

ORGAN DONATION WORLDWIDE: SOLUTIONS TO INCREASE ORGAN
DONATION RATES

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Abstract:

The purpose of the research was to conduct a critical review of the literature surrounding organ donation. The paper discusses the different types of legislation involved in organ donation and solutions to increase organ donation rates. A systematic literature review and analysis of recent peer reviewed journal articles was conducted to assess different organ donation systems around the world. Medline, PubMed, Proquest and ScienceDirect databases were used.

The majority of countries with high organ donation rates have an opt-out organ donation system. There are a variety of confounding factors that might explain this correlation, such as the transplant capacity of the country, health expenditure and high mortality rates relevant to organ donation. Countries have implemented various strategies to increase organ donation rates. Some of these include changing consent systems, adopting the Spanish Model of organ donation, the reintroduction of donation after cardiac death, public education campaigns, training health workers to approach families for consent, incentives and developing a nationally coordinated system.

The gap between the supply and demand for organs continues to widen. Countries need to focus on maximising all organ donation opportunities. There is not a single solution to increase organ donation rates. A multi-sectoral approach is needed to reduce the gap between the supply and demand for organs. This thesis adds to the growing body of literature surrounding organ donation.

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Introduction:

The continual shortage of organs for transplantation is a major public health issue for many countries (Abadie and Gay 2006). Organ donation can save and improve people's lives (Smith and Murphy 2008). The waiting list for organ transplantation is very long in many countries around the world (Rithalia et al. 2009). Many people die whilst on the waiting list (Jansen et al. 2010). The UK waiting list is increasing by about eight percent every year (Rithalia et al. 2009). A major reason for the widening gap between supply and demand for organs is the high refusal rate of families when approached to donate. Around 50% of families that are approached to donate in the US and UK refuse. This figure is significantly lower in Belgium and France with 10.5% family refusal rate (Jansen 2010). Ageing populations and the increasing incidence of type2 diabetes worldwide will further put pressure on the availability of donors (Rithalia et al. 2009).

There are different types of legislation worldwide to do with organ and tissue consent processes. The first aspect is the registration process. This is either an opt-in or opt-out system. The second aspect is the influence of the family and next of kin. This can be no influence or the family and next of kin are consulted and have the power of veto (Delriviere and Boronovskis 2010). There are few other public health issues that raise as much public debate as organ and tissue legislation (Matesanz 1998). Other reasons for the variation in organ donation rates between countries may include availability of donors, wealth and investment in healthcare, public attitudes and organisation and infrastructure of the transplantation service (Kidney Health Australia Submission [KHAS] 2011). Donors per million population (dpmp) is the international measure for organ donation rates (Delriviere and Boronovskis 2010). Spain had the highest number of dpmp in 2010 followed by Croatia, Portugal, USA and France (Global Observatory on Donation and Transplantation [GODT] 2010). This paper discusses the different rates of organ donation around the world, possible reasons for the discrepancies and solutions to increase organ donation rates.

Opt-in system verses opt-out system:

An opt-in system is when people register their intent to donate through an organ and tissue donation register (Delriviere and Boronovskis 2010). An opt-out system or presumed consent system is when people register their intent to refuse to be a donor. Any person who does not register their intent to refuse to be a donor is considered to be pro organ donation (Delriviere and Boronovskis 2010). In 2010, the top three countries for dpmp had an opt-out system (GODT 2010). A survey conducted with members from the International Society for Heart and Lung Transplantation and the Foundation for the Advancement of Cardiac Therapies found that 75% of the 739 respondents favoured the opt-out system. Thirty nine percent of the members thought this was the single most important factor to increase donation rates (Oz et al. 2003). One of the main arguments against the opt-out system is that it takes away a person's right of autonomy over their body (Scott and Jacobson 2007).

Belgium is an example of a country with an opt-out system. One main reason for introducing this system in Belgium was that 95% of the population were in favour of organ donation. The responsibility was placed on the minority to register their refusal to donate. Another reason given was that family acceptance would result from a clear system capturing the entire population. After three years of the implementation of the opt-out system, organ donation rates doubled from 11 dpmp to 22 dpmp (Delriviere and Boronovskis 2010).

Spain also has an opt-out system. This was introduced in 1979. Donation rates did not increase until 1989. Brazil introduced the opt-out system in 1997. This was followed by a decrease in organ donation rates. This system was changed back to an opt-in system one year later. One of the reasons for this was the mistrust in the medical system (Delriviere and Boronovskis 2010). There were insufficient education campaigns about the organ donation process especially in regard to the concept of brain death. There were concerns in the public that organs could be removed from a person before they were dead. Many Brazilian people from a low socio-economic background did not have a personal identification card or driver's license and as a result had no way of objecting to

organ donation (Neto, Campelo and Nunes da Silva 2007). The USA and Ireland have the same donation rates as Belgium in spite of having an opt-in system (Delriviere and Boronovskis 2010).

Countries differ in terms of how much importance is placed on the next of kin's views on organ donation. The terms 'hard' and 'soft' are often used. Spain's opt-out system is described as 'soft' because doctors make sure the next of kin are supportive of organ donation. Austria's opt-out system is described as 'hard' because doctors do not consult the next of kin's views and organ donation proceeds unless it is known the deceased objected to organ donation (Rithalia 2009).

The UK Organ Donation Taskforce investigated the possibility of an opt-out system and published the results in 2008. The taskforce included members from a wide range of backgrounds including ethicists, medical lawyers and clinicians. The main objective was to review evidence from different countries on the effect of an opt-out system on organ donation rates. Five studies that compared donation rates before and after the implementation of an opt-out system were reviewed. The studies consisted of three countries. These were Belgium, Austria and Singapore. All three of these countries organ donation rates increased after implementing the opt-out system (Rithalia 2009).

