

Exploring organ donation with bereaved relatives, healthcare professional's experiences in three European countries

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Abstract

Bereaved families are the crucial link in obtaining organs for donation and are invoked in the organ donation decision making process. The challenges of requesting organ donation from relatives have been widely documented often resulting in organs for donation being lost [6, 7]. Despite this, a study of the Healthcare Professionals (HCPs) experiences with relatives in the decision to donate an organ in 3 European countries ($n = 42$) using a phenomenological methodology [1, 2] demonstrated that the family involvement in the organ donation decision making process was vital, even in countries where legislation allowed the removal of organs for transplant if no objection had been recorded by the deceased [5].

Analysis of this data demonstrated not only were there different levels of education for the HCPs requesting donation and different protocols of practice in use for the approach to relatives at this difficult time, but in addition, the HCPs discussed their own views on the benefits and challenges of involving relatives in the decision to proceed to organ donation. The HCP reflections on their experiences in exploring organ donation with relatives not only described the reaction of relatives to the news of the impending death of their family member but in addition provided insights into the beliefs, attitudes and values of the HCP in relation to requesting organ donation.

This paper summarises the experiences of these 3 groups of HCPs in their efforts to balance the need to respect the wishes of the dead in relation to donating their organ with their professional responsibilities to support the bereaved relatives and the factors which would influence their decision to proceed or decline to proceed to organ donation.

Introduction and aim

Bereaved families are the crucial link in obtaining organs for donation as under the Human Tissue Act 2005 and Human Tissue (Scotland) Act 2006 (HT (S) A 2006), as they will be asked to reaffirm the deceased's intention to donate their organs and are therefore involved in the organ donation decision process. The challenges of requesting the bereaved relatives to authorise the donation are widely documented [6, 7] and often result in organs being lost. Critics of this 'opt-in' system however, suggest the adoption of presumed consent legislation or 'opt-out' will prevent the need to approach relatives to gain their consent to proceed to organ donation and in so doing, obtain more organs for transplant. Little research exists that explores the impact of the health care profes-

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sionals (HCPs), the bereaved relatives, the health care system and society overall of any change to presumed consent legislation. A study was therefore undertaken the aim of which was to explore the views and experiences of the HCPs who utilise this legislation in their practice and identify the role of the family in the decision to proceed to organ donation. As part of this exploration the HCPs reflections on their experiences in exploring organ donation with bereaved relatives was revealed. This paper summarises the experiences of 3 groups of HCPs in countries which have high levels of organ donation, in their efforts to balance the need to respect the wishes of the dead in relation to donating their organs with the professional's responsibilities to support the bereaved relatives.

Methods

Adopting a mixed method approach this study, utilised the responses to an initial questionnaire and interviews with HCPs with direct experience in organ donation in three European countries, Portugal, Norway and Belgium to capture the experience of the professionals in these countries who use this approach to organ donation.

Results

The initial survey of HCPs in the three countries yielded 31 responses (10.6%, $n = 300$) from Portugal, 47 (10.4%, $n = 450$) from Norway and 44 (35.7%, $n = 123$) from Belgium, providing data relating to their experiences in applying presumed consent legislation in organ donation, together with the benefits and challenges of their particular organ donation system. Subsequently, using data from these responses semi-structured interviews were undertaken with 14 HCPs in Portugal, 13 HCPs in Norway and 15 HCPs in Belgium to explore those responses in more depth. Analysis of data gathered during field visits to the three countries, the responses from the questionnaires together with those obtained during the interviews with the HCPs demonstrated a number of key findings related to the impact of this legislation on the bereaved families and the health care system in each of the three countries taking part in the study.

Legal and administrative structures underpinning organ donation

A different approach to the application of this legislation occurs in these three countries, as a result of varying infrastructures utilised to underpin organ donation. In Portugal and Belgium a register of objection to organ donation had been established where an absence of the deceased's name on this register is viewed by the HCP as consent to organ donation. In both these countries a computerised register has been developed to record this information. The requirement to record positively a wish to donate organs was only available within a specific part of the legislation adopted by Belgium, where the individual had the option to express consent to organ donation. In Norway no formal register of consent or objection to organ donation had been established however the next of kin of the deceased were invited by the HCP to indicate if the deceased had expressed any objection to organ donation. Public confidence in the organ donation system had been developed via the provision of extensive public education campaigns providing information on the legislation and the importance of organ donation.

