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Ethical issues concerning the implementation of an opt out approach for human organ donation in South Africa.

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The human body cannot for long remain intact after death. It is perishable and will, as has been chronicled in art and literature since time immemorial, inevitably decay, disintegrate and turn to dust.

Harris 2003: 133

1. Introduction

1.1 The scarcity of human organs for transplantation.

The ability to successfully transplant a kidney or heart in order to prolong another's life is considered a major achievement of medical science. Renal transplants entered medical practice in 1954 and heart transplants have been undertaken since 1967. Throughout the world as a whole there are more than an estimated 700 000 patients receiving renal dialysis. In Europe there are 40 000 patients awaiting a kidney, of these only 10 000 are fortunate enough to receive one (Harris 2003: 130). In South Africa the chances of benefiting from an organ transplant are even lower. There has been a significant decline in the number of transplants being undertaken over the last three years in South Africa according to the Organ Donor Foundation of South Africa's (ODFSA) statistics[1].

[1] The Organ Donor Foundation of South Africa keeps a registry of those members of South African society who have made an explicit choice to donate their organs. This foundation also maintains statistics on the number and type of organ transplants carried out in South Africa each year.

During 2007, there were only six hundred and eighty eight organ and cornea transplants in the entire country. This is almost half of the number of transplant procedures undertaken during 2005. Fifty eight percent of these were corneal transplants and twenty one percent were kidney transplants. Of the 144 kidney transplants that were undertaken during 2007, 34% of the kidney donors were living donors who were related to the recipient indicating the very low number of people in South Africa who voluntarily donate organs upon their death (ODFSA 2007).

This shortage of organs coincides with increasing morbidity and mortality in all South African population groups. A large contributor to the morbidity from renal disease is directly related to the rapidly increasing incidence of diabetes mellitus and human immunodeficiency virus (HIV) in the last decade (van Rensburg 2007: 155; Venter *et al.* 2008: 183). Organ transplantation not only saves people's lives but can greatly enhance quality of life allowing previously ill people to become fully participative members of society once more (Laupacis *et al.* 1996:235).

There are three major areas of concern surrounding the transplantation of human organs from one person to another. The first problem is rejection of the donor organ, the second is the universal shortage of the supply of organs and the third is the expense associated with organ transplantation (Chadwick and Schuklenk 1998: 394). This paper will focus on the second problem namely the constraints on organ supply available for transplantation and one of the possible methods to alleviate this shortage.

Although modern medical technology has made it easier for us to live "a significant life"[2] by being able to pass on our organs after our death, the paucity of organs available for donation is a phenomenon experienced worldwide regardless of the type of health care system and socio-political context (Glannon 2003: 153). A number of different possibilities have been suggested in an attempt to address the shortage of organs. These include non-consensual harvesting of organs from the dead, presumed consent, an opt in system of organ donation, xenotransplantation and therapeutic cloning. The latter method may become feasible in the future and will raise further ethical issues.

One particular method will be examined in detail from an ethical point of view for possible application in South Africa. This is the opt out system of organ donation. The opt out approach may also be referred to as presumed consent, that is that every member of society is presumed to have agreed or consented to donating his or her organs upon death unless he or she specifically takes action to be excluded from the process. This system differs significantly to the current system in South Africa and many other countries where an opt in system exists (Pike, Kahn and Jacobson 1990: 264).

The opt in system relies on members of society planning for their own death and then taking positive steps to record their wish to donate. People must make a positive election to donate their organs on death, and then take effective steps to ensure that medical personnel can act upon that election. Most people are uncomfortable with doing this and delay addressing this issue until it is too late due to a number of psychological reasons

[2] As noted by Portmann (2002) this term is used by Nozick (1979) describing people who yearn for the satisfaction of knowing that there lives made a significant difference.

(Jacob 2006:294).