Kidney donation rates increased from 18.9 to 41.3 per million populations per year over a three-year period in Belgium. Donation rates increased from 4.6 to 27.2 per million populations over a five-year period in Austria. Kidney donation rates increased from 4.7 to 31.3 per million populations over a three-year period in Singapore. The study designs in the five studies did not rule out the possibility of other factors that may have resulted in an increase in organ donation rates. Changes may have taken place at the same time as the change in legislation such as an increase in publicity surrounding organ donation and organisational and infrastructural changes. As a result it is not possible to determine what increase in donation rates were attributable to the presumed consent system (Rithalia 2009).

Eight studies were also reviewed that compared countries with and without presumed consent legislation. The four best studies in terms of the study design found an increase in donation rates in countries with an opt-out system. The results of these studies were an increase in donation rates of 25-30%, 21-26%, 2.7 more donors per million and 6.14 more donors per million. These studies could also not determine whether increased donation rates resulted from an opt-out system or other factors. The studies found that a variety of other factors might have played a part in the different organ donation rates between countries. These included availability of donors, deaths from motor vehicle accidents, transplant capacity (number of transplant centres per million population), gross domestic product, health expenditure, the percentage of the population with a higher education, religion and access to information. One of the studies found that transplant capacity was the most important factor in determining organ donation rates. Another study found that gross domestic product and health expenditure were the most important factors (Rithalia 2009).

The members from the UK Organ Donation Taskforce had a variety of opinions on the different consent systems. The review found that 60% of the public would support a change to a presumed consent system provided that it was appropriately implemented so the rights of the minorities were protected. The Taskforce advised that there were no legal or ethical issues to adopting a 'soft' opt-out system. A 'hard' opt-out system was not an option considered. The problem with a 'hard' opt-out system is that people might not register their objection for a number of reasons such as being busy, people might have learning difficulties or communication problems. The problem with not consulting the family in an opt-in system is that people might register their intent to donate but change their minds at a later date without unregistering. Involving the families in the donation process is also important in order to gain medical and behavioural history of the deceased. A 'hard' opt-out system in the UK could also result in legal challenges under the European Convention on Human Rights (UK Organ Donation Taskforce [UKODT] 2008).

Health professionals warned the Taskforce that an opt-out system could harm the important relationship between clinicians, patients and families. Public trust

was discussed as one of the most important factors to the organ donation system. If public trust was damaged then organ donation rates could decrease significantly. They also warned that it would make critical care more difficult and intensive care professionals could be reluctant to take part in organ donation programmes. Recipients of organs expressed their feelings to the Taskforce that they would want to know the organs they received were given freely by donors and their families. The taskforce also concluded that switching systems would be practically very difficult and costly. If the opt-out system were to go through then there would need to be mass communication campaigns to inform the public of the changes (UKODT 2008).

The Taskforce discussed concerns about the security of information in an opt-out system register. Incidences in the UK involving the loss or breaching of government data has made some members of the public weary about the security of their personal information. A secure IT system would need to be implemented. There were members of the public and patient groups that felt an opt-out system could be 'dehumanising'. Some faith leaders expressed opinions that an opt-out system could result in anti-donation feelings and campaigns (UKODT 2008).

Mandated Choice was also discussed by the Taskforce. This involves people being legally obligated to register their intent to donate or not to donate. A person's decision to donate or not to donate on the register over rides the views of the family in the event of their death. The Royal College of Physicians submitted a paper to the Taskforce outlining the advantages of a mandated choice system compared to an opt-out system. Their findings were that a mandated choice system would result in increased involvement by families in organ donation. They also stated that it would make the wishes of the deceased more clear. The Taskforce found that there would still be many issues such as when a person changes their mind about organ donation but does not change their wishes on the register and at what age should people legally be required to register. People may also fail to register but may wish to donate and there is still the issue of whether the views of the family should be considered. Citizens in the

UK do not have to vote. A mandated choice system would not be consistent with this legislation (UKODT 2008).

The decision at the end of the review was that switching to an opt-out system may improve donation rates but the risk that it might have negative effects were too high. Recommendations were made with the aim to increase donation rates by 50% after five years. If donations rates did not increase at this rate then an opt-out system would be reconsidered (UKODT 2008).

A study in the US reviewed 22 countries over a ten-year period to assess the impact of presumed consent legislation. The study controlled for other variables that may affect donation rates such as level of wealth, religious beliefs, education, social norms and medical infrastructure. The results found were that cadaveric donation rates are around 25-30% higher in countries with an opt-out system (Abadie and Gay 2006).

Another study in the Netherlands reviewed data on organ donation rates for 10 countries in Europe. The aim of the study was to assess whether different consent systems result in higher donation rates after accounting for differences in mortality rates. The study found that 80% of the deceased who became organ donors were from cerebral vascular accidents or motor vehicle accidents. Therefore the focus was on these mortality categories. In order to control for confounding factors, the countries reviewed in the study all had similar historical backgrounds and similar health care systems. Data was reviewed from the period from 2000-2002 (Coppens et al. 2005).

The study concluded that after accounting for the difference in mortality rates, there is no evidence that an opt-out system increases organ donation rates. Countries with high mortality rates relevant to organ donation had high organ donation rates and vice versa. Another finding was that even though countries have different consent systems, in practice most systems are similar. This is due to the fact that the next of kin is normally consulted (Coppens et al. 2005).

Mossialos et al. reviewed a cross-national comparative survey called Eurobarometer in order to determine whether different consent systems change people's attitudes to donate their organs. Eurobarometer is conducted regularly

to assess social and political attitudes of European people. There were 16,230 participants aged 15 years and over from 15 European countries. The data was collected from 2002. Two survey questions relating to organ donation were analysed. People's willingness to donate their organs was found to be dependent on the type of legislation and the level of understanding of the legislation in place (Verheijde et al. 2009).

