three decades of research, communication has always been ranked as the number one concern for families in the ICU setting. ICNs' have also expressed that they would benefit from educational input in that respect, to enable them to effectively communicate.

Strengths and limitations

A more extended and complex literature search in other databases could have been interesting in terms of possibly identifying other influencing factors. The authors could also have performed a more thorough check of reference lists to possibly include more adequate articles. If the articles with a low CASP score had been included, it might have affected the result. More experienced reviewers would possibly have chosen another methodological and theoretical method, possibly highlighting other themes. Factors such as the publicly debated opt-in or opt-out options, the cultural and religious effects on relatives' decision-making could have revealed other dimensions.

Implication for practice

This synthesis would suggest the further need to develop more structural approaches to hospital based training for the ICNs', increasing their knowledge and skills. This would have to include focus on what information to provide, and how to interact in a sensitive and appropriate manner with the relatives. The findings also imply a need to develop a culture of developing and using procedures and checklists in the process, and to help set routines. Interactive interdisciplinary teams training could be very beneficial to the interaction process overall to relatives in the organ donation process.

Conclusion

In conclusion, the major identified factors that seemed to affect the relatives' decision regarding organ donation in interaction to the intensive care nurses, were comprehension of brain death, decedents wish, organizational factors and perceptions and attitudes. It also transpired a significant underlying factor; lack of education and experience within the intensive care nurses regarding comprehension of brain death, brain death criteria, the donor process, communication skills. This underlying factor influenced the ability to provide relatives with adequate information continuously in the donor process. The results also indicated that written information and adapted conditions in the intensive care unit would positively affect the relatives decision-making in a positive way along with improved communication skills among the intensive care nurses.

Author contribution

ME and CH were responsible for the study approach and overall design.

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Factors affecting relatives' decision regarding organ donation in interaction with intensive care nurses