In the United Kingdom (UK) where an opt in system exists seventy percent of the population surveyed state that they would be willing to donate their organs and yet there are in fact only twenty percent of the population that carry an organ donor card (English and Somerville 2003:147). Thus many potential life-saving organs are lost due to procrastination and the requirement that one must actively make known one's willingness to donate one's organs. The concept of presumed consent has been a topic of discussion in the British Medical Association for almost a decade already. During July 1999 the Lancet reported that doctors attending the British Medical Association's conference that month, had voted for the introduction of a system of presumed consent for organ donation (Ashraf 1999:230).

More recently Gordon Brown, the prime minister of Great Britain, made a proposal that the organs of the deceased would be taken for transplant, with their consent presumed, unless they had opted out prior to their death or their family members objected to the use of such organs (Meilaender 2008:1).

Cadaver Organs

A person who requires a kidney transplant clearly has an interest in the preservation of his or her life. It would seem that the interests in preserving life should always take precedence over other interests. In the case of a live human donor, free and informed

consent would be obligatory requirements; but is this the case with cadaver donors? Cadaver donors can neither consent nor withhold consent.

There seems to be a conflict of ethical views here as many hold that we have an interest in controlling what happens to our bodies after our death (Hamer and Rivlin 2003:198). This is related to the concept of autonomy that Beauchamp and Childress (1994:126) originally put forward 'to recognise that person's capacities and perspectives, indicating his or her right to hold views, to make choices and to take actions based on personal values and beliefs.'

Yet others feel that these interests after death are of less relevance than the interests of the person who requires an organ in order to experience continued life (Harris 2003:131). The wishes of a dead person, it can be argued, should not be considered as having the same status of those of living donors. "Indeed one needs to ask whether it makes much sense to apply the ethical concept of personhood to a dead body" (Chadwick and Schuklenk 1998: 395). What about society's interests?

Society's Interests.

One of the major advantages of organ transplantation is that people who had previously been chronically ill and in hospital much of the time, can become productive members of society once more. In addition to that specific person enjoying a much improved quality of life, the community where they reside and work can benefit from their skills and knowledge.

Furthermore, in recent years the medical costs of transplantation have decreased significantly, making some types of organ transplantation, notably renal transplantation, a cost-effective intervention (Etzioni 2003: 2) and allowing funds that would have been allocated to ongoing renal dialysis to be allocated to other medical interventions thus benefiting society.

1.2 Objectives of research.

The main objective of this research report is to examine the ethical and legal arguments pertinent to the consideration of an opt out approach for human organ donation, in order to create a framework of moral reasoning for policy makers in South Africa.

In the first part of this paper the opt in system will be described and briefly examined. This system is currently prevalent in many countries including the majority of the states in the United States of America (USA), Canada, the United Kingdom, Australia and South Africa. Thereafter the ethical considerations surrounding the opt out approach will be considered in some detail in an attempt to establish whether this approach is morally defensible and practically preferable. The South African legislation governing human tissue and the donation thereof will be examined. Recommendations as to any changes that may be required to facilitate the opt out approach will be suggested. Mandated choice will be mentioned as an extension of the opt out approach. Finally issues peculiar to South Africa will be considered and conclusions drawn about whether the opt out

policy for organ donation could be considered to be ethically and legally feasible as a means of addressing the organ shortage.

2. Methods to alleviate the organ shortage.

The main focus of this chapter will be to provide an overview of different methods that have been suggested in the literature as possible mechanisms to alleviate the organ shortage that is experienced in many countries. These methods are the opt in system, reciprocal altruism, mandated choice, payment for organs, routine removal of organs and the opt out system.

2.1 The Opt In System

The current system of organ donation in South Africa is an opt in system where members of society express voluntary consent. Those who wish to donate their organs make it known to friends or family that this is their desire and may include these intentions in their will. Such organ donors may also join the Organ Donor Foundation of Southern Africa [3] who keep a register of potential donors and who provide cards indicating that this choice has been made. This voluntary consent may be strong or weak. A strong express consent system usually disregards the views of relatives in favour of the wishes of the deceased donor (Blackbeard 2003:55). In a weak express consent system, although the wish to donate has been expressed by an individual, a family member who is

[3] Organ Donor Foundation of South Africa. www.odf.org.za

uncomfortable with organ donation may not honour this instruction. There is a weak express consent system currently in South Africa.

