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Change of focus: from intensive care towards organ donation

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Summary

To progress from identifying a potential organ donor to implementing the actual organ donation effectively is a challenging process for all involved. The nurses might find the change of focus difficult, as the donor organ acquisition process often starts before the relatives had been informed and have had the time to reorient themselves about the severe situation of the patient and have been briefed on the option of organ donation. The purpose was to investigate the hospital-based education in organ donation at the 28 Norwegian donor hospitals, and elicit the needs of the intensive care nurses for imparting of required knowledge and support in shifting their focus from intensive care towards the process of organ procurement. Hospital-based education and guidelines in organ donation were analyzed by scrutinizing the documents available. Eleven units were found to have their own guidelines and only three hospitals had organ donation in their educational programme. Intensive care nurses at three hospitals participated in focus groups. The main finding was the need for collaboration and mutual understanding within the treatment team. Nurses expounded the multiple responsibilities that they discharged during the course of intensive care. In reorienting their focus from intensive care to donor organ procurement, the time of death was explained as the crucial turning point. The knowledge of intensive care staff and professional competence were crucial in winning the relatives' trust and were central in the communication processes. Donor hospitals should implement systematic training and debriefing, where both nurses and physicians contribute to this process. Well-prepared protocols for organ donation at hospitals can define responsibilities assigned to different members of the donor organ acquisition team.

Introduction

In Norway, kidney transplantation has been an established treatment for patients with terminal kidney failure since 1969. In 2005, Norwegian donors averaged 16.3 [1], while Spain and France averaged 35.1 and 22.2, respectively [2]. However, the demand for donor organs has increased worldwide, while organ donors have not increased at the same rate [3–5]. Although the donor rate in Norway is higher than or equal to the rate prevailing in other Scandinavian countries, the average reported in Spain and France implies that there is scope for considerable increase in organ donation in Norway. As Spain introduced a network of healthcare professionals responsible for organ donation, referrals have increased from all the hospitals. Even allowing for that, it is still felt that there is much room for improvement, especially in the area of motivating the reluctant relatives for organ donation [6].

To progress from identifying a potential organ donor to effectively implementing the organ donation process is

a challenging process for all involved. To ensure vascular circulation and preservation of solid organs, the treatment to the potential donor will often become more intensive and this would be at odds with the pattern of care of other patients who die in the intensive care unit (ICU). At the same time, intensive care nurses are also responsible for the care of next of kin who might be in shock and need practical, emotional and cognitive support [7,8]. Deaths, in cases where organ donation is an option, are usually unexpected and relatives generally may not be emotionally prepared. They need time to assimilate the information given [8–10]. The nurses might find the change of focus difficult, as the donor organ acquisition process has been set in motion even before the relatives have assimilated the severe situation and have been briefed on the option of organ donation.

Intensive care staff play a central role in the process of donor organ acquisition in identifying a potential donor, in taking care of the relatives' need for pertinent information and also in briefing them on the question of organ donation [7,11,12]. There can be psychosocial, organizational and professional barriers to organ donation. Studies show that the staff's level of knowledge and experience influence their confidence in discussions and briefings on organ donation both with their own colleagues and also with relatives/power of attorney for the patient [3,11–15]. The nurses' requirements for knowledge and understanding of the process of organ donation, definitions of death and various changes that occur in relation to the death processes, as well as the needs of next of kin, have been documented in several studies [5,11,16–20]. The authors of these documents also underscore that intensive care staff need practice in communication with next of kin and knowledge about organ donation practice guidelines as to how and when to make the request for organ donation. In the USA, educational programmes have been developed that enable the nurses to introduce the matter of tissue and organ donation to relatives. These educational programmes emphasize imparting professional knowledge of different types of transplantation, effective communication processes, proper care of the bereaved and being sensitive to religious views on organ donation [21].

