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EDITORIAL II

What are the issues in organ donation in 2012?

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Organ donation and transplantation (ODT) is a modern day success story: everything about it can be seen in a positive light. For the donor and their relatives, something good has emerged from a disaster. For the recipient, there is the opportunity for a new independent life, free from many of the constraints of supportive therapy. For the medical profession, there is an opportunity to bring about a cure for an otherwise intractable acute or chronic disease, and for society as a whole, it provides an exceedingly cost-effective solution. The 'Holy Grail' of treatment for organ failure remains the ability to regenerate individual organs for an individual patient using stem cell technology. However, ODT is currently the most realistic option for chronic organ failure, which (particularly in the case of renal failure) can occur in an otherwise fit and healthy individual. Indeed, solid organ and tissue transplantation, either singly or combined, is being used for increasingly complex diseases and situations way beyond those currently considered usual, such as the kidney, liver, pancreas, heart, and lung. Furthermore, composite tissue transplants (e.g. involving the trachea, the face, or a whole limb) are being developed; undoubtedly, these will become more routine in the future.

Despite this success, organ donation carries with it significant moral and ethical obligations. In most developed countries, organ donation is an entirely altruistic act irrespective of whether the donor is alive or dead. Hence, the recipient is obliged to do their utmost to ensure the survival and success of the organ. This includes enrolment in clinical trials and long-term compliance with appropriate medication to support its continuing function. Health-care professionals involved in the donation and the transplant must ensure that the organs are obtained in optimal condition and that the care provided to the donor, the donor's family, and the recipient is of the highest standard.

Despite its widespread potential, the continuing success of organ donation depends upon an adequate supply of organs. It is increasingly apparent that the number of organs obtained in the traditional way from brain-stem dead donors has reached a plateau. In the UK, there is still around a seven to one discrepancy between those requiring a kidney transplant and the number of donors. Furthermore, this imbalance between the need and availability of suitable donor organs is set to continue, for kidney and other transplants.

Why cannot we be as successful as Spain?

The UK Organ Donation Task Force made a number of recommendations to try and improve organ donation rates, either directly or indirectly.[1] Several of these, such as developing the concept of donation after cardiac or circulatory death (DCD), have the potential to increase donation rates. The introduction of legislation to adopt presumed or even mandated consent could have a similar effect. It is frequently asked why donation rates are so much higher in countries such as Spain, and in particular whether this results from the use of presumed consent? Other factors are probably involved. First, there are far more intensive care unit (ICU) beds in Spain compared with the UK, which are available for the care of patients before becoming donors. Secondly, in a predominantly Catholic country, positive decisions to withdraw life-sustaining treatment are made far less often than in the UK. Nevertheless, organ donation is undoubtedly a normal part of end-of-life care in Spain, is accepted as such, and has the confidence and support of the general public. The fundamental concept is that donation, when appropriate, should be viewed as a usual component of end-of-life care. This is a cornerstone of the Taskforce's recommendations and must be one of our key aims for the future.

Consent and the organ donor register

Presently, successful donation in the UK often depends on the unequivocal and readily accessible confirmation that the patient had expressed the wish to become an organ donor, both by signing up to the organ donor register (ODR) and by discussing the issue with their relatives. In such circumstances, donation can be regarded as a clear, end-of-life choice. However, less than a third of UK donors are on the ODR and only 50% of consents to donation are based upon specific knowledge of the individual's wishes. Hence, there is still considerable scope to increase donations. Perhaps, we should be more active in engaging with younger potential donors, embracing modern technologies such as smartphone applications or social networking sites?

Consent to organ donation may be viewed differently to consent in other situations. Agreeing to inclusion on the ODR may merely be an authorization for one's organs to be used after death. In this issue, Farsides[2] argues that consent to a procedure after death, where the individual does not have to live with the consequences, should not require all the characteristics demanded of a morally robust consent to living donation, but nonetheless, it provides an adequate basis on which to proceed with donation after death. If the UK-wide Donation Ethics Committee (UKDEC) were to recommend a less rigid approach to consent to organ donation, those who question the adequacy of consent implied by the ODR might find it easier to approach individuals and their relatives. Thus, more organs might become available.

An alternative approach would be the introduction of presumed consent to organ donation or mandated choice and the legal aspects of these are discussed by Price[3] in this issue. As of 2010, presumed consent (opt-out) was being used in some form in 24 European countries, with the most prominent and limited opt-out systems in Spain, Austria, and Belgium, yielding high donor rates. A 'soft' opt-out is also to be debated by the Welsh Assembly in the near future. The strength of the opt-out relates to the degree by which lack of the donor's expressed objection is considered in conjunction with the views of the relatives. Thus, in a case where no objection to donation has been recorded by the individual, donation would go ahead even if the relatives do not agree ('hard' option) or only if they agreed ('soft' option).