In addition doctors sometimes make requests of families in the hospital setting when a family member is about to die. ”We should not underestimate the difficulty of getting consent, and in particular consent from newly grieving relatives: the experiences of transplant teams and policy makers are instructive here again” (Ashcroft 2000: 410). Notwithstanding this difficulty the greatest source of transplantable organs worldwide is the hospital based cadaveric donor (Bell 2003:176).

One of the reasons suggested by Giles (2005:189) for an inadequate number of donors post mortem is that people do not see sufficient benefit for themselves in consenting to be a cadaveric donor. They receive nothing or not enough out of this act. This has resulted in the United Network for Organ Sharing to recently endorse United States legislation that will study incentives for donation.

Delmonica et al (2002: 2002) have also recognized the limits of altruism and volunteerism and have approved of ideas such as a medal of honour and payment of funeral expenses. Others have suggested tax related incentives on the deceased’s estate. In many countries those who make generous contributions to charity are allowed to claim this on their tax returns. Savulescu (2003a: 129) suggests that a similar approach could be taken in order to reward those who donate their organs for transplantation. These tax benefits could be applied as part of an opt in or opt out approach.

One could argue that the opt in system could be significantly improved by public and professional education campaigns. Measures to simplify the process of donation and retrieval of organs would also enhance the number of organs retrieved. However Kennedy et al (1998:1651) believe that the same effect can be achieved by the opt out system but with greater certainty as has been shown in countries that have changed to this option.

2.2. Reciprocal Altruism

Giles (2005:189) goes further to suggest that one could create an incentive for people to pledge their organs upon their death by implementing a system where those who have agreed to donate are assured that they will receive priority to receive a transplant should they require it during their lifetime. This approach recognizes the self- motivated desire for giving. However this approach, which may be termed reciprocal altruism,[4] introduces further ethical difficulties pertaining to the allocation of scarce resources. An organ allocation system is obliged both ethically and legally to fulfill both equity and efficiency criteria in order to achieve distributive justice (Veatch 2004: 2). Steinberg (2004: 4) points out that there are both utility and equity considerations associated with the choice of such a policy.

[4] reciprocal altruism occurs where one confers a benefit on another in the expectation of future reciprocation. Koppelmann-White 2004

From the utilitarian viewpoint this approach will be regarded as successful as it is likely to result in an increase of available organs. However the real basis for rewarding donation requires that it is fair and equitable to provide some acknowledgement of altruistic actions and not to create clinically unjustifiable priorities (Veatch 2004:1). This approach therefore may require too great a compromise if we agree that need is and should be a dominant factor in determining the allocation of health care (Koppelman-White 2004: 26).

2.3 Mandated Choice

There is a further option when considering consent to organ donation and this is termed mandated choice. Mandated choice requires competent adults to decide whether they wish to donate their organs after their deaths. In this system they may choose whether to donate and they may specify which organs they will donate but they must register their wishes (Chouhan and Draper 2003:158). Relatives may be given the responsibility of making the final decision but this right must have been granted to them explicitly and conversely they may not veto an individual's decision in the case where they have not been granted this power.

The particular method of ensuring that all adults in a certain state make a choice is left to the policy makers but it needs to be as all encompassing as possible. Suggestions such as a form attached to the tax returns or vehicle licensing have been made but will not reach

everyone. Both Veatch (1976:272) and Spital (1995:506) have advocated mandated choice in the USA.