Mossialos et al. concluded that participants in opt-out countries were more willing to donate their organs compared to participants in opt-in countries. The researchers reason for this was that people in presumed consent countries accepted organ donation as an ideology. Mossialos et al. stated that this ideology is based on "a mechanism by which individuals pay back society for the inclusion and social support that they have already experienced and hope to experience in the future." The survey did have some limitations. These included the way the survey questions were constructed. The first question asked whether a person would donate one of their organs after their death. This terminology is incorrect. The organ donation procedure may begin before death. Therefore the question should be reframed to asking whether a person would donate one of their organs at the end of life. Another limitation was that it was not possible to determine the level of knowledge of the participants surrounding organ donation. Respondents may have not known the difference between heart beating and non-heart beating donation and also the different procedures involved with various consent systems (Verheijde et al. 2009).

An article written in the British Medical Journal by Veronica English, the deputy head of medical ethics at the British Medical Association and Linda Wright, a bioethicist at the University of Toronto, debate the issue of presumed consent. English says that "presumed consent is the way forward because people who are in favour of donation do not have to make an effort to guarantee that their wishes are upheld" (English 2007). This statement is incorrect because as stated by English in the article, the next of kin in the UK would still be consulted with the final decision. Therefore people who are in favour of donation still need to go to the effort of discussing their wishes with their next of kin, otherwise their wishes might not be followed. This is supported by the fact that there is a 40%

refusal rate for organ donation in the UK when the family are not aware of their relative's wishes (English 2007).

English also states that presumed consent is "good for families because they are then relieved of the burden of decision making when they have just been told their relative has died or is dying." (English 2007). This statement is also misleading. If a person fails to register their objection to organ donation then that does not necessarily mean they are pro organ donation. There are a number of reasons why a person may not have registered their objection to donate (UKODT 2008). Therefore if the person has not discussed organ donation with their family then the family will not know their wishes and will not be relieved of the burden of making a decision.

Wright argues that presumed consent is not the answer to the organ donation shortage and that presumed consent is controversial because it refers to laws that allow the retrieval of organs without explicit consent. The US Institute of Medicine is apprehensive about presumed consent laws because donation rates could be reduced if the public are not supportive. This is especially the case in countries where people value their independence. People are more willing to donate when they feel they have control over the donation process rather than the system dictating that donation is the right thing to do (Wright 2007).

Research by the John Hopkins University of Medicine in 2011 found that switching to a presumed consent system would not likely increase organ donation rates in the US. Dorry Segev, an associate professor of surgery at the John Hopkins University of Medicine, said, "Opt out is not the magic bullet. It will not be the magic answer we have been looking for. With opt-out, the perception becomes, 'We will take your organs unless you take the time to fill out a form.' That's a dangerous perception to have. We only want to use donated organs from people who intended to donate." The research suggested that a presumed consent system has many ethical implications and it could harm the relationship between the transplant community and the public (Desmon 2011).

The researches conducted interviews with transplant experts from 13 European countries with presumed consent systems. The results were that the processes

involved in organ donation were similar to the US despite having an opt-out system. Six of the 13 countries had legal requirements to consult the next of kin for permission to proceed with organ donation. All of the countries would not proceed with organ donation if the family objected except Portugal. The reason's given for this was to protect the well being of the grieving families and to prevent negative press. Segev said, "Implementing presumed consent legislation would take a huge amount of time and energy with minimal payoff. Many countries with presumed consent have much lower rates of organ donation than the United States" (Desmon 2011).

A discussion paper was written by the head of the Western Australian Liver and Kidney Surgical Transplant Service and the Manager of Donate Life Western Australia in 2010 after a request from the Minister of Health to consider the option of an opt-out system in Western Australia. A 'soft' opt-out system was considered due to the ethical and legal barriers in Australia if the next of kin was excluded from the organ donation process. The paper discusses various problems with the opt-in system. One of these is that 77% of the population is in favour of organ donation but less than 40% of people register their wishes on the donate register. Sixty percent of the population inform their next of kin of their wishes but may not register their opinion. Therefore there is 40% of the population who do not know the wishes of their next of kin (Delriviere and Boronovskis 2010).

It is estimated that a change in system to opt-out would reduce the refusal rate of 35% by families to around 20%. The paper also concludes that health care professionals will have a clear understanding of the wishes of the deceased (Delriviere and Boronovskis 2010). This is not always the case as stated previously that there are a number of reasons why a person may not have registered their objection to donate (UKODT 2008).

Other reasons for adopting an opt-out system included that organ donation would become a key debate in society and family discussions on the topic would increase. The profile of organ donation would also be raised through the involvement of parliament and increased media coverage about the change in

system. An opt-out system could also increase people's attitudes that organ donation is the morally right option. (Delriviere and Boronovskis 2010). Research from the relevant literature found that an opt-out system gradually gains support over time with health care professionals and the general public living in countries with an opt-out system (Verheijde et al. 2009).

There were a number of risks identified in the discussion paper in changing to an opt-out system. One of these is that there is a chance that there might be a high number of objections to donate. Minority groups may also be negatively affected. Health care professionals may have problems with the change in system due to ethical reasons and as a result participation levels might decrease. Trust in the health care system surrounding organ donation processes may be harmed (Delriviere and Boronovskis 2010).

