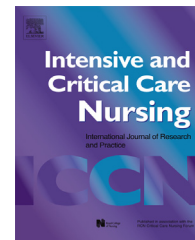




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ORIGINAL ARTICLE

Experiences of donor families after consenting to organ donation: A qualitative study



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KEYWORDS

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Summary

Aim: The aim of this study was to investigate the experience of Norwegian donor families during organ donation after brain death.

Methods: This was a qualitative study using personal interviews. Twenty donor-family members from thirteen different situations were interviewed about their experience of being a close relative in an organ donation situation. The principles of qualitative content analysis were used.

Findings: An experience of strain caused by the organ donation situation was identified. Lack of comprehension and awareness of the process of organ donation contributed to this, and continuing information after the consent was given appeared to be necessary. Reconciliation with the decision of organ donation and the subsequent situation was gained through understanding the organ donation process, through recognition of the increased strain and through satisfaction resulting from the contribution made by organ donation. Healthcare personnel were key persons in contributing to such understanding and recognition.

Conclusion: When attending to families in an organ donation situation, the focus must be on ensuring comprehension of the situation both through information provided in the hospital and during follow-up. It seems essential to arrange for a period of parting that can contribute to reconciliation, and to offer follow-up according to individual needs.

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Implications for clinical practice

- In a situation of organ donation, it is important to communicate clearly and to provide information about ‘‘what is going on’’ and ‘‘what is going to happen’’.
- One should not expect family members to know the consequences of consenting to organ donation, even though they have a clear opinion on organ donation when asked.
- One should not assume that family members understand that brain death equals death, and that death is the premise for organ donation.
- It is important to recognise the positive impact on donor families of spending time with the dying patient, or dead patient who still looks alive, and to arrange for a parting that clarifies the transition between life and death before organ removal.

Introduction

The demand for transplant organs has become a growing concern worldwide. Consent to organ donation is of the utmost importance both to the individual in need of an organ and to society. Looking after families during donor situations has been described as most challenging (Orøy et al., 2011; Sque et al., 2003). In addition to experiencing the tragic situation of losing a loved one, the organ donation process is viewed as complex and difficult to comprehend by relatives (Cleiren and Van Zoelen, 2002; Long et al., 2008). Adequate attention to family members experiencing organ donation may influence the reputation of donor activity and in turn have an influence on organ procurement.

One component of giving consent is that family members must part from their brain-dead loved one who still looks alive when taken to the operating theatre or transported to a transplantation centre. The understanding of brain death has been thoroughly investigated (Long et al., 2008; Ormrod et al., 2005; Siminoff et al., 2003), and authors emphasise the confusion and uncertainty created by the persisting physical signs of life (Frid et al., 2001; Pelletier, 1992; Siminoff et al., 2003). The way relatives are looked after during a hospital stay in an organ donation situation affects their subsequent grieving process (Jensen, 2011; Kesselring et al., 2007; Sque et al., 2003). Meeting other donor relatives in a similar situation, obtaining answers to questions about the donation, and knowledge about what has become of the organs is important (Alnæs, 2001; Sque et al., 2003; Thomas et al., 2009). Research on follow-up programmes for donor families is scarce, in particular follow-up by in-hospital healthcare personnel. Further knowledge may provide a greater understanding of consenting individuals’ and families’ needs, and promote a high quality of care for people in this demanding situation.

The Norwegian context

Norway has approximately 5 million inhabitants. The donation rate reached a peak of 24.5 per million people (pmp) in 2011 (ETCO, 2012) and the overall national consent rate was 79% (Oslo University Hospital, 2011). The donation rate is higher than in other Scandinavian countries (15.5 pmp in Sweden and 13.0 pmp in Denmark), but lower than in Spain (35.5 pmp) (ETCO, 2012). Norway has one transplantation centre and 26 donor hospitals. The experience among personnel caring for potential donors and their relatives in each

hospital is therefore limited. Most hospitals have an appointed nurse and physician in ICU to contribute to securing the quality of the organ donation activity. At the study-site, due to its size, two specialist nurses in organ donation and one physician have part-time defined positions. National guidelines for organ donation were developed by the transplantation centre in cooperation with the Norwegian resource group for organ donation in 2004 and later revised (NOROD, 2011). According to Norwegian legislation, withdrawal of organs for the purpose of donation is permitted by presumed consent (The Transplant Act, 1973), but in reality the relatives are always asked for permission. Guidelines recommend making the request when relatives realise there is no hope for survival and clinical signs of brain death are unambiguous. Unlike most other countries, cerebral angiography before donation is mandatory to confirm brain death (Ministry of Health, 2011). However, there is an ongoing discussion about changing these criteria because of technological developments, resource requirements and international practice. Norwegian guidelines recommend that healthcare personnel facilitate the opportunity to say goodbye to their deceased relative prior to organ retrieval and cooperate with the family on how to organise the parting. Relatives are recommended to see the dead person after organ removal. After donation, the donor hospital receives a letter from the transplantation centre accounting for the use of organs and expressing gratitude for the ‘‘gift’’. Guidelines recommend providing this information during a follow-up meeting or after a follow-up telephone call from a member of the ICU where the donor situation took place. Since 2009, an annual commemoration event has been arranged for donating families who have been looked after at the study site and other hospitals in South-eastern Norway. These gatherings and follow-up meetings are not yet standard measures at all Norwegian donor hospitals. At the study site, National guidelines are well implemented, and families’ experiences are expected to reflect compliance to these. However, no other source of information than participants’ memory and experiences was used in this study and varying practice according to situations and individuals in charge is reflected.

Aim

The aim of this study was to investigate the experience of Norwegian donor families during organ donation after brain death.

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