The latter conducted a survey amongst young adults where ninety percent where in favour of mandated choice and only sixty percent approved of presumed consent (Spital 1992:242). Mandated choice is also the preferred option of the American Medical Association and of the United Network for Organ Sharing but to date has not been implemented in any of the states of the USA even as a pilot programme. (Chouhan and Draper 2003: 158).

2.4 Payment for Organs

Amongst the suggestions made to alleviate the organ shortage is the creation of a market where organs and other tissues may be sold (Erin and Harris 2003: 137; Savalescu 2003: 29; Slabbert and Oosthuizen 2007: 49). There are several undesirable side effects of such an approach including treating organs as a commodity, injustice and costs (Etzioni 2003:1).

Erin and Harris (2003: 137) provide caveats about the possibility of explicit payment for organs. They advocate a strictly regulated and highly ethical market that could be created within a nation state or the European Union as a distinct geopolitical area. Although Erin and Harris explicitly state that there would be no exploitation of low income countries and their populations, no explanation is provided as to how this problem would be

prevented. This would be a justified concern as there are vast differences in income and access to health care amongst the different member states of the European Union.

When contemplating the development of a market in human organs it should be borne in mind that the majority of these organs would be harvested from living donors. This would result in serious ethical issues about whether people should be allowed to sell parts of the body (Savulescu 2003:138) and legal problems pertaining to whether a person has property rights in his organs while alive. To propose a market is to presuppose ownership of one's organs both while alive and when deceased. From a legal perspective a corpse has traditionally been viewed as an object incapable of being owned. Human body parts have been regarded as *res extra commercium* and commerce in body parts has been viewed as *contra bonos mores* (Slabbert and Oosthuizen 2007: 53). The fact that property rights in body parts have intentionally been precluded is a widespread occurrence upheld in the USA, UK and South Africa. While Slabbert and Oosthuizen (2007: 49) put forward the concept of the establishment of a market in human organs in South Africa, no consideration has been given to the significant moral hazard that will be suffered by recipients, health care workers and society in general.

In the current environment where commerce in organs is prohibited in South Africa there have unfortunately been a substantial number of cases of international organ trafficking with at least 38 illegal transplants having been performed in a private hospital in Durban several years ago. This unwanted scenario would be likely to increase should a market in organs be established in South Africa. The illegal exploitation of human tissue as a

tradeable commodity will continue to occur for as long as there is an enormous gap between supply and demand for human solid organs (Bass 2005:42). I will argue that the opt out system is likely to provide sufficient organs and tissues for transplantation thus precluding the need for the development of a market in organs and the associated unwanted consequences and the enormous costs that would be required to regulate such a proposal.

2.5 Routine Removal of Cadaveric Organs.

This view questions whether consent is an absolute requirement for organ recovery from cadavers. Spital and Taylor (2007: 300) believe that the obligation to honor the family's wishes of the deceased is, prima facie, not absolute and that it ceases to exist when the cost is unnecessary loss of human life. Consent for recovery of transplantable organs should be neither required nor sought when a person dies. If a government adopts such an approach and uses a coercive power to promote the public good this moves society forward where individuals will not, by private volition, act in their own best interests. This type of coercive action by governments does occur in most countries in the case of being drafted to the military during wartime or in some countries by the imposition of jury duty. The vast majority of the populace accepts these interventions as necessary to promote the common good. It is argued that routine recovery would be the consistent with this approach. In addition it is the simplest and most economical proposal as no registers are kept, no training and education campaigns are required and there will be no need for stringent government regulation (Spital and Taylor 2007: 300).

2.6 The Opt Out System

In the opt out system, individuals are presumed to have agreed to the donation of their organs unless they have indicated otherwise. In strong presumed consent jurisdictions relative's views are not considered and the clearly expressed will of the deceased is the sole criterion for objection to organ removal. Austria, Poland and Switzerland have implemented a strong presumed consent model. Norway, however, has a weak presumed consent system where neither the deceased nor the nearest relative objects to the removal of the organs, there are no grounds for assuming that the procedure would be contrary to the fundamental convictions of the deceased or the nearest relative (Blackbeard 2003: 56).