An analysis of 17 member countries of the Organisation for Economic Co-operation and Development (OECD) between 1990-2002 compared rates of cadaveric donation. Three reasons were given for the association between countries with a presumed consent system and higher donation rates. The first of these is that the strongest presumed consent system does not consult the next of kin. In practice all of the countries in the study consulted the next of kin except in Austria. Another reason is that presumed consent laws may change the public attitude to organ donation. Donation could become the normal decision to make when the next of kin is approached. As concluded in other studies, when presumed consent laws are brought in, changes in infrastructure also follow. There may be an increase in training of staff and media campaigns (Healy 2005).

Solutions to increase organ donation.

Spanish Model:

The Spanish model of Organ Donation is internationally recognised as the best model worldwide in terms of increasing donation rates over a sustained period of time (Matesanz and Miranda 2002). The model has overcome barriers to organ donation such as undertrained health workers, failure to identify donors and approaching the families to ask for consent to begin the organ donation process (Matesanz, Miranda and Felipe 1994). Spain has a presumed consent

system. The families are always consulted with during the organ donation process (Rithalia 2009). The model consists of a transplant coordination network. This network includes hospital, regional and national levels. Each of these levels has their specific roles in the organ donation process. There are coordinators at the hospital level that are directly involved in this process. The number of transplant procurement hospitals increased from under 20 in 1988 to 156 in 2007 (Matesanz and Dominguez-Gil 2007).

The profile of the hospital transplant coordinators in Spain is one of the main defining features when examining organisational and structural transplant systems in Europe. The transplant coordinators are normally intensive care unit specialists who are assisted by nurses. These coordinators are employed even in small hospitals. This is a major reason for the high organ donation rates in Spain (Matesanz and Dominguez-Gil 2007). This is not possible in many countries around the world. Spain has 8.75 intensive care unit (ICU) beds per 100,000 populations compared to Western Australia, which has only 3.63 (Delriviere and Boronovskis 2010).

The Spanish model also includes a constant audit on brain deaths in ICUs. These audits review the organ donation processes and identify areas that need to be improved. The audits allows for analysis to be made between the number of brain deaths in ICUs and the number of these brain deaths that result in organ donation. In the period from 1999-2005, 12.3% of deaths in the ICUs were brain deaths. Fifty point eight percent of these deaths resulted in the deceased becoming organ donors. The audits found that the main reasons for donor losses were medical contraindications (27.1%) and family objections (14.7%) (Matesanz and Dominguez-Gil 2007).

Training professionals thoroughly is another main aspect of the model. This includes donor detection, legal issues, organisational issues and developing skilled workers to approach families. This has resulted in reduced refusal rates from families. In 1993, 27.5% of families refused to donate family members organs compared to only 15.2% in 2006. A 24-hour telephone hotline is also in place together with an official website. These services provide information

regarding organ donation and answer questions from members of the public as well as health professionals (Matesanz and Dominguez-Gil 2007).

The Spanish model has shown success but there are some other factors that might play a role in Spain's high organ donation rate. One of these is that in most countries a donor is recorded when at least one organ is donated and transplanted. In Spain a donor is recorded when at least one organ is donated but not necessarily transplanted. As a result there is the potential for donors to be counted in Spain, where as in other countries they would not be counted. (Royal Australasian College of Physicians [RACP] 2008). The international donor rates can also be misleading. These figures do not take into account the overall potential for donation (Luskin and Delmonico 2003). Countries would be able to better assess the success of their organ donation system with a rate that measured the proportion of potential donors that actually became donors (Department of Health 2008).

A study conducted comparing organ donation rates based on age and mortality rates found that Spain's potential cadaveric donor pool is around 50% larger than Canada's (RACP 2008). A country such as Australia has a relatively small donor pool. One of the reasons for this is the reduced deaths from cerebral vascular accidents in the elderly. This is a result of the high quality of health care and low smoking rates. Another reason for the small donor pool is the decreased number of road traffic accidents as a result of successful campaigns to reduce drink driving, speeding and the compulsory wearing of seatbelts (KHAS 2011).

Another study found that Spain's high donation rates is mainly due to the use of older donors. If the US were to use the same proportions of older donors then their donation pool would be around 40% larger. As a result of using older donors in Spain, 25% of donated kidneys are not transplanted because they are not medically suitable. This figure is less than five percent in Australia (RACP 2008).

Implementing the Spanish Model into other countries is not always possible for a variety of reasons. These include the type of health care system, the economic resources committed to health, the number of physicians, ICU beds and the age

distribution of the population (Matesanz and Dominguez-Gil 2007). Italy is one country that has best been able to implement the Spanish Model with success (Healy 2005). The area of Tuscany increased its organ donation rate from 13dpmp to 26dpmp in one year after adopting the model (Simini 2000). Countries in Latin America have also had success in adopting the Spanish Model in recent years. Twenty one Latin American countries developed a program to train health professionals in their respective countries about the processes involved in organ donation in Spain. This training was conducted in Spain over a period from two to six months. Uruguay increased its donation rate to 25.2 dpmp in 2006. Argentina doubled its donation rate from 6-12 dpmp over three years. Colombia, Venezuela, Chile and Cuba were other countries that recorded substantial increases in donation rates in 2006 (Matesanz and Dominguez-Gil 2007).

Donor Action Model:

The Donor Action Model, which operates mainly in Europe, has shown sustained success. The model is based on best practice from the US, Spain and Eurotransplant. It is implemented in over 400 hospitals in 17 countries. The model includes five core modules, which contains the major processes involved in organ donation. A database is used containing over 62,000 medical record reviews from all the participating hospitals making it the largest international database of its kind. This enables hospitals to assess where improvements can be made to improve the organ donation process. A study on this model in ten participating countries found that there was an initial average organ donation rate increase of 59% and continued success over a period of time (RACP 2008).