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Establishing patient consent and relatives' lack of objection

Interviews with the health care professionals in Portugal and Belgium confirmed that utilising the processes described within the legislation, establishment of the individual's lack of objection to organ donation would be achieved by the transplant co-ordinator's review of the register of objectors. The absence of the deceased's name on this register would be taken as an indication of consent. The relatives however would be approached to confirm if the deceased had any objections or if they, 1st degree relatives or next of kin, had any objections. Those interviewed suggested that again when approaching the family they are not asking the family to take the responsibility for the decision to progress to organ donation, however they were confirming what the deceased had already indicated by their lack of registration no objection to organ donation. In Belgium, a register has also been established for individuals to record a positive intention to donate their organs and this would also be consulted in the event of a donation opportunity.

In Norway there is currently no register of objectors to organ donation in existence and therefore the next of kin is approached to establish that the deceased at no time expressed an objection to organ donation, either verbally or in writing. However a view expressed by many of the HCPs in all three countries that they are not asking the relatives to give permission for organ donation, but rather exploring if the deceased expressed any wishes or objections to organ donation. Using this approach the family are not making the decision on their own, but using the deceased's views prior to their death to guide this decision. It was reported that any family objections to organ donations raised during this decision making process will veto the organ donation procedure despite a lack of objection to donation recorded by the deceased.

Involvement of relatives in decision making process

Responses from the participants suggested that despite the various versions of the correct procedures as detailed within the legislation in all three countries relatives are involved throughout patient care and kept updated of the patient's subsequent deterioration and identification as a potential donor. The HCP's considered the exclusion of the family from the decision making process as detrimental to their wellbeing and public confidence in organ donation. The family's understanding of the patient's cerebral condition, their deterioration and assessment of brain death, including an understanding of the tests used by the professionals to establish brain death, was viewed as crucial if the eventual agreement of the family to proceed to organ donation was to be achieved. The degree to which relatives were informed of the patient's condition throughout the period of the patient's care and the decision to progress to organ donation did vary across the three countries. In Portugal relatives were informed of the patient's deterioration and potential to become a donor, i.e. the relatives were informed of the results of the brain death assessments. Rather than relatives being invited to express their views on organ donation, they were normally informed of the legislation and the intention of the professionals to proceed to organ donation. In Norway, a more determined attempt was made to facilitate the relative's involvement and gain their agreement to proceed to organ donation, achieved by frequent discussions with the immediate family to identify the next of kin and ensure their lack of objection. In Belgium having established that the deceased had placed their name on the organ donation register or their name did not appear on the register of objectors, the HCP was under no obligation to approach the relatives prior to progressing to organ donation.

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Approach to relatives

The participants suggested that previous understanding of the legislation and procedures for organ donation made the exploration of organ donation less traumatic for the donor family and had promoted trust in the HCP. In addition, many of those interviewed suggested the approach to the relatives adopted by the team caring for the donor to be important in gaining the trust of the family. Many interviewed, in all three countries expressed the strong view that confidence and trust in the HCP proposal to consider organ donation was developed in the family as a result of their involvement in the patient situation at every stage of their care, demonstrating an attitude of openness and honesty by the HCPs in relation to organ donation procedures and practices. In the view of the staff the family being kept informed about the deterioration of the patient and efforts made by the multi-disciplinary team to save their life promoted confidence and trust in the health care professionals. As a direct result of this confidence the family would accept the patient status and not raise an objection to organ donation. Those interviewed went further, suggesting that not only was there was a potential for mistrust between HCPs if the family were not kept fully informed of decision making in regard to their relatives care and subsequent diagnosis of brain death, they also suggested that suspicion of the HCP would impact not only on the relationship with the individual family but could have an effect on society's response to the organ donation initiative overall.

