Expanding organ donation in the UK: ethical, moral and logistical dilemmas

In the UK, three patients die every day waiting for an organ transplant. Despite there being 18.7 million donors currently registered in the UK, donation rates remain low. This review discusses the legal, ethical and social aspects of organ donation in the UK, and looks at some controversial solutions adopted in other countries.

Organ transplantation is a viable treatment option for patients with end-stage organ disease. Organ transplantations fulfil some of the goals of medicine; to 'preserve life, alleviate suffering, cure diseases and restore function'. On the other hand, they violate some traditional principles such as: 'do no harm, respect autonomy and provide care for all who come to you in need' (Kuhse, 2001).

Organs for transplantation can be obtained from a deceased donor or a living donor. A deceased donor can be either following brainstem death, also termed a heart-beating donor, or following cardiac or circulatory death, also termed a non-heart-beating donor. In the case of deceased donor organ donation, criteria must be met before organ procurement including strict criteria for the diagnosis of brainstem death. In the case of living donor organ donation (kidneys, lung, liver and intestine), a decision must be made weighing up the benefits to the recipient against the risks to the donor, including anaesthetic and surgical complications. It is important to also take into account the psychological benefits to the donor.

In the UK, three patients die every day while waiting for an organ, yet the refusal rate for donation from a deceased donor remains more than 40%. In the UK between April 2012 and March 2013, there were 4212 organ transplants (a 6% increase from the previous year). However, in the same full year 7332 patients were active on the transplant list, with a further 2880 temporarily suspended (NHS Blood and Transplant, 2013).

As of March 2013, 19.5 million donors were on the NHS Organ Donor Register, but donation rates remain low as a result of a lack of consent and the circumstance of death being unsuitable for organ donation. Although 90% of the UK general public approve of organ donation, only 28% have registered on the Organ Donor Register. This has resulted in a serious shortage of organs for transplant (Mooney, 2011). These statistics clearly show there is a huge organ deficit in the UK. However, NHS Blood and Transplant (2013) announced that the number of deceased organ donors across the UK in 2012/13 hit 1212; a 50% increase since 2007–8 when the four UK governments accepted the recommendations of the 2008 Organ Donation Taskforce, and more than 3100 lives were transformed following deceased organ donation.

In the USA, organ procurement and transplantation network policies encourage the use of donors who are outside the normal criteria for donation, termed 'expanded-criteria donors', and these have facilitated efficient kidney placement to reduce the cold ischaemic time (time between procurement of the organ and transplantation) (Metzger et al, 2003). This was implemented in 2002, and by 2007, 21–3% of the deceased donor population were expanded-criteria donors, albeit with a discard rate of 44%. A drive by Donate Life America to increase enrolment in registries led to a 24% increase in registered donors from 2007 to April 2010, largely through drivers licence and ID card applications and renewals (Wynn and Alexander, 2011). Similarly, in Spain, a clear leader in organ availability, there has been an increase in the use of expanded-criteria donors and donation following cardiac death (Matesanz et al, 2011). An 'old for old' strategy has been developed, where irrespective of HLA mismatch, aged kidneys are allocated to aged recipients.

This article discusses some of the strategies that have been implemented in the UK and other parts of the world to address the organ deficit.

Opt-out system

The UK currently works on an opt-in system, with those willing to donate their organs on death joining the NHS Organ Donor Register, available recently through driving licence registration. An opt-out system shifts the default position to 'presumed willingness to donate' unless otherwise registered (Rieu, 2010). In the 'hard' opt-out system the family's wishes are not considered, whereas in the 'soft' opt-out system, families can disagree for any reason. The soft system has received 'strong support from the Prime Minister, the British Medical Association, the Chief Medical Officer, and a significant majority of the

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population, according to various polls' (Rieu, 2010). The support for a presumed consent or an opt-out system is increasing in the UK. The Welsh government have brought in a change to the law to bring in an opt-out system of organ donation. This bill has been overwhelmingly backed by 43 out of the 60 assembly members (BBC News, 2013). There is ongoing public consultation which will culminate in 2015. However, the Roman Catholic Church and the Orthodox Mission in Wales have called for a re-think, with other critics saying there is no evidence that changing the law will work (NHS Wales, 2012).