Donation after cardiac death:

Prior to the introduction of neurologic criteria for death in the late 1960's, all organ donations came from non-heart beating donors (NHBD) or otherwise termed donation after cardiac death (DCD). Donors after brain-dead (DBD) resulted in better outcomes and NHBD were no longer used in most countries (DeVita et al. 2001). NHBD has been re-introduced in recent years in some countries due to the growing demand for organs (Matesanz and Dominguez-Gil

2007). It has been proven to be an effective strategy to increase the potential pool of organ donors (Sladen and Shonkwiler 2011). NHBD can either be controlled or uncontrolled. Controlled NHBD occurs when organ donation proceeds after planned withdrawal of life support. Uncontrolled NHBD occurs when organ donation proceeds after “unexpected circulatory arrest and attempted, but unsuccessful cardiopulmonary resuscitation” (DeVita et al. 2001). The United States has increased its NHBD significantly. NHBD now makes up 10% of all organ donations in the US. The primary reason for the increase in deceased donation rates in the US over the last decade is the increase in NHBD (Hernandez-Alejandro et al. 2011). This is not the case in many European countries with only the Netherlands, United Kingdom and Spain increasing their NHBD rates considerably (Matesanz and Dominguez-Gil 2007). Fifty percent of all organ donations are from NHBD in the Netherlands. NHBD is the main source of organ donation in Japan (Sladen and Shonkwiler 2011).

The reason for the low rates of NHBD in many countries is the technical, ethical and legal issues that are involved in this type of organ donation (Kootstra 1997). There was fear created in the public by incorrect media reports in the US when NHBD was reintroduced. As a result the US Department of Health asked the Institute of Medicine to evaluate the processes involved in NHBD. The Institute of Medicine concluded that NHBD is an ethical form of organ donation (Edwards et al. 2006).

One issue that has been debated is whether the patient is actually dead (DeVita et al. 2001). A major controversy is the time gap between cardiopulmonary death and the retrieval of organs. Organ donation needs to begin as soon as possible in order to preserve the organs. In some states in the US the time gap between death and the retrieval of organs is 75 seconds. The time gap is five minutes in Canada and 20 minutes in Sweden (Souter and Norman 2010). The time gap is ten minutes in the Netherlands in order to make sure that the patient’s brain is irreversibly damaged. Studies over the last 20 years have shown that a ten-minute waiting period has the same outcome for recipients of kidney transplantations, which is the organ most in demand (Harrington 2009). There have been reports of autoresuscitation in animals and humans without

brain death after 10-15 minutes (Joffe 2007). Questions have also been raised whether controlled NHBD is active euthanasia (DeVita et al. 2001). The Canadian Council for Donation discussed NHBD at a national forum in 2005. The council was supportive of NHBD programmes commencing. One of the recommendations was ensuring the process of withdrawal of care is separated from the decision to consent to organ donation (Sladen and Shonkwiler 2011).

NHBD normally occurs when a patient who is dependent on life sustaining therapy or their family decide to withdraw medical support and donate organs after death. Withdrawal of life support often takes place in an operating room in order to reduce the time between cardiac arrest and organ retrieval. As a result patients are often separated from their families unless the hospital allows the family to be present in the operating room. Separation of the family at the sacred moment of death can cause emotional distress (Souter and Norman 2010). Some hospitals withdraw life support in the ICU so families are not separated (Sladen and Shonkwiler 2011).

An ethical problem with NHBD is that some people believe the patient might not receive adequate care because the focus switches to the needs of the recipient. The patient often receives treatments with the sole aim of preserving organs. These treatments can cause physical pain to the patient and emotional anguish to the families. An argument against this issue is that when the donor and family are fully aware of the processes involved in NHBD and give consent, then the pain experienced by the patient for a few hours or minutes can be warranted because of the benefits to recipient (Souter and Norman 2010). Another ethical issue is whether there is a conflict of interest for health professionals and institutions. Social support also needs to be provided to the patient and their families (DeVita et al. 2001).

The use of NHBD is more appropriate in some countries than others. In order to implement NHBD, emergency medical care facilities need to be of a high standard. Organ donation staff must also have a high level of training and motivation (Matesanz and Dominguez-Gil 2007). Another reason NHBD is controversial is the fact that organ donation normally takes place after brain

death. Patients and families may be confused whether a patient declared dead under heart-lung criteria is really dead (Aulisio, DeVita and Luebke 2007).

A study was conducted from 2006-2010 in Ontario, Canada to assess donor and recipient outcomes from NHBD. The study also examined the impact the re-introduction of NHBD had on deceased donation rates. Canada ceased NHBD after “brain death” was defined in 1968 and in 2005 re-introduced NHBD. Eighteen Ontario hospitals participated in the study from 2006-2009. During this period there were 67 successful NHBD out of 87 attempted. This accounted for 10.9% of deceased organ donations in Ontario. NHBD increased each year. In 2009, 17% of deceased organ donations were from NHBD. Ontario is the only province in Canada to show an increase in deceased donation rates over the last ten years. There was a 25% increase in deceased donation rates from 2006-2010. The major factor in the dramatic increase in deceased donation rates was the re-introduction of NHBD (Hernandez-Alejandro et al. 2011).

Outcomes from Kidney transplantation were equal for NHBD compared to those from DBD. The one-year liver survival rate was 78% compared to 82% for DBD. The lung transplantation outcome was 70% compared to 82% for DBD. The study concluded that a number of stakeholders working simultaneously together are needed in order to establish an effective NHBD program. Other regions in Canada have not increased NHBD rates at the same rate as Ontario. Reasons given for this are the ethical concerns involved in NHBD and the lack of resources in hospitals in many regions of Canada (Hernandez-Alejandro et al. 2011).