PRISMA 2009 Flow Diagram

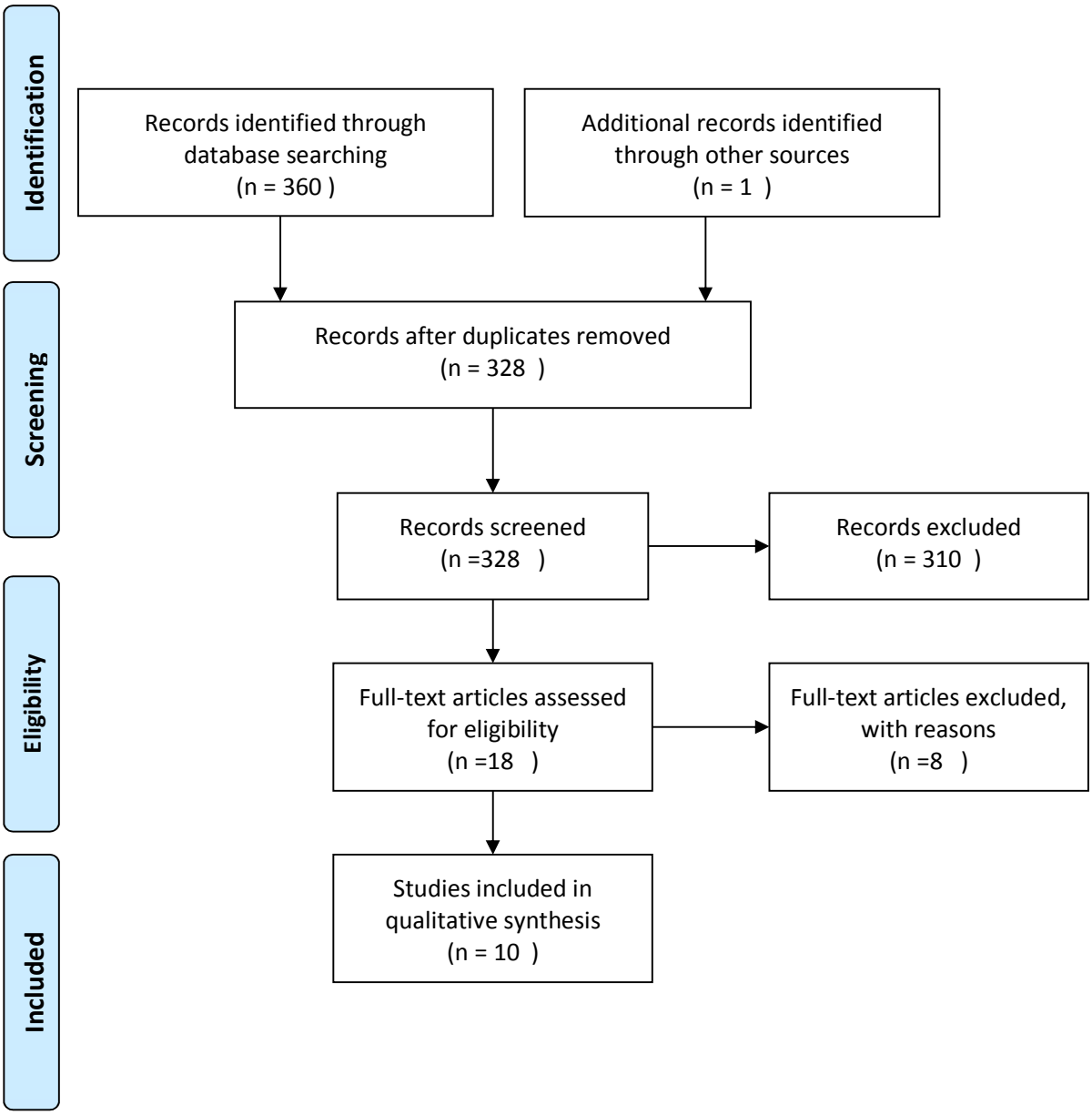

Figure 1 PRISMA flowchart overview of literature searches

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org

Table 2: Critical Appraisal (CASP)

QUALITATIVE RESEARCH CHECKLIST (included)										
CRITICAL APPRAISAL SKILLS PROGRAM (adapted)	1.Anker& Feeley (2010)	2.Berntzen & Bjørk (2014)	3.Collins (2005)	4.Floden & Forsberg (2009)	5.Forsberg et al. (2014)	6.Groot et al. (2015)	7.Manuel, Solberg & MacDonald (2010)	8.Meyer, Bjørk & Eide (2011)	9.Orøy, Strømskag & Gjengedal (2013)	10.Sque, Long, Payne & Allardyce (2007)
Was there a clear statement of aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the research design appropriate to address the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y/N
Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y	Y	Y	?	Y	Y	Y
Was the data collected in a way that addressed the research issue?	Y	Y	Y/N	Y	Y	Y	Y	Y	Y	Y
Has the relationship between researcher and participants been adequately considered?	?	Y	?	N	N	Y	?	Y	Y	?
Have ethical issues been taken into considerations?	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Was the data analysis sufficiently rigorous?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
How valuable is the research?	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
Total score	**9**	**10**	**8**	**9**	**9**	**10**	**7**	**9**	**9**	**8,5**
Note: Y = Yes (1 point); N = No (0 point) and ? = Undecided (0 point)										

QUALITATIVE RESEARCH CHECKLIST (Excluded)						
CRITICAL APPRAISAL SKILLS PROGRAM (adapted)	Gjengedal et al. (2013)	Jawoniyl & Gormley (2015)	Ormrod, Ryder, Chadwick & Bonner (2005)	Lloyd-Williams, Morton & Peters (2009)	Vincent & Logan (2012)	Monforte-Royo & Roque (2012)
Was there a clear statement of aims of the research?	Y	Y	Y	Y	Y/N	N
Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	N
Was the research design appropriate to address the aims of the research?	Y/N	Y	Y	Y	N	N
Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y	?	N
Was the data collected in a way that addressed the research issue?	Y	?	Y	?	?	N
Has the relationship between researcher and participants been adequately considered?	N	?	N	?	?	N
Have ethical issues been taken into considerations?	N	N	Y	N	N	Y
Was the data analysis sufficiently rigorous?	N	N	N	?	N	N
Is there a clear statement of findings?	Y	Y	N	Y	N	Y
How valuable is the research?	N	Y	N	N	Y	N
Total score	**5,5**	**6**	**6**	**5**	**2,5**	**2**
Note: Y = Yes (1 point); N = No (0 point) and ? = Undecided (0 point)						