Spain has adopted an opt-out policy since 1979 and has the highest rate of organ donation in Europe (Rieu, 2010). The increases in donation did not begin immediately, taking 10 years to reach the target of no waiting list for organs. Other countries that have successfully adopted an opt-out policy are France and Belgium. However, families are still consulted before the organs are removed, and they do have the opportunity to veto the donation. In Belgium, the opt-out system has resulted in a lower refusal rate (13%) than the UK (40%) (Van Gelder et al, 2007).

The moral argument for the opt-out policy leading to automatic availability of cadaveric organs is a difficult debate, and relies on appreciating our moral obligation to society as a whole. Those who support presumed donation, perhaps without consent, argue that our moral concern as a society is focussed strongly on the dead and their friends and relatives. However, we should also have a moral obligation to those who are in need of a transplant, and indeed their friends and family. During organ procurement, the damage done to the recently deceased is less than that done to the potential recipient in the event of family refusal – hence how should we balance this moral concern (Harris, 2003)?

Some argue against the opt-out system as it undermines the idea of donation being a gift. They also believe the system will not increase the number of available organs unless the infrastructure is also improved. A more extreme opt-in model is seen in China, where the organs of executed prisoners are said to have been used without their consent. This practice has been condemned by every major transplant organization. This has been a source of transplant tourism, which has now been banned by the government of China. There are major problems involved with transplant tourism; not only as a result of unregulated practices and lack of follow-up, but also because of the ethical and clinical dilemmas involved when treating these recipients in their home country for complications following their transplant (Budiani-Saberi and Delmonico, 2008; Rhodes and Schiano, 2010).

Sale of organs for transplant

A clear dichotomy exists on the subject of payment for donor organs, with a clear majority worldwide against the concept (Rid et al, 2009). A critical appraisal is timely in view of the acute shortage of organs for transplantation. A regulated market for the sale of organs from living donors would involve a single institution, such as the NHS, which would purchase the organs (Rid et al, 2009). The market would be confined to a self-governing geopolitical area such as a nation state or European Union (Erin and Harris, 2003; Rid et al, 2009), and therefore only citizens resident within the union or state could sell into the system. The institution would ensure organs were distributed according to statutory criteria (Griffin, 2007) and were screened for infectious diseases such as HIV and hepatitis. There would be no direct selling or purchasing of organs, thus ensuring 'no exploitation of low income countries and their population' (Erin and Harris, 2003). Organ donors would be paid with public funds and receive medical follow up, along with priority access to an organ if they find themselves in need of a transplant (Rid et al, 2009).

A regulated market for the sale of organs from the deceased would involve a similar arrangement, with a central buyer, fixed prices and thorough screening. In exchange for organs, the patient could specify before death how the money is to be used, for example, if it is to go straight to a relative, be used for funeral costs or given to a chosen charity. This would only work if the donor had opted into the system before death.

In 2012, the Working Group on Incentives for Living Donation published a report on the proposed standards for an internationally acceptable system of incentivised organ donation, and suggested that until there are trials of incentives, the question of benefits and harms cannot be satisfactorily answered. The report proposes removal of disincentives (fear of financial hardship as a result of loss of income, fear of death and fear of lost opportunity) and a regulated system of incentives (autonomy, informed consent, financial help) under a system of protection, regulation, oversight and transparency (Matas et al, 2012). The report suggests clear guidelines for the development of a regulated system of incentives for deceased and living donation.

A counter-argument against this proposed system comes from the Philippines (Padilla et al, 2012), where between 2002 and 2008, a programme called the Philippine Organ Donation Program was established. This allowed prospective kidney providers to sign up, be allocated to prospective recipients and receive gratuities for their kidney, and limited foreign recipients to 10% of total kidney transplants care (Padilla, 2009). This was set up to adhere to all the standards outlined by the Working Group on Incentives for Living Donation. The programme also had set standards for procedures for transparency, creation of ethical guidelines, monitoring of transplant facilities and a donor registry, but it transpired that the reality was different. Reports indicate that there was no regulation of transplant tourism, which flourished, and organ brokers continued to be involved. There was no evidence of economic improvement in the donors' lives and a poor rate of medical follow-up was reported.

There are lessons to be learned from this before implementing any system of regulated incentivized living donation.