In Norway, there are 28 donor hospitals and one transplantation centre. Among the 28 donor hospitals, there are five regional hospitals, which refer most of the donors. This means that the number of potential donors, even at the larger hospitals, is not very high. Experience with donor organ acquisition among those who work in the various intensive care units will therefore vary. Rikshospitalet-Radiumhospitalet Medical Centre in cooperation with Norwegian resource group for organ donation (NOROD) developed 'protocol for organ donation – a guideline for Norwegian Hospitals' [22]. NOROD organizes seminars for intensive care staff, but there are no general practice guidelines for education and training of intensive care nurses related to change of focus from intensive care towards donor organ acquisition process.

The purpose of this study was therefore twofold: (i) to map out hospital-based education in organ donation for intensive care nurses at Norwegian donor hospitals and (ii) to elicit from the intensive care nurses a comprehensive set of their needs for knowledge and support in shifting their focus from intensive care towards donor organ procurement.

Material and methods

Documentation of hospital-based education in organ donation

All intensive care units at the 28 donor hospitals in Norway were invited to send their educational material and practice guidelines for organ donation. Twenty of the hospitals responded. The material was analysed by scrutinizing the documents made available.

Interviews in focus groups

Nurses at three hospitals were invited to participate in focus groups. The scope of a focus group interview is to use group dynamics to help acquire qualitatively good data about the participants' experience and opinions on the subject in question [23]. This particular method was chosen to facilitate the intensive care nurses to explore their own experiences in the organ donation process.

To tap the nurses' diversity in experience, focus groups were established at two university hospitals and one smaller hospital. Between three and six nurses participated in each focus group. The leadership of the departments was informed about the project and they gave permission to carry out the interviews. Criteria for inclusion in the focus groups were that nurses were certified intensive care nurses and had experienced at least one organ donation process. Nurse leaders at the wards recruited nurses to participate. Together with the invitation to participate, the nurses received written information about the project and a request for informed consent.

A semi-structured interview guide was developed to cover the topics such as collaboration among the staff, care of next of kin, donor organ acquisition, needs for knowledge and educational procedures. The interviews lasted 1 to 1.5 h, were taped and transcribed. Transcripts were analysed according to Kvale's [24] three levels of analysis of qualitative data. At the first level of self-understanding, a rephrased condensation of the

informants' own views was worded. The next level of analysis occurred at a more general commonsense level, where meanings were interpreted and merged into broader categories. These are presented in the results section of this paper. Kvale's third level implies investigating the categories in a theoretical context and this is presented in the discussion section of this paper. The tapes and transcribed material were treated confidentially according to regulations by Norwegian Social Science Data Services. The results are presented so that the identity of no one can be recognized in any publication.

Results

Documentation on educational material and practice guidelines

All responding units reported that 'protocol for organ donation – a guideline for Norwegian Hospitals' was used. In addition, 11 hospitals had developed their own guidelines. Some units also reported that they used several articles regarding organ donation as part of their educational material. Several units that did not have any educational material or procedures commented that they saw the need for structuring this part of the hospital's activity. Intensive care nurses from all units had participated in seminars arranged by NOROD. A compendium of literature and lectures given during the seminars was part of the educational material in the units. Only one unit had organ donation included in the educational programme for newly employed intensive care nurses. Another had unit education about organ donation once a year. They were, however, considering whether educational input should increase to once a semester because it was rare they had a potential donor and it was a challenge to keep up the experience and knowledge of the topic. Experience was often shared during internal education. Other examples of educational input were mentioned by a few hospitals, such as organizing evening teaching, arranging a study tour and a one-day educational seminar every alternate year for students and staff.

Findings from interviews in focus groups

Four major themes were developed through the analysis of data: multidimensional responsibility, organ donation as a process, time of death as a turning point and the importance of knowledge and professional competence.

Multidimensional responsibility

Intensive care nurses described several responsibilities in the donor organ acquisition process such as creating an environment that was conducive to donation and caring for the potential organ donor as well as the next of kin. It was very challenging to comfort and support the relatives while at the same time giving the type and amount of information that could lead to an understanding of the situation. One nurse explained:

> I think our focus changes in relation to the relatives. They need different information on another level, which is very demanding. It demands resources and it demands a lot of me as a person.