Richard Thaler, a behavioural economist and Cass Sunstein, a legal scholar, have recently written a book examining the deep and unthinking tendency humans have towards conforming. Understanding this conformity trait, that the majority of humans display, has led Thaler and Sunstein (2008: 129) to advise large corporations to change their strategy with regard to corporate retirement savings plans. Where previously employees could sign up for corporate retirement plans and receive a matching contribution from the company, thirty percent of those eligible for such plans failed to do so. Now many firms have moved to automatic enrollment with a change in system from "opt in" to "opt out." The authors term this intervention 'choice architecture" and believe that it could be used to bolster America's ranks of organ donors (Thaler and Sunstein 2008: 176). In an

experiment asking people to tick a box stating that they choose *not* to donate rather than a box stating that they choose to donate, the rate of donors increased from forty two percent to eighty two percent (Kiviat 2008: 55).

Presumed consent literature has introduced the term 'opting-out' or 'contracting-out' in relation to organ procurement (Jacob 2006: 293). There are a number of different methods used to declare that one wishes to opt out of organ donation. These include registering an objection on a computer registry, a verbal objection in front of a designated civil servant or ticking a box on one's driver's license.

3. Ethical aspects of an opt out policy.

This chapter will concentrate on an analysis of the main ethical arguments pertaining to the opt out approach to organ donation. Specifically the issues of patient autonomy and the limits to the right to liberty are explored. An examination of the complex matter of whether property can be attributed to the human body, either while alive or when deceased is undertaken.

It is important to acknowledge that there are a number of players involved in human organ donation who may each have distinct ethical and moral viewpoints regarding tissue donation. In the discussion that follows it is predominantly the donor's view that is

examined, although there is brief consideration of the attitudes of the potential donor's family.

One should bear in mind that the dying person's family has an ethical obligation of responsibility to the suffering member of society in need of an organ who is usually unknown to them. This obligation is grounded in the concept of mutual benefit of what we receive from and hence owe to each other as members of a community or society (Glannon 2003:155). The duty to the unknown person ought to be weighed up against any perceived duties to the deceased member.

The healthcare staff that care for the dying person and those treating the patient in organ failure also hold certain ethical responsibilities to the patient, his family and to the potential recipients of the organs. The physicians treating those with organ failure have explicit ethical decisions to make both in the procurement of the organs for their particular patients and more particularly in their decisions regarding the just allocation of these scarce resources. Lastly the recipient of the organ can be considered to have an ethical obligation in terms of looking after the organ they have received.

3.1 Patient Autonomy.

"Patient autonomy is the centerpiece of medical ethics and so it may appear a retrograde step even to suggest that the principle of explicit consent might be superfluous in some

contexts" (English and Sommerville 2003: 147). Does the opt out approach eliminate an individual's autonomy after death?

An essential element of the opt out system, where it is incumbent upon a person to positively register an objection to the donation of his organs, is that it still preserves the donors freedom of choice. However this system intentionally alters the balance away from the interests of the donor and toward the interests of the donee (Chadwick and Schuklenk 1998: 396).

Being able to choose freely is seen as valuable in many areas of life as this increases our capacity to satisfy our wants and gives us greater control over our lives (Dworkin 1988:8). Others have argued that the right to make choices in the context of organ donation is comparable to consent in medical therapeutic decision-making. But to what extent can the dead be thought to still own their bodies? Arguably, when one dies, one no longer has the same interest in one's body as one had whilst alive. Thus when one is alive and procedures are carried out on one's body they are inextricably done to one's self as the body is a component of our being. This cannot be said to be true once one has ceased living. It is doubtful that one could be thought of as owning one's body after death (Chouhan and Draper 2003: 159). Conceptually individual autonomy is inextricably bound up in the concept of human choice, will and life, all attributes which the dead lack.