Table 3: Summary of articles

Author/year	Aim	Method	Sample	Major findings	Strenght/limitations
1.Anker & Feeley (2010), USA	To recognize barriers to obtaining organ consent from families	Qualitative study Mixed Method Semi-structured Interviews compared with organizational performance rates	102 organ procurement coordinators	Lack of public education and interpersonal communication skills. Barriers to organ donation (timing, hospital procedures)	Study from OPC's view. Mixed method/ Study rely on barriers identified through interview process. Barriers may have been missed. No geographical variance/rigorous test
2.Berntzen & Bjørk (2014), Norway	To investigate the experiences of Norwegian families during organ donation after brain death	Qualitative study Explorative design Semi –structured Interviews. 3 family interviews and 10 individual	20 relatives of 13 cases participated	Several family members expressed emotional pressure even though consent to organ donation contributed to meaning and comfort in the situation. Lack of comprehension of	Interviews conducted in familiar surroundings/ More participants than expected. Interviewer summarised her perception / Who conducted interview/analysis. Only one hospital included.
3.Collins (2005), UK	Presenting results of a survey conducted in a general adult ICU. Investigate nurses' knowledge and educational needs towards organ donation.	Qualitative study. A questionnaire.	31/37 registered nurses participated.	Nurses had a lack of knowledge related to brain stem death and in approaching the patients' relatives.	Conducted in a small ICU – difficulties with transferability(?)
4.Floden & Forsberg (2009), Sweden	To describe ICU nurses perceptions of organ donation based on their experiences of caring for potential donors	Qualitative study. A phenomenographic study. Interview.	9 nurses from 3 different ICUs in 3 Swedish hospitals	The "ethos of caring is caritas" for the ICU nurses who is positive towards and promote OD. This means: • "Taking professional responsibility" • "Showing respect" • "Fullfilling the last wish" • "Preserving dignity at all times"	Authors identify the potential problems in relation to the unit. Managers choosing the participants.
5.Forsberg, Floden, Lennerling, Karlsson, Nilsson & Fridh (2014), Sweden	To investigate how ICU nurses deal with the after death care of a potential donor patient.	Qualitative study. Interview. Grounded Theory	29 nurses participated.	Transition from intense, technical, medical nursing interventions had to enable organ donation, to "candles and flowers". Transition from caring for patient to care for a body, and finally ensure a dignified farewell for donor and relatives.	9 ICU's in various geographical areas/ 26 of the 29 nurses were women.
6.Groot, Hoek, Hoedemaekers, Hoitsma, Smeets,	Gain insight in decision-making process by looking at the views of the	Qualitative study. 22 semistructured interviews	Relatives of 12 cases were interviewed.	Unresolved dilemmas like discrepancies between willingness to donate and refusal to donate. Protect body of deceased, and relatives	Adds new perspective from a non-donor perspesctive/ Sample not representative, and further

Vernooji-Dassen & Leeuwen (2015), Netherlands	relatives of brain dead donors.	Retrospective and explorative		feel incompetent to decide, therefore refuse.	intervention Research needed to confirm findings.
7.Manuel, Solberg & MacDonald (2010), USA	To help nurses gain better understanding of organ donation and the relatives of the giver and receiver.	Qualitative stud. Unstructed interviews Phenomenological approach.	5 women who consented to OD	Essense, is to "create a sense pf peace" for the relatives who struggle to "acknowledge death", have a "need for a positive outcome". This can come from "creating of a living memory" through organ donation. It also looks at "the significance of support networks in the organ donation process."	Participants reviewed transcribed interviews to validate info / Few participants
8.Meyer, Bjørk & Eide (2011), Norway	(To investigate theoretical, practical, ethical and social knowledge among nurses. Differences between demographic and contextual variables). Identify educational needs, to develop educational programs.	Qualitative review. A cross-sectional survey. Descriptive and inferential statistics for analysis.	572 nurses participated, 28 Norwegians Hospitals	Few nurses had extensive training and education in dealing with organ donation. Nurses in university hospitals had more experience but less training than nurses in the local hospitals.	Low internal validity and consistency in some areas of questionnaire. Needs elaboration and improvement. How would the answers of those who declined have affected result?
9.Orøy, Strømskag & Gjengedal (2013), Norway	To gain a deeper understanding of the interaction between ICU nurses and families when approaching the organ donation subject	Qualitative study. Hermeneutical phenomenological. Semi structured and Observation study.	32 participants (nurses, physicians, hospital chaplains) 12 cases	• Respecting wishes and values of the families • Participants wanted to support the family regardless of their decisions • Participants had a duty to obtain consent for donation	Researches came close to the situation and could therefore provide insight in the patient's families experiences. Researcher were in some cases involved after the subject of organ donation was introduced to the families. Not all the family members interviewed. Cultural limitations related to transferability of the findings.
10.Sque, Long, Payne & Allardyce (2007), UK	To explore the reasons why families decline to organ donation	Cross sectional, retrospective Qualitative interview study.	26 family members who declined donation	Protecting the dead body. Circumstances at the time of death. Lack of knowledge. Lack of education. Wishes of the deceased.	Recruiedt participants thru media, not via hospitals./The self selected participants may have had unresolved issues as a reason to join research.. Majority women