Mandated choice, in which an individual is required to express their wish in one way or the other, was endorsed by the American College of Physicians and was tried, but subsequently abandoned, in Texas and Virginia. More recently, the ethics committee of the Royal College of Physicians of London has called for an examination of mandated choice in the UK.[4]

Presumed consent or mandated choice might seem attractive options to increase the numbers on the ODR, but run the potential risk that 'the State' is perceived as bullying, or even dictating that ownership of one's organs ceases after death. The current system of voluntary sign up to the ODR is viewed by many donors and relatives as a positive decision which can help them take something positive out of a tragedy. Replacement of this system by presumed or mandated consent may therefore not be altogether helpful. Many would argue that the ideal way to increase donor numbers is to give health-care professionals and the public such confidence in all aspects of ODT that a willingness to donate after death is considered a normal part of end-of-life care, as seems to have developed in Spain.

ODT remains an attractive option in treating acute and chronic illness; it is generally the best solution in terms of quality of life, but is not without problems. While the actual organs may be free in financial terms, there are emotional considerations. These are particularly relevant if the organs are not ultimately suitable for transplantation (e.g. because of delays and a prolonged warm ischaemia time or because a suitable match cannot be found). The organs may subsequently be used for research, but this will not be viewed as a success by relatives unless it has already been discussed and agreed. Undoubtedly, this is an area which needs additional promotion to be seen as a positive outcome.

Donation after cardiac or circulatory death

Despite being used for the first cardiac transplant, DCD is still considered a relatively new technique. DCD has the potential to increase the number of available donor organs significantly. This technique is still poorly understood by many health-care professionals not directly involved in ODT and even more so by the general public, many of whom believe that organs are obtained solely from brain-dead patients (DBD). In many respects and through the commitment of staff in several major centres, the UK has led the world in the development of a sound ethical and professional framework for donation after circulatory death as detailed in the article by Manara and colleagues.[5] The result of this is that in 2009/10, 35% of all donors in the UK were from a DCD source (623 DBD compared with 335 DCD).

UK Donation Ethics Committee

One of the recommendations of the Organ Donation Task Force[1] was the establishment of a UKDEC. Its remit was not to increase donation rates *per se* but rather to address the obstacles which prevent donation occurring in the first place, or prevent the conversion of a donation into a successful transplant. The Committee, whose members do not represent any particular organization, comprises a wide range of professional and lay expertise. These encompass medical ethics and law, adult and paediatric transplantation surgery and medicine, intensive care medicine and nursing, patients, the public, and experts from both NHS Blood and Tissue and the Human Tissue Authority. We began our work 18 months ago with a call for ideas and questions, which was distributed as widely as possible and received an encouraging variety of responses from those involved in all aspects of ODT. The members then identified a significant number of points which have been discussed subsequently in detail. These include issues around the diagnosis and confirmation of death, building on the Code of Practice produced by the Academy of Medical Royal Colleges[6] and clarification of issues surrounding withdrawal of life-sustaining treatment and the patient pathway leading to organ donation.

Dilemmas and conflicts of interest in intensive care

We have also being particularly interested in the dilemmas facing intensive care staff. These include caring for dying patients, pressure on ICU beds, and the difficulties that staff experience when an individual they have been looking after for many days subsequently becomes a donor. It is very difficult for those not directly involved in ICU to imagine the roller coaster of emotions involved in these situations. One of the imperatives for UKDEC is to ensure that any guidance takes full account of such factors. For example, how does acknowledging a patient's best interests, as defined in the Mental Capacity (England) Act[7] or in the Adults with Incapacity (Scotland) Act,[8] and their expressed wish to become a donor, interact with an appropriately compassionate withdrawal of life-sustaining treatment?

It is vital that senior staff accept responsibility for the supervision of all aspects of organ donation to ensure that wherever possible, there is a positive outcome, whether in- or outside normal working hours. Those involved in retrieval and transplantation should provide a service that minimizes the disruption faced by a donating hospital. Policy makers at all levels must respond when clinicians identify gaps in existing frameworks, which are clearly inhibiting donation. At present, whether for logistical, emotional, or other reasons, a significant number of potential donors are never approached, or donations fail to happen despite consent.

ODT presents significant conflicts of interest to medical or nursing staff in ICU,[2] which may be real or perceived. For example, how does an ICU doctor who is also a Clinical Lead for Organ Donation (CLOD), or a Specialist Nurse for Organ Donation (SNOD) who is also working in an ICU, care for a patient who ultimately becomes an organ donor? Must individuals in official roles such as these completely divorce themselves from the care of a potential donor? How realistic would this be, particularly at a time of staff shortage, for example, in a small hospital at a weekend? How should limited ICU resources be allocated equitably when there is perceived conflict between the possibility of a single successful organ donation (which may help several organ recipients) and the immediate needs of another acutely ill patient? In addition, if we were able to increase the number of donors significantly, would there be sufficient capacity (within ICUs, operating theatres, or hospitals) to cope with the numbers of donors or recipients? Clear and sensible guidance on these matters is needed.