Furthermore it is important to understand that the status quo system (the opt in approach) has an imperfect relationship with autonomy as personal choices about organ donation may be trumped by the next-of-kin (Robertson 2004: 47).

Although autonomy is seen as one of the major principles of biomedical ethics, it should be borne in mind that it "has only prima facie standing and can be overridden by competing moral considerations" (Beauchamp and Childress 1994: 126). Limiting the autonomy of the individual to promote the common good has already been accepted by society in the form of the military draft, taxation, mandatory vaccination and autopsy when an unnatural death is suspected. It is therefore not unreasonable to request that society considers limiting the autonomy of the individual in order to optimise cadaveric organ donation, thereby directly saving lives.

Eric Cassell (2007:22) implores us to consider his assertion that in addition to an ethics of individuals (autonomy) it is time for us to consider an *ethics of responsibility*. This ethics of responsibility is equally important when considering our relationship to nature and the preservation of the environment and in our relationships to our fellow man such as in the case of organ donation.

3.2 Liberty.

Mill (1982: 68) maintained that the protection of liberty is no justification for harming others and that protection from harm is the only instance under which an individual's

liberty may be limited. The principles relevant to this argument are the "benefit to others" and the "harm" principle. The "harm" principle states that there may be situations where it is morally justified for a government to interfere with a person's behaviour in order to protect other citizens from the harmful sequelae of the undesirable behaviour. The benefit to others principle holds that it is morally legitimate to restrict an individual's liberty to produce some benefit for other persons. These principles arguably support the opt out approach to organ donation because substantial benefit can be gained for those requiring organs and substantial harm to recipients can be averted. At the same time it could be argued that this restricts the liberty of the living in planning for their eventual deaths by imposing a burden on them to explicitly signify their choice. This restriction on the liberty of the living may be justified by the benefit to and avoidance of harm to organ recipients (Harris 2003:133). It cannot be said from a utilitarian perspective to restrict the liberty of the dead, since according to that perspective the dead lack the attributes to enjoy liberty.

The case for limiting liberty can be strengthened if the benefit to others can be obtained with very little effort by the individual. This is the duty of easy rescue (Savulescu 2003:129). There are two primary conditions to be fulfilled for the duty of easy rescue. These are firstly that the act makes a great difference to another and that secondly the act does not present great costs or risks to the rescuer (Chouhan and Draper 2003:160). These requirements are met by an opt out approach to organ donation. The donation of organs confers great benefits on the recipient and contributing is very easy to do in terms of time and effort. No effort is required to donate, and there is a relatively low burden

imposed upon one should one wish to opt out. If a person registers a wish not to donate (i.e. they opt out) this too can be seen as an easy rescue as they provide an easy emotional rescue of their relatives who are left in no doubt of the deceased's intentions.

3.3 Property and the Human Body.

Some argue that attributing the concept of property to the human body during life or after death is biologically inaccurate and morally wrong. The body should be regarded as on loan from the biomass to the individual until death, when it will return as a cadaver (Emson 2003:125). From the moment of birth until death the soul and the body are one inter-twined entity. Once the soul has departed from the body, the body can never again be part of the person.

Emson, (2003:127) a forensic pathologist, believes that the human cadaver should become a resource for those who may benefit from donation of its organs at the point at which life departs. Furthermore due to the failure of the voluntary approach he believes that it is morally and practically necessary for society to act to overcome this failure and this can be done by making the cadaver the responsibility of the state to determine its disposition. After death the body inevitably decays regardless of whether acceptance of death has been denied or delayed. While alive a person has a right to bodily integrity and this is upheld by the law that prohibits murder and assault. But the same rights are not necessarily conferred upon a cadaver and the cadaver is not seen as property that may be

disposed of for gain in the law. The law charges one to dispose of a cadaver in accordance with society's customary practice and public health requirements. This was the case prior to the development of immunosuppressive medication that permits transplantation to occur thereby changing people's lives from that of a chronic invalid to a fully functional human being enjoying a good quality of life, and often able to contribute to society.

