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The role of families in organ donation: International evidence review

Research Summary

Social research

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This report provides a general overview of extant research involving the families of potential organ donors (both those who consented to donation and those who refused donation).

Factors associated with family consent to organ donation

Research highlights a number of potentially modifiable factors which are associated with family consent rates. Many of these relate to the approach made by medical staff to the family, such as the timing and experience of professional(s) making the donation request.

Many of the reasons for family refusal to donate documented in the research literature stem from misinformation or misunderstandings. For example, due to fears of unfair organ allocation or organ selling (Vincent and Logan, 2012).

Certain demographic characteristics have been found to be associated with higher family consent rates. For example, consent rates have been found to be higher when the donor is male (Siminoff et al., 2001), younger (Rodrigue et al., 2006; Van Leiden et al., 2010) or of white ethnicity (Rodrigue et al., 2006).

Dadansoddi ar gyfer Polisi



Analysis for Policy

Arguably the most important factor in determining the family's decision to consent or not is their knowledge of the deceased's organ donation wishes. When the deceased's organ donation wishes are known, in the majority of cases, family members will make consent decisions in accordance these wishes. Where the next-of-kin know that the deceased wished to be an organ donor, family consent rates are approximately 90 per cent (NHSBT, 2012).

Experience of families members of potential organ donors

Qualitative research suggests that in knowing what the deceased would have wanted, relatives felt that they did not have to 'make a decision' but that they were fulfilling the wishes of the deceased by facilitating the donation (Sque et al, 2003).

The experience of the next-of-kin of potential organ donors is highly stressful and sensitive. The health professionals with whom the family interact are important in shaping this experience. A UK-based qualitative study found that

respondent's positive or negative feelings towards the health professionals remain, long after the death of the organ donor (Sque et al, 2003).

Communication with family members about organ donation wishes

A recent Welsh Government survey (2012) indicates that the majority of adults living in Wales have not discussed their organ donation wishes with their family.

International studies have found that individuals who are well informed about organ donation and those who intend to be an organ donor are more likely to have discussed their donation wishes with they family, compared to those who are less well informed and those who do not wish to be an organ donor.

Conclusions

This report highlights the complexity and multi-factorial nature of organ donation decision-making, which involves not only the deceased's family members, but

also the healthcare staff making the approach.

The role of the family is crucial under opt-in and opt-out systems of organ donation. Given that relatives' awareness of the donation wishes of the deceased is one of the most important factors in determining the decision made, campaigns promoting familial discussion about organ donation wishes may be of value.

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