Iran implemented a regulated organ market about 20 years ago, with more than 20 000 vendors participating. Donor support includes $900 USD, 1 year's medical insurance and hospital charges covered, as well as extra compensation from the recipient's family. A transplantation candidate can get a kidney from a cadaver, or a living relative or a living stranger between the ages of 18 and 35 years. In Iran, 76% of kidneys come from strangers; only 12% of kidneys are from deceased donors (Griffin, 2007). Some studies in Iran show that the organ transplant list has not been eliminated by a regulated market (Griffin, 2007), while others claim that the waiting list has disappeared. It is difficult to make a conclusion about the Iranian system and its success at increasing the number of organs available for donation as data are difficult to extrapolate (Rid et al, 2009). Pro unrelated-donation groups have claimed 95% satisfaction with the decision, whereas those that oppose it have claimed 76% of donors feel that it should be banned (Zargooshi, 2001a). A report suggests that the system is plagued by financial bargaining, victimization of the poor, and lack of follow-up and prospective studies despite such a large donor population. However, it is encouraging to note that following the 2008 Organ Transplantation and Brain Death Act legislation, there has been an increase in brain death donation, and the Iranian government is now diverting funds from the unrelated-donation programme to deceased donation after brain death (Delmonico, 2012; Mahdavi-Mazdeh, 2012).

The follow-up and medical care for commercial donors has come under much scrutiny. In Egypt, where 80–90% of living kidney donors are unrelated or commercial (Barsoum and Bakr, 2000), 82% reported a deterioration in health (Budiani-Saberi and Mostafa, 2011). The Coalition for Organ Failure solutions, a non-governmental organization, provides care for commercial donors in Egypt. Although many transplant centres do provide post-donor surgery care, many donors do not attend follow up, as they do not feel comfortable returning to the same centre for follow up. In Iran, donors get offered a year's free health care, although long-term follow up is difficult (only 5% of 100 donors responded) as the donors do not want to be identified, because of the stigma and because most donors are young men who do not like visiting the doctor (Zargooshi, 2001b).

One study in the UK has shown that 70% of people thought cash rewards would encourage donations (Haddow, 2006). Some people may be uncomfortable donating for money because they hold the belief that the body is regarded as 'on loan' (Haddow, 2006) and is therefore not ours to sell. 'Dichotomists' believe the body and soul are separate, completely different entities and therefore the cadaver is left as 'a unique and invaluable resource' (Emson, 2003) which is otherwise going to decay. This belief supports the use of the body as a 'source of continued life' (Harris, 2003) and as such, if not used it will be disposed of. This opinion is further supported by the theory that what happens to the body after death can be regarded as 'person affecting' (Harris, 2003): that is, the dead person is not affected after death and the effect is on the organ recipient who will benefit from the organs which could be harvested from the cadaver.

Legalizing the sale of organs not only increases the number of organs available for transplant, it also offers a means to escape poverty and improve life for the donor. It has the potential to save at least two lives: that of the recipient from illness, and that of the donor, from poverty. It does not deny people the freedom to decide their fate but gives 'powerful reasons to do something' (Harris, 2003). It must be remembered that policemen, firemen and soldiers put their lives at risk in return for payment (Kunin, 2005), and people regularly take risks for money and should therefore be able to make the decision to take the risk of donating an organ for money and serve a worthy cause at the same time.

Exploitation of the poor is the primary problem with a regulated market for the sale of organs. Offering financial incentives is more likely to coerce the poor into selling their organs than it is to affect the decisions of the already well-off. The 'exchange of organs for money inherently involves unequal distribution of power, hence vendor exploitation' occurs (Epstein, 2011). Then again offering compensation for organs does not necessarily lead to exploitation, because a regulated market would ensure exploitation was minimized. Studies in Iran have shown that all socio-economic classes are the recipients; it is not solely the rich who receive the procured organs (Zargooshi, 2001b).

It is important to consider that by selling organs, the act of altruistic donation of organs disappears which may deter people from donating. It deprives people of the opportunity to donate through generosity as the focus shifts to money. It is thought that offering money for organs could offend rather than inspire people and that body parts should therefore be 'given and not sold' (Kuhse, 2001). Conversely, it is a lot to ask organ donors to act purely on the basis of altruism. When considering the issue of exploitation, it could be argued that altruism is exploitation, as the only one that does not benefit from the process is the donor.