A number of participating nurses declared that introduction of the issue of organ donation was a duty towards the potential donor and if the question was not approached, the deceased's possibility to donate vanished. All nurses stated that life-sustaining therapy was possible even though organ donation was on their mind. They saw their efforts to preserve organs as a meaningful and important task, i.e. to ensure the best quality of the gift, hence the recipients got the best possible benefit and life continued in a way. The letters from the transplantation centre, detailing which organs could be used and how the recipients were recovering, were highly appreciated by the few nurses who had seen them.

Aesthetics, dignity and respect were underscored as focus of nursing towards the potential donor and the patients' next of kin. Some families had never thought about death and for the most part bereavement came as a shock. Time and effort were required from the nurses to take care of the family in this extraordinary situation. Nurses viewed protection of donor and the relatives as their special responsibility, more than the physicians' responsibility. All groups agreed that this responsibility required two nurses, one to take care of the relatives and another for the donor organ acquisition. One nurse stated that it was an honour to be there when someone died. Another said it this way:

> …at the same time I feel that even if it is a donor, we can have lots of fine conversations. We talk a lot about how they want it and some times some of them want to join in the nursing of the body as well. I feel it can be quite good, as when we are waiting for someone to die, actually.

All nurses maintained that the termination of treatment ought to be ceremonious. Two of the groups discussed the importance of giving the relatives an opportunity to see the deceased after the donor operation. They could visualize that this may entail practical difficulties as the retrieval of the organs often was time-consuming. Nevertheless, the relatives should have the opportunity to return to the ward when the donor was back from the theatre. Nurses who had been part of this described it as dignified and considered it as a good ending for next of kin as well as for the nurses.

Organ donation as a process

Many nurses described organ donation as a process where both relatives and health personnel prepared themselves for the bereavement. Intensive care nurses pointed out collaboration and mutual understanding within the treatment group as essential for a good process. If the treatment team did not cooperate, organs for transplantation could be lost.

> It is not a personal or ethical conflict if everyone agrees, but it becomes a problem as soon as someone starts signalling that this is not okay. Even if I am convinced that what I am doing is preservation of organs towards a donation, it gets ugly if someone starts mentioning violation, desecration of the body or not doing enough to preserve life. Then, we do not have a donor situation anymore, and my experience is that we lose organs.

One of the groups gave an example of disagreement within the team: the time for cerebral angiography.

> There are discussions in the ward if someone feels that the decision about angiography is premature or too late, or booked and then cancelled. This creates 'waves', but after angiography silence comes…

Several of the nurses asserted that the donor process was complicated because they could not be honest towards the relatives before organ donation was decided. For example, it was difficult to explain the taking of numerous tests. This was a breach of confidence. Also, when doctors refused to inform relatives about the accurate situation, the process became problematic. Improved teamwork related to information and orientation of relatives could make it easier to speak right out, be open and take whatever came. Information in an earlier stage was seen to be preventive; hence relatives did not have to make a decision when everything else was happening. All of them underlined that experienced health workers often grasped early if there was a potential donor and that donation might be introduced in a conversation few hours after the arrival in the ward. Transition from intensive care towards organ donation was described by many nurses as a development without distinct steps or changes, a more or less seamless process. One nurse said:

> That point in time when you change from one focus to the other – that is the clue, but when does it really start? It does not end with one thing and start with the other. There is no sudden change the way it is written in the literature or as you are taught in lectures.

Nurses believed that most relatives mentally prepared themselves, even though they did not give up hope before life was gone. Thus, it was important to facilitate a process so families might find time to settle things between themselves. Relatives displayed many different reactions and nurses expressed the need to be proficient in different strategies for these circumstances:

> We have to act on every reaction that comes. If it is denial, crying, anger, anything. So to practise, at least cognitively, how I can cope is important.

A number of the nurses explained that they defused at the end of the shift, which was easier if there had been two nurses involved in the process because then they could enter the situation right away.

Time of death as a turning point

Intensive care nurses experienced the time of death as a turning point. They comprehended the importance of not talking to the deceased but rather to turn to the relatives and speak about the deceased. If the relatives did not receive or understand, the exact clinical status of the patient at that point, new hope might arise when tests and treatment were seen to be continued.