Table 6: Thematic Extraction

THEMATIC EXTRACTION ANALYSIS OF SELECTED ARTICLES FACTORS INFLUENCING CONSENT FOR ORGAN DONATION(s) Based on experiences of health care personnel and relatives of donor		
Line of argument	**For Donation**	**Against Donation**
Comprehension of Brain Death	Ambivalence (2) "Provide time for decision-making before obtaining consent for organ donation" (5) "It is important to explain brain death criteria, and allow time for the family members to work through this definition" (7)	Families often thought brain-dead patients could recover (1) Only 61% nurses felt they could adequately explain BSD (3) Request made straight before expected BD or straight after confirmation of BD (6) "..unable to understand information, not accepting the death" (6) "..conflict of being able to understanding the concept of brain death and being able to accept this was the case.." (7) "..perceptions of their theoretical knowledge about the donor operation and death criteria were quite low, even though they reported making frequent use of the organ donor protocol." (8) "Perceived prolonged suffering of the of the deceased" (10)
Decedents Wishes	"the positive attitude of the donor was experienced as burdensome" (2) .."easier for families who had discussed these issues previously" (4) "..many family members found it meaningful that the organs were of use and that the will of their loved one had been fulfilled" (4) If registered or wish was known, relatives mostly agreed (6) Interpreted they were following the wishes of their deceased, if they had a giving and kind personality (7) "By moving the focus of the decision from the family to the patient, this physician helped the family decide"..(9)	If decedents' had expressed decline/unwilling/unknown, 40-50% of family declined donation. (1) 14 % perceived unsigned donor wish on drivers licence as expressed decline (p241) (1) "..nurses felt frustrated when they perceived that the deceased had been deprived of the possibility of donation" (4) Hard to make decisions on behalf of deceased (6) If deceased had made statements contra donations (6) Organs with "special significance" not donated (6) ",if the deceased person had stated that they did not want to donate their organs and tissues and the participants knew their wishes, then donation did not take place". (10)
Organisational Factors	74% believed the person who had established a significant relationship with family should ask for consent (3) 61% felt timing should be after first set of BSD tests (3) Unsure if relatives should be present during BSD testing (3) "When the dead person's will was not known, only families with a physician with a pro-donation attitude gave their consent" (4) .."Lack of structured teams to conduct the OD procedures seems to be a limiting factor" (4) "According to Swedish legislation,, every hospital should have a Donor Responsible Physician and a Donor Responsible Nurse who support the ICU staff,.." (5) Distinct guidelines are outlined (5) ICU staff are offered the opportunity to participate in the European Donor Hospital Programme (5) "Achieving a basis for organ donation through dignified and respectful care of the deceased person and the close relatives" (5) "Demand and ensure appropriate and dignified behaviour from all professionals involved" (5)	Donation a lengthy process Non OPC's making request Poor relationship between family and hospital staff (242) (1) ".".neutral" collegues were less proactive in promoting OD" (4) "Double trauma", sudden loss of family member, and having to deal with question of organ donation (4) Time limit and grieving process made it hard to focus on request (6) Relatives didn't feel competent to decide in a state of crisis (6) Takes too long, i.e prolongs grieving (6) Unable to be present at visable death (6) "Inappropriate timing may worsen the situation, and the family can question whether the health care professionals are more interested in the organs than in the patient's care" (9)