Commoditization is the act of turning an object which has not previously been a commodity into a commodity. The risk of allowing the sale of organs is that precious body parts will become commodities and therefore a price will be put upon the organs. It 'makes calculable the value of an organ' and therefore the whole human being to which it is integral (de Castro, 2003). If the human body has a price tag, it and its organs are no longer regarded as priceless and it has been argued that the 'integrity of the human body should never be subject to trade' (Kishore, 2005). A monetary transaction does not

necessarily commodify something: there are certain limits to what can be bought and sold as commodities after all (de Castro, 2003). Pope Dius XII stated that: 'it would be going too far to declare immoral every acceptance or demand for payment... it is not necessarily a fault to accept it' (Healy, 1998). At least with a regulated market, if organs are to be regarded as commodities, indecent price escalation will be prevented.

Research has highlighted that transplantations from live donors have a better success rate than those from cadaveric donors. Transplants from live donors last longer, hence extending the time until the recipient needs a replacement organ. However, there is concern that a regulated market would lead to a decrease in the quality of organs for donation, as it is thought it would primarily be the poor donating their organs, who are more likely to be malnourished with poor health. However, studies in Iran, where 84% of the donors are poor (Ghods et al, 2001), have shown that kidneys transplanted within the regulated market last nearly as long as those transplanted in other countries.

Publicity, training, taskforce organization and forced choices

Publicity campaigns to highlight the problem of organ shortage and promote organ donation are the government's responsibility. Charities, patient groups, companies, schools and universities should be encouraged to promote organ donation and joining the organ donor register. Although there is no significant evidence that awareness campaigns and press coverage increase the number of organ donations, they undoubtedly improve public understanding of the issues surrounding organ donation (Pioli and Lawton, 2006). Although the idea of joining the organ donor register while applying for a driving license is a very effective one, other opportunities must be made for people to join. Evidence has shown that a more targeted approach would be more successful, for example focusing on people in hospital, schools and universities.

The media can be both useful in promoting, and also in potentially adversely affecting organ donation. High profile cases such as the Alder Hey enquiry, news of organ trafficking, doubt regarding brainstem death and the perceived unfairness in organ allocation have lead to a stream of negative publicity. In 2013 NHS Blood and Transplant and Transplant Sport UK held 'Donate Life' – a concert involving a 'transplant choir' made up of both adults and children who have either had a life-saving transplant, are on the waiting list for a transplant or are members of a donor family.

Another dimension in publicity is that of a 'story', in which donors are connected to patients through an emotional story. This may lead to increased altruistic organ donation. For this to be successful, donors must be educated in a personalized and culturally sensitive manner, and risks and new surgical techniques (laparoscopy) discussed. Furthermore, recipients need to be educated about the benefits of living organ donation and move away from the feeling of guilt often associated with accepting altruistic donation (Davis, 2011).

One of the most successful countries at achieving deceased donors is Spain. The Spanish model of organ donation and transplantation is based on two basic principles: organization and adaption to change. The transplant coordinators are based in the hospital, and consist mainly of critical care physicians, supported by nurses, who have a part-time dedication to transplant coordination activities. This is further enhanced by training and education, by working closely with the media, and by reimbursement of the hospital for donation activities (Matesanz and Miranda, 2002; Matesanz et al, 2007).

Role of religious and community leaders

Organ donations among ethnic minorities in the UK remain low. Ethnic minorities comprise approximately 6% of UK population of which approximately 4% are of Indo-Asian origin (India, Pakistan, Sri Lanka, Bangladesh). While people of Indo-Asian ethnicity comprise 13% of the renal transplant waiting list, donation rates remain low (1%). This poses particular challenges for potential recipients in terms of blood group and/or HLA matching for transplantation. With a high prevalence of diabetes, hypertension and renal disease, the overall utility of donors from Indo-Asian ethnicity will be low. Nevertheless, the perceived social and religious objection to organ donation needs to be addressed and widely publicized. For example, The Council of Muslim Religious Leaders of Europe unanimously approves of organ donation (Ghaly, 2012). Community and religious leaders can play a vital role in changing the hearts and mind of people.