> It is important for me to distinguish between the two phases, before and after the patient is dead, so the relatives also comprehend that he is dead. I have experienced that relatives can become confused, so I try to be conscious of not talking to the patient at all, because now he is dead.

To follow the practice guidelines at this turning point was considered very important. The prescribed diagnostic tests are a stepwise movement towards angiography. However, angiography ahead of time was sensitized to be a consequence of not following guidelines. It might be easier for relatives to comprehend the situation if the nurses could persuade the doctors to give orientation and do clinical tests before angiography. Staying while the apnoea test was carried out was one way to make it easier for the relatives to comprehend. It might also make it easier for the physicians to approach the question of organ donation more gracefully.

The importance of knowledge and professional competence

Intensive care staff's familiarization and knowledge were recognized by all groups to be essential for cultivating and maintaining the relatives' trust, and central to the communication processes. It was pointed out that relatives should know the one who gave the information and approached with the request for organ donation. The doctors' skills and confidence in how they break the subject and make the request for organ donation were described as critical for how relatives faced the process. One nurse gave an example:

> I consider him very clear, which illustrates that if you have the skills and know what you are talking about, it becomes clear and sincere. The explanations are understandable. It actually becomes beautiful.

Some of the nurses said that they frequently yearned to make the request themselves. They tried to influence the conversation, while others claimed that it was not their responsibility. In one hospital, the nurses were implicitly expected to be part of the conversation. In another, it was the doctor's choice. Often the inexperienced doctors chose to break the information on death of the patient to the relatives on their own, while the experienced preferred to involve the nurses. A guideline for the appropriate time when to give the information and on enhanced collaboration between physicians and intensive care nurses was considered to be a factor that improved the donor organ acquisition process.

Mutual understanding was seen as supporting and also formation of a team created confidence in the process. Intensive care nurses' knowledge, level of experience and attitudes were described as important as to when and how the shifting of focus took place; as one nurse explained:

> If I have thought that this is a potential donor and the other one has not reached that point yet… you know at once when the other one is at the same stage as you. And I can not hasten one who has never experienced a similar situation to follow my thoughts….

'Knowing yourself" was identified by several of the intensive care nurses as central to their feeling of security, when meeting the next of kin. They explained that relatives who met a nurse who appeared uncomfortable with organ donation might not feel taken care of and further, all agreed that a nurse who was not at ease should be able to skip the situation. One of the nurses said that her knowledge about death and sorrow had helped her in meeting and understanding the relatives' needs. Another one stated:

> Previously I hoped the relatives would refuse organ donation, but today I feel confident and I wish they will give their consent.

All groups said that their personal knowledge had been acquired through perusal of literature and discussions in the ward. On the other hand, training and education in organ donation were not structured enough, and most nurses had experienced to 'have been thrown into their first donor organ acquisition process'. Time for reflection was seen as an essential factor.

> It is important that nurses who have been in this kind of situations tell their stories about 'what was done and said, and what made it right in the end'. That way, those who have not been in similar situations can gain knowledge. That is how I remember best, if someone tells me stories; it is a way to be taught. And we are not good at that.

Everyone who had the exposure missed proper debriefing, which they considered as important for education. It could be a way to share knowledge and experience to strengthen the personal competence of the nurses.

> …part of being a good nurse is to be able to communicate, to use your own experience and others' experiences. So I think it is important to have time for that kind of education in order to survive as an intensive care nurse in the ward and be able to give relatives what they need….

None of the units had routines for debriefing, though it was often facilitated if someone expressed a need. All groups were in favour of debriefing where everyone in the treatment team contributed. Such support could improve the next situation. At the end of one focus group interview, one nurse sighed:

> This was debriefing. It is exactly what we need.

Most of the nurses had participated in the various seminars organized by NOROD. The seminars were recognized as part of the nurses' education about organ donation. The participation of health workers with different professional backgrounds was highlighted as the strength in these seminars.