Public education campaigns:

Public education campaigns are another strategy that has been used in order to increase organ donation rates (Morgan et al. 2005). The association between public education campaigns and organ donation rates is difficult to assess. The time gap between the exposure and the desired behaviour could be years apart (Lawlor et al. 2007). Some transplant professionals argue that the low rates of organ donation are due to the failure of public education campaigns (Oz et al. 2003).

A controversial Dutch 'Donor Show' was aired on television in the Netherlands in 2007. The show was based around a terminally ill 37-year-old woman who selected one recipient out of three candidates to donate one of her kidneys. Despite the controversy, 12,000 registrations were reported in the weeks after the television show was broadcasted. One reason for this was the increase in public awareness surrounding organ donation created by the media months before the television show was aired (Jansen et al. 2010).

A study in the US investigated different types of public education campaigns and the effect they had on the organ donation decisions on donor and non-donor families in the six months prior to making the decision. One hundred and forty seven donors and 138 non-donors participated in a telephone survey, which consisted of 115 questions. The results of the study concluded that the next of kin were more likely to give permission to organ donation when they had been exposed to increased donation messages in the months prior to a family member's death. There was also an association between public education campaigns and positive attitudes and beliefs towards organ donation. Participants were also more likely to discuss their wishes with others after been exposed to organ donation messages (Rodrigue, Cornell and Howard 2009).

The most common source of public education information reported by the participants was newspaper and magazine articles. White and educated adults reported increased exposure to organ donation messages compared to minority groups and people with a lower level of education. The study concluded that greater efforts need to be made to disseminate information to minority groups. Public education campaigns must be culturally appropriate and use champions that are known amongst different minority groups (Rodrigue, Cornell and Howard 2009).

Educational programs in high schools are another strategy that has been tried with success especially in Spain (Matesanz and Miranda 2002). High school students are important target groups because the programs can also indirectly affect their families (Weaver et al. 2000). A randomised control trial was conducted in 16 high schools in Italy to test whether educational programs affect

opinions on organ donation. Eight intervention schools and eight control schools were randomly selected to participate in the study. The educational program in the intervention school consisted of a questionnaire followed by two lessons and a post questionnaire. The control schools completed two questionnaires (Piccoli et al. 2006).

The results from the intervention schools found that 33.7% of students were opposed to organ donation pre-intervention. This was reduced to 16% post-intervention. Twenty five point two percent of the students in the control schools were opposed to organ donation. After the second questionnaire this was reduced to 23.8%. The study also found that television and newspapers were the main sources that students obtained information about organ donation. There was also a lack of knowledge of the term brain death and the importance of the next of kin in regard to the organ donation process. A limitation of the study was that it was only able to assess short-term changes. The results may be different if questionnaires were administered to student's years later (Piccoli et al. 2006).

An educational program was developed in the Netherlands for high school students aged between 15-18 years. The program consisted of a DVD discussing organ donation and the registration process, an interactive computer program and practice in how to complete an organ donation registration form. An evaluation of the program was conducted with 39 randomly selected high schools. The results showed that students who participated in the program were more willing to become organ donors. The participants were also more likely to fill out the registration form indicating their preference on organ donation. One reason given for this was that students increased their knowledge on how to fill out the form. Due to the positive results of the program, the Dutch Foundation of Donor Education implemented the education program in 350 schools in the Netherlands (Reubsaet 2004).

Skilled health workers to approach families for consent:

Training health care professionals with the difficult job of speaking with families about organ donation is another key area to increase organ donation rates (Williams et al. 2003). Health care professionals who care for potential donors

often lack the skills needed to approach families with the option of organ donation (Evanisko, Beasley and Brigham 1998). This issue often does not receive enough attention (Sque, Long and Payne 2005). High family refusal rates for organ donation is common in many countries (Siminoff, Gordon, and Hewlett 2001). Dissatisfaction with the request from health care professionals is a common reason why families do not consent to organ donation (Dejong et al. 1998). The family refusal rate for potential donors in the Netherlands is 53.5%. This is compared to 46% in the US, 41% in the UK and 10.5% in France and Belgium (Jansen 2010). Families are more likely to consent to organ donation when the request is made in a private setting. The family also needs to be able to understand the term brain death before a request is made and the involvement of the organ procurement organisation transplantation coordinator in the organ donation process is crucial (Williams 2003).

The Dutch Transplant Foundation implemented a training program for health professionals who approach families to ask for consent to proceed with organ donation. The program was based on the European Donor Hospital Education Programme. Training was conducted with health professionals in their hospitals over a four-hour period. The program consisted of communication techniques and skills on how to approach a grieving family. The aim of the program is to enable families to have a better understanding of the organ donation process and as a result they are able to make a more informed decision (Jansen 2010).

A study conducted in the US interviewed donor and non-donor families. The aim was to assess the different experiences of the participants in relation to the organ donation process. One hundred and sixty four people participated in the study. The interviews were conducted four to six months after the participants family member passed away. More non-donor participants than donor participants disagreed with the question asking whether the medical staff member who approached them to donate their next of kin organs were sensitive to their needs. Non-donor families also disagreed more with the questions asking that they felt comfortable talking with the medical staff about organ donation, they were given enough information to make an informed decision and that they were approached in a private setting. Non-donor participants also disagreed

more often to the questions that organ donation was discussed in a language they could understand, the requester was able to answer all of their questions and the setting they were approached in was private. The study concluded that medical staff should receive better training in requesting consent for organ donation from family members (Dejong et al. 1998).

Another study conducted in Spain conducted interviews to find out the reasons why Spain's refusal rate for organ donation has decreased. The refusal rate in 1993 was 25% followed by a decrease to 15.2% in 2006. The survey was conducted with 1,288 participants in 1993 and 1,126 participants in 2006. The results of the study found that there were no major differences in the attitudes towards organ donation of the participants from 1993-2006. The Spanish Model includes a major focus on training medical staff that has the responsibility of approaching families for consent for organ donation. The study found that one of the main reasons for Spain's decreasing refusal rates is that requestors use an effective technique to approach families and they support the families in their time of mourning (Dominguez-Gil et al. 2010).