Based on experiences of health care personnel and relatives of donor		
Line of argument	**For Donation**	**Against Donation**
Organisational Factors	"..these situations burdensome, there is also a grooving clinical but tacit experience that experienced nurses handle this type of care in a very professional way." (5) Some relatives found HCP to be very supportive (7) "The OPC's were depicted as caring individuals, providing donor families with support and information on their relative's condition and the organ procurement process" (7) "It is critical to determine the most appropriate time to approach time to approach relatives for donor consent and to evaluate whether or not (x)	
	The challenge was to find the best possible time and to address the issue in a comprehensive, respectful, and meaningful manner, as required by regulations." (9) "healthcare professionals approached the subject with respect and empathy.(9) "Beneficial to another individual" "..meaning to the life of the deceased (7) "They are living on" (7) Buy time for "deceased" to recover by consenting, or come to terms with death and say goodbye (7) "Finding the best time to address the subject was reported as being challenging, but it was of crucial importance to approach the family without causing distress". (9) Some stated they felt guilty that they had not consented to donation, as it was the decedents wish, and that it could have improved someone else's life. (10)	
Perceptions and attitudes	Most perceived consenting as a "positive", as a gift of life (2) "Experiencing meaning and recognition" (2) Majority of public for consumed consent (3) "It seems evident that nurses who have a positive attitude towards organ donation have a favourable effect upon families and are more likely to optain consent for donation" (3) Families could gain comfort from donating (3) Families felt feelings of guilt, sense of responsibility and ambivalence in regards to consenting (4) "Caring for potential donor..dramatic situation" (4) "By adopting behaviour that adheres to strong organ donor advocacy, they fulfil their professional responsibility, which seems to create professional pride" (5) Values: 'aiding other people', giving people a better life', 'small effort', 'great benefit', 'reciprocity', 'solidarity' (6) "..comfort or relief in their grief" (6) Live on in someone else (6) Utilitarian view (6) Pride in helping others (6) "I want something good to come from it "(7) Turn negative to positive (7)	Major rejection based on disfigurement of diseased 80,4% (1) Unfair allocation of organs (1) Belief that organs are not suitable for donation (1) Majority of nurses against consumed consent (3) Can create conflicts within families(3) Organs could potentially be rejected and that way cause heartache to transplant recipient and family (3) If physicians/nurses do not believe in donation, will not raise the question (4) If impression is that families have a negative attitude, question will not be asked (4) "My duty is to care for the living, not the dead " (4) HCP remain neutral if negative towards donation (4) Values: 'integrity' if decedent wish was no, or wanted to protect body (keep it whole) (6) Ambivalence (6) "Has suffered enough" (6) Anonymity of recipient (6) Relatives experienced lack of information, lack of knowledge, poor communication, insensitivity from HCP (7) "Although the healthcare professionals were aware of the significance of organ donation, some had conflicting feelings". (9) Protecting the dead body was reported as primary reason for 15 out of 26. (10) "..should be allowed to die in peace" (10)

Note: (1) Anker & Feeley; (2) Berntzen & Bjørk; (3) Collins; (4) Floden & Forsberg (5) Forsberg (6) Groot, Hoek, Hoedemaekers, Hoitsma, Smeets , Vernooji-Dassen & Leeuwen (7) Manuel, Solberg & MacDonald (8) Meyer, Bjørk & Eide (9) Orøy, Strømskog & Gjengedal (10) Sque, Long, Payne & Allardyce

Table 6 Continuation: Thematic Extraction

THEMATIC EXTRACTION ANALYSIS OF SELECTED ARTICLES FACTORS INFLUENCING CONSENT FOR ORGAN DONATION(s)		
Educational needs identified, that could have a positive impact on organ donation rates / Implications for practise		
Line of Argument	**For Donation**	**Against Donation**
Comprehension of Brain Death	Provide more time to family to decide (1) Lack of information given to the relatives regarding criteria and diagnosis after consenting (2) "To enhance comprehension, written, verbal and visually (2) 26% of nurses could not effectively explain BSD, 13% unsure (3) Only 45% aware of legal criteria for BSD (3) .."being certain about the meaning of the concept of BD and clear about one's attitude were perceived as a precondition for being able to care for a (potential) organ donor (4) Nurses lack knowledge about tests to establish brain death (4) Helps to separate "warm death" from "cold death"(5) "Listen to stories of organ donors and their families can help nurses better identify and prioritize their needs, as well as clarify any areas of ambiguity, such as brain death criteria" (7) "..reactions to the diagnosis of brain death may be different between paediatric and adult organ donor families" (7)	Designated public education campaigns (1) Give family written information (1) Donation process complex and hard to comprehend by relatives (2) "Enhancing the comprehension of family members may contribute to a resolution of the cognitive dissonance they experience" (2) "..the general public has a poor understanding of the concept of "brain death, believing that a person who is "brain dead" is still alive (4) "The tradegy and the circumstances behind the death of the potential donor are seldom given much attention in this publicity" (5) "..cessation of brain stem circulation, death notification itself can be considered a process..transition from dying to death can be invinsible to the eye." (5) Paradox..dead, but looks alive (5) "..lack of understanding surrounding brain death criteria and the medical procedures used to diagnose brain death" (7)
Decedents Wishes		Campaigns encouraging people to register as donors and express/advocate their wishes (1)
Organisational Factors	Explain donation as similar to a surgery/respectful medical procedure (1) Request for donation surprising, overwhelming (2) "..educational programmes to provide knowledge, awareness and communication skills..essential" (3) 90% declared they would attend study day (3) "One has a responsibility as a colleague to support and relieve the pressure on him/her and that he/she could perhaps receive help to deal with these situations by means of education" (4) Honesty considered fundamental to avoid distrust (4) "..the care of these patients is rarely a routine matter for nurses in most ICU's." (5) Follow up conversations with relatives and participating in post organ donation staff conferences leads to reflection and improvement (5) Study revealed increased focus/support from supervisors than before (5) Clearly organise what profession/who should be available for relatives, to support them and inform.(6) Coaching during decision making (6) "Be available all the time" (6) Have counsellors available (6) Relatives express HCP should be more empathetic when asking for request, less technical, and emphasise they can save lives by donating (6) Recognize relatives' emotional conflicts and support them, help them cope (7)	Campaign targeting myths surrounding donation (1) Need more time, information, more support from HCP (6) "Public education is essential to fostering a broader understanding of organ donation and increasing donation rates" (7)