Discussion

Intensive care nurses sought to develop a donor organ acquisition process where both the staff and the next of kin together prepared themselves for the bereavement. Insufficient or absence of collaborative spirit within the treatment team could cause difficulties in the process. Distrust from the next of kin and even loss of organs could be the result, if the team did not have a mutual understanding and strategy as to when and how to approach the relatives. Who should be responsible for giving the information and how to inform depending on the situation and the family structure could be part of this strategy. Teamwork and close co-operation during the process are emphasized in regard to communication with the bereaved family in the European Donor Hospital Education Programme [18]. Another study has shown that working environments that maintain support and mutual respect facilitate a culture where discussions about postmortem intentions freely take place [11].

Another complexity was lack of formal practice guidelines in donor hospitals. When to inform and what kind of information next of kin needed were a subject for discussions as well as appropriate time for cerebral angiography. Legislative regulations are overriding, but do not give directions in these challenging situations. Studies have shown that protocols or quality control systems can improve the donor organ acquisition process. Per one study, implementation of a protocol for communication promoted a mutual holistic experience and the whole team saw the process through. Professional responsibili-

ties were defined and co-ordinated and this reduced role vagueness and conflicts [20]. In Spain, the network of health professionals working with donors made everyone feel involved and responsible. The network also developed a quality control system and guidelines for common practice during donor organ acquisition in the ICUs [6]. How to approach the question of organ donation and attitudes towards work with potential donors were discovered as obstacles to organ donation, in a study among Swedish physicians. Sanner suggests that the hospitals should give a higher priority for the organ donation process and that a proactive donor detection programme could be a key to success [15].

The experience of multiple responsibilities was another central finding. The responsibilities demand resources, particularly nursing resources, as the nurses claimed to have a greater responsibility than the physicians. In another study, intensive care nurses clearly saw their professional responsibility and central role in the donation process [14] but this differs from the conclusions of Chernenko's study, where the physicians felt more responsible for identifying a potential donor and approaching the family than nurses [19]. Both Riley, Sque and Chernenko argue that nurses play a vital role in identification of potential donors and caring for the next of kin. They should be actively involved in the donor organ acquisition process and in emotionally supporting the bereaved [13,14,19].

Knowledge and professional competence among staff are important to create trust when meeting the relatives in a donor process. Systematic and repeated education is needed for all professions. Professional input and shared experience can be gained in different ways such as debriefing, hospital-based education and courses. Education about transplantation and donation as well as training in communication skills is required to make the staff confident and experienced in meeting the relatives' need for information. Consent for donation often relies on the relatives' experience when approached with the request for organ donation [15,18,19]. Hospital-based programmes can change the organ donation practice and educational strategies [6]. Debriefing works both as a common emotional valve and as professional support and is a forum for sharing experiences and gaining skills. In addition, collaboration and mutual understanding in the treatment team improve [20]. Several earlier studies support the findings in the present study and highlight the need for more knowledge and training among intensive care staff involved in the donor organ acquisition process.

Conclusions

The creation of a good donor organ acquisition process depends on all the staff involved. Knowledge and experience as well as mutual understanding are significant factors while interacting with the relatives. To increase the number of donors, knowledge about transplantation and donation is important, but even more essential are the skills in meeting the relatives' needs for information and communication. Diagnostics, legislation, care for the bereaved and communication should all be part of the hospital-based education both for the nurses and for the physicians serving in intensive care units. Practice guidelines for organ donation can be an instrument in defining responsibilities and procedures for disseminating information, diagnostics and in interacting with the relatives after the donation process is over. Debriefing that involves everyone in the process and promotes a free discussion can improve common understanding of the mission and teamwork. The letter from the transplant centre informing which organs could be used and how the recipients were recovering should be included in the debriefing. Further investigation is needed to explore physicians' attitudes and knowledge in organ donation in Norwegian hospitals. Relatives' experience with the donor process is an area of importance for future investigations. This theme is, however, a delicate matter.

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Authorship

KM designed the research study, collected the data, analysed the data and wrote the paper. ITB designed the research study, analysed the data and wrote the paper.

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