A report written by the Council for Europe on strategies to improve organ donation rates, highlighted the importance of the way families are approached for consent. In the US staff must approach all potential donor families for consent to proceed for organ donation otherwise the hospital does not receive Medicare and Medicaid reimbursements. Even with this legislation in place, 20% of potential donor families are not approached with the option of donating their next of kin organs. One reason staff gave for not approaching families was that they thought it might add to the family's grief. A study conducted by the Partnership for Organ Donation and another in Spain showed that organ donation could help families with the grieving process. Eighty five percent and 86% of families in both of these studies said that organ donation was a positive outcome from the death of their family member. Families who refused to donate were contacted one year later and 30% said they wished they had consented to organ donation (Council of Europe 1999).

Another reason staff gave for not approaching families for consent was they thought they had a conflict of interest and most alarmingly they lacked the knowledge of the organ donation process. The report states that all health professionals involved in approaching families should receive mandatory training. This will enable staff to have the self-confidence to talk to families about organ donation and as a result increase the consent rates. Evaluation of all organ donation requests should also be obligatory in order to improve the way staff approach families (Council of Europe 1999).

A study in the US examined critical care physicians and nurses and their ability to handle request for donation. One thousand and sixty one critical care staff members from 28 hospitals participated in the research. Participants answered questions regarding their level of knowledge about organ donation, brain death, previous training in approaching families for organ donation and their comfort levels with the organ donation process. The results of the study found that there was a significant correlation between organ donation rates in hospitals and staff training in requesting organ donation from families. Overall less than 30% of staff had received training in how to explain brain death and the best way to approach a grieving family for consent. Fifty two point nine percent of staff received training in hospitals that had high rates of donation compared to only 23.5% of staff in hospitals with low rates of organ donation. The study concluded that critical care staff does not have the appropriate training to effectively approach families for consent (Evanisko, Beasley and Brigham 1998).

Incentives:

Another proposal to increase organ donation by the US based Organ Procurement and Transplantation Network and the United Network for Organ Sharing is to offer incentives for people who donate. These include a medal of honour and financial support for the donor's funeral. Another suggestion was people who register their intent to donate their organs receive priority for transplantation (Giles 2005).

A study conducted in the US tested whether health care professionals were in favour of offering incentives as a strategy to increase organ donation. Two

hundred and forty nine transplant surgeons, 143 transplant coordinators and 134 critical care nurses participated in the study. The policy with the highest percentage of support was a donor recognition program. Almost half of the surgeons and half of the coordinators supported offering \$1500 to help cover funeral expenses. The main reason given for not supporting this policy was that it is unethical and that health care professionals did not want to offer grieving families financial incentives during such an emotional distressing time. Some participants argued that it could result in organ donation rates decreasing. In 1994, the US state of Pennsylvania implemented an incentive program offering families of donors \$3000 to cover funeral expenses. This program was stopped because of fears that legal issues might arise from the federal law prohibiting the selling and trading of organs (Jasper et al. 2004).

World's Best Practice Approach To Organ and Tissue Donation For Transplantation:

The Australian Government developed a national reform package in 2008 called "World's Best Practice Approach To Organ and Tissue Donation For Transplantation" (Delriviere and Boronovskis 2010). The two objectives of the package were to "Increase the capability and capacity within the health system to maximise donation rates and raise community awareness and stakeholder engagement across Australia to promote organ and tissue donation" (Donate Life 2012). The package aims to meet these objectives by implementing nine key measures at a total cost of \$151.1 million over four years. The first measure is a new national approach and system including a national authority and a network of organ procurement organisations. This measure will create Australia's first nationally coordinated organ and tissue donation system with the goal of achieving similar results as a country such as Spain, which has a nationally coordinated system in place (Department of Health and Ageing 2008).

The second measure is to employ specialist hospital staff and systems dedicated to organ donation (Donate Life 2012). This proposal will result in an improvement in identifying potential donors, increased support for donor families and medical testing conducted by specialist health workers (Department

of Health and Ageing 2008). The third measure will increase funding to public and private hospitals (Donate Life 2012). The funding will help finance extra health workers, ICU beds and new infrastructure needed for the organ donation process (Department of Health and Ageing 2008). The fourth measure is to improve national professional awareness and education (Donate Life 2012). The national authority will organise training programs for health workers involved in organ donation. Organ donation will also be more of a focus at medical and nursing schools (Department of Health and Ageing 2008).

The fifth measure is to coordinate ongoing community awareness and education (Donate Life 2012). The aim of this initiative is to increase the knowledge and the confidence of the public surrounding the organ donation process. This will in turn increase family discussions about organ donation and lead to increased consent rates by families. Strategies that have been implemented to increase community awareness include developing an organ donor awareness week and donor recognition (Department of Health and Ageing 2008). The sixth measure is improving support for donor families (Donate Life 2012). The family of the deceased donor will be provided with support such as counselling. The funding will help improve the support resources offered to grieving families (Department of Health and Ageing 2008). The seventh measure is to develop a safe, equitable and transparent national transplantation process (Donate Life 2012). This measure will improve the management of transplantation waiting lists. Regular audits will be conducted to identify areas of weakness so appropriate changes can be made to improve the process (Department of Health and Ageing 2008).