Some interviewees highlighted that families may express views on donating particular organs and withholding others. In their view if this was respected, then the donor family would be more at ease with the concept of organ donation. Many interviewees expressed the further view that the key element in building the relationships with the family was the ability to spend time with relatives prior to the request for them to consider organ donation. The use of the multidisciplinary team approach to confirmation of death and request to consider organ donation, comprising nurses, psychologists and in some situations members of the clergy, promoted a trust in the family. All of the HCPs interviewed expressed the need to separate the news of the patient being confirmed as brain dead from the news that they were now eligible to be considered as an organ donor. Linking these two concepts was considered detrimental to the success of the family not objecting to organ donation, as the family would not have been given sufficient time to come to terms with the news of the death and been suspicious of the HCP's motives for pronouncing their relative as brain dead. They suggested that the separation of these two elements allowed the relatives time to come to terms with the death before the introduction of the concept of organ donation.

Making the request to relatives and support practices and protocols

In addition to the practices and protocols developed for the technical identification of care of the donor, the HCPs interviewed reported the adoption of procedures for the approach to and support of family during the organ donation event. Many of those interviewed reported the existence of internal protocols for this role, highlighting the use of a multidisciplinary team approach to providing psychological care to relatives and included specialist input from crisis counsellor staff, but was led by a member of the clinical team looking after the potential donor. The family will be informed of their relative's brain death and allowed time to come to terms with this before an approach was made to explore their views on organ donation and thus decoupling information about death of the patient from the request to the family to consider organ donation.

In Belgium, it was revealed that a unique system of bereavement crisis intervention for relatives had been developed to support relatives in the event of a potential organ donation, involving the provi-

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sion of specially prepared staff, called Social Nurses, to provide detailed information and support to the relatives in this event. These Professionals were involved with the nursing and medical staff caring for the patient, in the communication and support of the relatives from the initial admission in the Emergency room, through the patient's admission and care in the ITU and subsequent deterioration and assessment as a potential organ donor. Using detailed communication and bereavement crisis support these staff helped the relatives to understand the complex issues involved in brain death and organ donation and enabled them to participate more fully in the decision to consider the patient's condition and their potential as an organ donor. It was reported that in some instances a clear policy had been developed to structure the communications between the multidisciplinary team and the family.

HCP education on the law and organ donation practices

Those interviewed in all three countries reported that they had a good level of awareness of their country's legislation together with the donation organisational systems. In Norway, HCPs interviewed suggested that their knowledge had been gained from a combination of personal experience of patient care and personal reading on this subject, receiving specialist input on the legislation from the transplant co-ordinator teams. This had often taken place during a post-registration intensive care course or during input to their orientation programmes when they took up a post in the intensive care unit. This input related to the requirement in law to confirm the patient's brain death, together with the protocols of care for the donor. Another group of HCPs reported their attendance at a two day Norwegian organ donation course run by the transplant co-ordinator teams. This programme is a version of a European Donor Hospital Education Programme (EDHEP) provided by the European transplant co-ordinators organisation, during which the health care professional can learn about a variety of aspects of organ donation to assist them with this demanding role.

In Portugal it was reported that preparation on the legal and ethical aspects of organ donation had been obtained during the undergraduate programmes for both medical and nursing staff, where bio-ethical aspects of care was a theme. In addition to this, many of those interviewed suggested that organ donation was a frequent topic of discussion of Portuguese professional conferences. The majority of the professionals interviewed in Portugal, however, reported that they had not received any formal educational preparation in relation to their roles and that any knowledge they had was gained through media coverage or as part of orientation programmes for new staff to the ITU. Those interviewed in Portugal also suggested that frequent discussions in relation to the issues raised by organ donation took place within the intensive care units who were involved in organ donation. These discussions helped staff share information regarding the application of the law. The majority of the HCPs interviewed in Portugal did not appear to have had the opportunity to attend any formal short education courses on organ donation provided by the transplant co-ordinator teams across Europe. Any information on their role in relation to organ donation, including the technical aspects of diagnosing the patient as brain dead and care of the donor prior to transplantation had been gained via experience of working within the multidisciplinary team caring for a patient who became an organ donor.

Interviewees in Belgium had similar experiences to their colleagues in Portugal where their undergraduate degrees had contained organ donation information. Medical and nursing staff interviewed both reported that there was some formal input to the undergraduate degree programmes relating to organ donation, and this provided some level of knowledge for the newly qualified healthcare professional.