Educational needs identified, that could have a positive impact on organ donation rates / Implications for practise		
Line of Argument	**For Donation**	**Against Donation**
Organisational Factors	".. use their therapeutic listening skills to gain a fuller understanding of the organ donation experience itself" (7) "..development of a plan of care reflective of and sensitive to the individual needs.." (7) Ensure all family members take part in decision making (7) Novice nurses need to be mentored by nurses who are more who are more experienced with organ donation" (7) ",aspects of organ donation were not often discussed on the ward." (8) "..no important difference between types of hospital", in how they perceived their competence (8) Hospital-based education, discussions on the wards, reading literature and NOROD- seminars were considered important. (8) "Educational input related to how to break bad news and to proceed with the process was described as necessary.." (8) "the majority (75 %) indicated that the frequency of courses should be once a year." (8) "..the time between identification of a potential donor and the request for organ donation and communication with relatives in the transition between the life and death as difficult." (8) "Educational input that enhances ICU nurses' various types of knowledge and experience could be beneficial in the organ donor process" (8)	
Perceptions and attitudes	Interpersonal Communication (1) "Little opportunity to practise skills" (3) Lack confidence and knowledge related to organ donation (3) "Felt inadequately prepared to care for a multi organ donor patient" (3) Nurses not knowledgeable about what organs/tissues can be donated, and many not aware of contraindications "Create a dignified situation" (4) Collegial support essential (4) "Be aware of owns attitude" (4) If physician lacked knowledge and experience, increased burden for family, and "left the nurse feeling abandoned and exposed" (4) Nurses must be present, humble, professional in relation to family .."not to lose herself" (4) "Sense of duty..,based on nurses awareness.." (4) "Nurses need specific knowledge and skills to participate in the organ procurement process. Continuing professional development and employee orientation programs" (7) "..all nurses need to become more active in public education" (7) "..perceptions of socially mediated knowledge was higher than that of their theoretical, practical and ethical knowledge." (8) They scored their overall professional competence in caring for an organ donor as low. (8)	Need to be informed throughout process, predictability (2) Follow up programs necessary (2) Did the donor suffer during organ removal (2) Relatives feel guilty (2) "Premature death" (6) Mistrust, believe not full treatment will be given if they consent (6) It was found that the majority of those who declined donation on behalf of the decedent, had a positive outlook on donation themselves (10)

Note: (1) Anker & Feeley; (2) Berntzen & Bjørk; (3) Collins; (4) Floden & Forsberg (5) Forsberg (6) Groot, Hoek, Hoedemaekers, Hoitsma, Smeets , Vernooji-Dassen & Leeuwen (7) Manuel, Solberg & MacDonald (8) Meyer, Bjørk & Eide (9) Orøy, Strømskog & Gjengedal (10) Sque, Long, Payne & Allardyce

Journal of Advanced Nursing Author Guidelines

(adapted from: http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1365-2648/homepage/jan_essentials.htm)

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• whether you have clearly outlined the relevance of your manuscript to the subject field internationally and also its transferability into other care settings, cultures or nursing specialities

• if your manuscript explores focussed cultural or other specific issues, have you clearly placed the discussions within an international context?

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