The eighth measure is the development of a national eye and tissue donation and transplantation network (Donate Life 2012). This measure is important because the eye is the organ with the highest number of transplantations from deceased donors. Seven priority action areas will be the focus of the national network such as the development of a national eye and tissue donor database and national eye and tissue allocation protocols (Department of Health and Ageing 2008). The ninth measure is improving living donation programs (Donate Life 2012). This measure will develop protocols for paired kidney exchanges. This measure is

significant because 43% of Australia's kidney transplantations are from live donors (Department of Health and Ageing 2008). After the introduction of the reform package organ donation rates in Australia increased from 10 to 11.3 dpmp in 2009 and to 13.5 dpmp in 2010 (Delriviere and Boronovskis 2010).

United Kingdom Taskforce Recommendations:

The UK developed a taskforce in 2006 to find solutions to increase the organ donation rate. In 2008 these results were published. Fourteen recommendations were made with the aim that implementing these measures would result in a 50% increase in organ donation after five years. The first recommendation and the most important measure to be put in place is the introduction of a UK wide organ donation organisation. One of the benefits of this is the ability to better identify and allocate organs for patients. The second recommendation is that the organ donation organisation should be the responsibility of the National Health System (NHS) Blood and Transplant. The third recommendation is that a UK wide Donation Ethics Group should be established (Department of Health 2008).

The organ donation process has many ethical issues. One of these issues include providing treatment to a patient for the sole purpose of preserving organs and whether this is in the best interest of the patient. The Donation Ethics Group will assist health workers in understanding what is good practice. The fourth recommendation is that the NHS should accept organ donation as a usual event. An audit conducted on potential donors in the UK showed that there is no formal discussion with the families of around 15% of potential donors after brain stem death (BSD). It is suggested that clinical 'champions' be employed with the responsibility of making sure staff receive appropriate training and to develop and implement local policies to increase donation rates. The fifth recommendation is that a set of criteria for potential organ donation should be established (Department of Health 2008).

The sixth recommendation is that the number of potential donors compared to actual donors should be measured. When donation does not proceed then an assessment needs to be made to identify the point in the organ donation process

that may have resulted in donation not taking place. The seventh recommendation is that BSD testing should be conducted in every patient where BSD is a likely diagnosis. The eighth recommendation is the financial costs of the organ donation process should be reimbursed to the hospitals. The ninth recommendation is that health workers need to be trained with the difficult task of approaching families for consent to proceed with organ donation. Training needs to include legal and ethical issues associated with consent and enable health workers to have an appropriate level of knowledge of the organ donation process (Department of Health 2008).

The tenth recommendation is that organ retrieval teams should not be dependent on the donor hospital for anaesthetic, theatre or surgical staff. The teams should be on hand 24 hours a day and be able to cope if there is more than one donor in the same area on the same day. The eleventh recommendation is that organ donation should be included in the curricula in medical and nursing schools. This would raise the profile of organ donation and students would graduate with the appropriate knowledge of the processes involved in organ donation. The twelfth recommendation is that organ donors should be publicly recognised. Suggestions include a memorial garden, an eternal flame and a register on the internet (Department of Health 2008).

The thirteenth recommendation is that effective public campaigns need to be developed to promote organ donation especially to black and minority ethnic communities (BME). Twenty five percent of the UK public has registered their wish to donate. It is estimated that 90% of the public are in favor of organ donation. The aim of this measure is to increase the percentage of the public who register their intent to donate and to decrease the family refusal rate for donation. Only three percent of deceased organs came from BME communities between 2003-2004. Public campaigns need to focus on increasing organ donation rates in BME communities due to the fact that it is often difficult to find suitable organs for patients from Asian and African-Caribbean backgrounds. The fourteenth recommendation is that formal guidelines need to be developed for coroners concerning organ donation. Some coroners refuse organ donation

when a post mortem examination is required if the death resulted from criminal actions while some coroners agree to organ donation. A set of formal guidelines will result in more consistent decisions (Department of Health 2008).

Conclusion:

The gap between the supply and demand for organs continues to widen. The demand for organs will continue to increase in many countries due to ageing populations and the increasing incidence of type2 diabetes. Deceased organ donation is only possible in a small percentage of deaths. Therefore countries need an effective organ donation system in place in order to maximise organ donation opportunities. Recent organ donation reforms in the United Kingdom and Australia have focused on developing a nationally coordinated system. The Spanish model, which has produced the highest organ donation rates in the world, also includes a nationally coordinated system. Organ donation rates vary greatly in different countries around the world. As discussed in the paper there are many reasons for these discrepancies.

Decreasing high family refusal rates for organ donation requests is a key issue that needs to be addressed. One major reason that families refuse to donate is they do not know the wishes of their next of kin. The family discussion is crucial. When the families do know the wishes of their next of kin, the family refusal rate is substantially lower. Greater emphasis needs to be placed on public awareness campaigns that focus on promoting discussing organ donation within the family. Training health workers with the skills needed to approach families for consent to proceed with organ donation has also shown to be effective in decreasing family refusal rates. The Spanish model has a large focus on training health workers on the appropriate techniques to discuss organ donation with families. Spain also has a relatively low family refusal rate.

The legislation surrounding organ donation varies between countries. Most of the countries with the highest dpmp have an opt-out organ donation system. An opt-out system does not always result in higher organ donation rates. Countries such as the US and Ireland with an opt-in system have similar dpmp as Belgium

which has an opt-out system. It is difficult to assess the correlation between opt-out systems and higher dpmp due to confounding factors. Some of these factors include deaths from motor vehicle accidents and transplant capacity in different countries. Not all countries have had success with a change to an opt-out system. Brazil's organ donation rates decreased after changing systems. There are concerns amongst some health professionals that an opt-out system could damage public trust in the organ donation system, which would be difficult to repair.

There is no one solution to increasing organ donation rates. Governments need to develop strategies that include a multi-sectoral approach.

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