Education and preparation in the approach and care of relatives

The majority of those interviewed in Norway and Belgium reported that they had attended one of the EDHEP short courses on organ donation. This course had provided them with more detailed information regarding the application of the organ donation legislation to practice, and with information on the technical procedures for organ donation such as the procedures to determine if the patient had suffered brain death and protocols for the preservation of the organs. There are clear similarities in preparation of the HCPs in Portugal, Norway and Belgium providing them with a good understanding of the legal and ethical principles that underpin organ donation, together with knowledge and skill in the technical practice of organ donation via the provision of specialist practice education courses.

Despite having a reasonable knowledge of the legislation and organ donation practices gained from access to undergraduate and post graduate information, the role of the health care professional in the approach to the family, breaking the news of the patient's brain death and subsequent consideration as a potential organ donor proved the most difficult to manage. Staff reported that applying the legislation and care of the family at this time presented them with difficulties, especially when the family were not aware of the legislation in organ donation or the concepts of brain death. This lack of understanding sometimes resulted in the family's inability to accept the death of the patient believing that they could receive care elsewhere to resolve their problems. Applying the legislation therefore meant that not only had the health care professional to explain the reality of brain death to the distressed family and assist them to understand and accept the cerebral death, but also, they have to explain the legislation and provide family support during the donation procedure. The interviewees agreed that the requirement for psychological care and support of the relatives during the organ donation event was one of the most important aspects of their role. This role was especially difficult and stressful for the HCP where the donor in the had recorded no objection to organ donation but this was challenged by the relatives. Many of those interviewed expressed the view that their lack of formal preparation in this aspect of their role was problematic and that they saw a need for education in how to approach the family and provide psychological care during the organ donation process.

As previously suggested many of the professionals interviewed in Norway and Belgium, had undertaken a short course on these aspects of organ donation. These EDHEP courses run by European Transplant co-ordinators group acknowledged these difficulties and provided training to HCPs, input within these courses helped the HCP understand and manage the organ donation event, especially in relation to breaking bad news to the family and detailing the procedures to be adopted to ensure that there was no objection recorded by the deceased to organ donation. In addition to this particular educational input aimed at preparing the staff for the psychological support of the family, it was identified that specifically trained nurses within Belgium, called social nurses, also provides education for nurses and medical staff in the psychological care of the family, experiencing the organ donation event. This specialist education input includes the development of practical skills in providing psychological care to the relatives. This team have also developed a protocol to support the approach to the relatives and the sensitive exploration of the family's views on organ donation. This short specialist programme is available to medical staff from critical care areas who would potentially be involved in breaking the news of the donor's death to the family and exploring organ donation.

Discussion

The application of presumed consent legislation produces many legal, ethical and clinical practice implications for the HCP. Chief amongst these is the requirement to provide a high standard of care for both the donor and the bereaved family that achieves acceptable clinical and ethical standards. The HCPs view the involvement of the family in the organ donation decision-making process as essential to gaining their agreement to proceed to organ donation and the well being of the bereaved relatives. To achieve this, a trusting relationship must be established between the bereaved families and the HCPs via the development of strong communication and support systems. Interviews demonstrated that a variety of good practices exist to guide the approach to informing the family of the brain death of their relative and provide psychological support of the family at this time. In Belgium, clear policies and practices for this had been developed; however, in Norway and Portugal no clear protocols of practice had been developed for this role. The establishment of clear protocols for the approach to relatives and their psychological care would be beneficial to organ donation in that this may reduce the numbers of relatives who raise objections. In order that HCPs involved in organ donation are adequately prepared to undertake their demanding role they also require specialist education and preparation. Not only does this education require to contain information aimed at the development of the health care professional's knowledge and skills on the legal and ethical aspects of the donation process and technical aspects of organ donation practice but additionally any education provided must also help the professional develop competence in the physical and psychological care of the family during the organ donation process. Lack of preparation in this area may result in the relatives objecting to organ donation.

Conclusion

Formal protocols for the psychological and emotional aspects of supporting bereaved relatives during organ donation should be developed. Systematic education for HCPs requires to be developed to accompany the implementation of this approach to organ donation. This education programme must prepare the HCP to manage the psychological and emotional care of the family during the organ donation event.

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