UKDEC has also spent considerable time discussing the ethical background to the relationship between withdrawal of life-sustaining treatment and the requirements of successful DCD donation. Although standardized end-of-life care pathways do exist,[9] most current practice depends on the policy of the individual ICU and often on the practice of the individual clinician responsible. While it is difficult to imagine the widespread adoption of a standardized protocol for the withdrawal of life support, we need some consensus in order that death can be managed in such a way that warm ischaemia time is minimized. Furthermore, if we are to avoid missing potential donors, we must consider whether it is acceptable ethically to modify end-of-life care with the aim of improving a patient's potential to donate after death, before consent has been obtained?

Faith and ethnicity issues

In its broad approach to ethics, UKDEC is also considering the significant issues existing around faith and ethnicity, which inhibit or prevent organ donation. Although most faiths support ODT in principle, considerable uncertainties exist in the individual interpretation of certain laws and beliefs.[10] Hence, when confronted with the inevitable need for an urgent decision, the outcome is often refusal. It is not so much that different faiths do not accept the diagnosis and confirmation of death and the way in which this is carried out as defined by the Academy's Code of Practice,[6] but rather how they define death as an event and at a particular point in time. This, together with anxieties over the body of the deceased remaining intact and free from violation after death and the necessary religious observances which follow death in certain faiths, undoubtedly produces obstacles to donation. However, many of these can be significantly helped by sympathetic understanding and dialogue.

It is well established that certain ethnic and associated faith communities have a significantly greater prevalence of certain illnesses than that in the general population, for example, the incidence of hypertensive renal disease in the black and ethnic minorities. This, coupled with a high incidence of uncommon blood groups (e.g. Group B) in these patients, means that the availability of organs for transplantation is severely limited unless suitable donors come forward from the same ethnic background. UKDEC has developed a role in trying to liaise with such communities and understand the issues they face. We believe that the building of confidence and understanding is crucial to increasing donation rates.

Conclusion

While some may believe that the solution to increasing donor rates is the adoption of presumed or mandated consent, others would argue that the ideal solution is to increase the public's confidence in the ways in which end-of-life care is managed and death is diagnosed. If this were achieved, anxieties might be addressed sufficiently to increase donor numbers. The processes of dying and death itself are rarely discussed. As a result, few of us, even though we may have signed the ODR, ever contemplate end-of-life care, let alone confer with those closest to us. It would be much easier for those involved if clear choices, including those related to ODT, had been made in advance without coercion, discussed with one's relatives and clearly documented. Although not the sole answer, achieving this would be a major step forward in meeting the ever-increasing need for donor organs.

Declaration of interests

Sir Peter Simpson is Chair of the UK Donation Ethics Committee. The views expressed in this editorial are his own.

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EDITORIAL III

Brain death: time for an international consensus

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Death is the great certainty of life—its inevitable end. In this issue of the journal, Gardiner and colleagues[1] present a comprehensive review of the history and current status of the diagnosis of death, and discuss the determination of death by neurological criteria (brain death) in some detail. Although it is more than 40 yr since the concept of brain death was first introduced into clinical practice, many of the controversies that surround it have not been settled. These include the relationship between brain death and death of the whole person, the international differences in the nomenclature and criteria for the determination of brain death, and the inextricable links between brain death and organ donation.

The concept of brain death emerged during the 1950s when, as a consequence of developments in critical care, clinicians were faced for the first time with the prospect of an apparently 'alive' patient sustained by mechanical ventilation long after brain function had ceased. The development of organ transplantation and the associated need to determine death before organ retrieval led to the publication of the first widely accepted standard for the confirmation of brain death by an *ad hoc* Committee of the Harvard Medical School in 1968.[2] Although this early link with organ donation might give the impression that brain death was a construct designed only to facilitate donation, this is incorrect. Most importantly, the confirmation of brain death allows the withdrawal of therapies that can no longer conceivably benefit an individual who has died.

In the UK, a Conference of the Medical Royal Colleges and their faculties produced guidance for the diagnosis of brain (stem) death in 1976[3] and, in a subsequent memorandum 3 yr later, equated brain death with death of the whole person for the first time.[4] In the USA, the 1981 Uniform Determination of Death Act (UDDA) gave equivalence to death determined by neurological and cardiovascular criteria, although it did not mandate a standard by which brain death should be determined, confirming only that this should be in accordance with accepted medical standards.[5] There is broad consensus, particularly in Western cultures, that human death is ultimately death of the brain and that this crucially involves the irreversible loss of the capacity for consciousness, combined with the irreversible loss of the capacity to breathe.[5] Taken together, these elements represent the most basic manner in which a human being can interact with their environment. Confusingly though, brain death is defined in two different ways based on 'whole' brain and 'brainstem' formulations. The UDDA relies on the whole-brain formulation and states that 'an individual who has sustained irreversible cessation