Role of the multidisciplinary team and the family

The family's refusal of organ donation remains the biggest impediment to increasing the number of organs for donation. The UK's family refusal rate remains one of the highest in Europe. An article from the *Student BMJ* proposed that 'medical students' and junior doctors' lack of familiarity' (Essman and Thornton, 2006) with the issue of donation may contribute to the low donation rates, as they are not becoming doctors who are trained to discuss issues surrounding donation with the donor family. The clinical management of donations is complex and research has shown that junior doctors' awareness about organ donation and donor management is inadequate. Therefore key opportunities for increasing organ donations are missed. Relatives struggle with concepts such as brainstem death, and junior doctors do not feel confident about bringing up the difficult topic of organ donation at an already sensitive time.

In 2003, following a series of poor rates of donation in the UK, and 'as part of a radical overhaul, the Organ Donation Taskforce recommended that all parts of the

NHS embrace organ donation as a usual rather than an unusual event and make it a routine part of end of life management' (Akgun et al, 2003). Therefore, educating and encouraging doctors to talk to patients about organ donation makes it a more approachable and less taboo topic.

Similarly, the National Institute for Health and Clinical Excellence (2011) guidelines on improving consent rates for donors suggest that every hospital should have a policy and protocol for identifying potential organ donors and managing the consent process, and that the 'pathway for organ donation (from identification to consent) should be coordinated by a multidisciplinary team, led by an identifiable consultant (clinical lead in organ donation) working in close collaboration with the specialist nurse for organ donation'. The multidisciplinary team should include faith representatives where relevant. It does, however, warn that the discussion should take place, be it with patients, or their parents, families or guardians, only when the inevitability of the death is fully understood. Once this has been confirmed, the family must be made aware that discussion about organ donation is a normal part of end of life care, and should be approached in a positive manner, avoiding the use of apologetic or negative language.

Conclusions

These are just a few ideas as to how the organ deficit may be resolved. The issues discussed do not directly represent the views and opinions of the authors, but are discussed to provide 'food for thought' in the ethical, moral and logistical dilemmas facing organ donation. Other strategies that have been considered include expanding the definition of eligible donors, identifying non-human sources of organs, and dividing single organs among multiple recipients. Simple education of both health professionals and potential donors has the power to increase organ donation, without the ethical debates.

Although many options exist, the mainstays of recent discussions in the UK have circulated around the opt-out system and the procurement of organs by payment. The recent move by the Welsh government is a strong statement in support of organ donation and recognition of the organ deficit, but whether a soft system will be effective is yet to be seen. Although met by much criticism and vetoes by the government, these do have significant benefits. Transplant tourism has been condemned by the international transplant community (International Summit on Transplant Tourism and Organ Trafficking, 2008), and organ demand needs to be met in order to prevent transplant tourism to poorer countries (Matas, 2008), which can involve harm, exploitation and coercion. Between 5 and 10% of 66 000 kidneys transplanted worldwide in 2006 were estimated to be related to transplant tourism (Shimazono, 2007).

Increasing living donor by payment is fraught with problems, however. The issue of exploitation proves much ethical resistance, and particularly in countries where the matching system and pre-donation work-up may not be as robust as our own, organs may be of poor quality, and donors may withhold vital information to secure much-needed payouts. In countries where commercial living donations exist, the follow up has been reported to be sub-standard. If this becomes legalized, a 'world consensus', with appropriate follow up and care of donors, must exist and appropriate governing bodies be set up to ensure worldwide compliance and transparency. Currently, commercial donation remains a no-go zone, as the World Health Organization confirmed in 2010:

'Cells, tissues and organs should only be donated freely, without any monetary payment or other reward of monetary value. Purchasing, or offering to purchase, cells, tissues or organs for transplantation, or their sale by living persons or by the next of kin for deceased persons, should be banned.'

Many lessons may be learned from other models, including those in The Philippines, Spain, Iran and Egypt. Much discussion is required, and a consensus needs to be reached by governing bodies, medical association and patient representative groups. **BJHM**

KEY POINTS

- In the UK, three patients die every day waiting for an organ transplant.
- The refusal rate for donation from deceased donors remains more than 40%.
- Spain has adopted an opt-out policy since 1979 and has the highest rate of organ donation in Europe.
- A clear dichotomy exists on the subject of payment for donor organs: Iran has implemented a regulated organ market spanning two decades, with more than 20 000 vendors participating.
- Legalizing the sale of organs not only increases the number of organs available for transplant, it also offers a means to escape poverty and improve life for the donor, but exploitation of the poor is the primary problem.
- The family's refusal of organ donation remains the biggest impediment to increasing the number of organs for donation.

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