I would agree with Emson (2003:126) who says: "from the strictly practical viewpoint, from being an object with no intrinsic value destined only for disposal, the cadaver became at one leap a vital resource, something quite new in human experience."

4. Objections to an opt out approach.

The focus of this chapter is to recognise and assess those standpoints that are expressed when objections are made to the opt out approach. Frequently raised objections include fear of premature death, minimizing altruism, the persisting interests of the dead, the inability to opt out and cultural and religious beliefs about organ donation. I will argue to dispel these concerns and to show that these issues frequently alluded to by those who object to an opt out approach can be remedied.

4.1 Fear of premature death.

For some there is a fear, not only of what will happen to the body post mortem but that there may an incentive to hasten death (Sodeke 2004: 48) in order to harvest the organs so necessary to others[5].

This fear may be based on the fact that organ transplantation has led to death being defined in a manner that optimizes the retrieval of healthy organs thereby maximizing the likelihood of success of the transplant. Fears of this nature can be addressed by ensuring that formal protocols exist about when death can be declared and is generally accepted by medical professionals as occurring when the brain stem is no longer functional. A further method to alleviate fears of premature death is to ensure that a number of clinicians possibly two or three where feasible, confirm that the person is brain dead. Moreover this decision should be explicitly separated from the domain of the surgeon who is undertaking the transplant as he may be seen as acting for the person in need of the organ and may be perceived as unduly biased.

In terms of the Human Tissue Act 65 of 1983 section 7 (2) and the National Health Act 61 of 2003, Chapter 4, at least two medical practitioners are required to verify the death of an organ donor. Neither of the medical practitioners that verified the death are permitted to be involved directly or indirectly in the transplantation of the tissue removed from the body of the deceased into the body of the living person.

[5] In a study by Siminoff and Mercer in the USA, non-whites were far more concerned that if doctors knew they were organ donors, they would do less to save their lives.

A utilitarian may suggest that in the case where a potential donor is so close to death that there is no likelihood that the patient may lead a normal life again then the interests of the potential recipient should still prevail (Chadwick and Schuklenk 1998:396). However making this view known may cause loss of faith in the medical profession and so the more cautious approach mentioned above will be more likely to engender trust in the profession and allay fears that the public may have about the possibility of hastening death of a loved one for the harvesting of organs for an unknown other. There is great value in adhering to proper protocols to ensure that death is not hastened to facilitate organ harvesting.

4.2 Minimizing altruism

A further objection, although a seemingly weak one, is that by taking an opt out approach one minimizes the possibility of displaying altruism (ibid 1998:396). However the statistics in most countries indicate an overwhelming apathy as far as organ donation is concerned and it is because of this generalized apathy that the presumed consent has been suggested as a more feasible option.

4.3 Persisting interests of the dead.

The persisting interests of the dead, that is those interests that survive their death, may also be cited as a reason why the opt out approach is not easily accepted by some.

However the damage to the persisting interests of the deceased appear to be very small when contrasted with those of the persisting interests of the living whose very lives depend on these interests (Harris 2003:132).

4.4 Inability to opt out.

Another issue suggested by those who oppose the presumed consent approach is that those on the margins of society may not be aware that they are required to opt out and may not have the means to do so. Marie-Andree Jacob (2006: 297) points out that this same constraint exists with the application of the opt in system. She also reminds us that the relevant framework in this discussion is one of consent, rather than ownership or property.

4.5 Cultural and religious beliefs about organ donation.

Some cultural and religious beliefs appear to preclude donating organs. Portmann (1999: 291) asserts that the aversion to mutilating and cutting the human body is related to early Christian thought where the importance of keeping the body intact both before and after death was emphasized. This he terms the "guardianship tradition." These beliefs still occur today as many black South Africans assert that they cannot be buried without their organs as their ancestors will not accept them (Ross 2008: 389). Presumed consent allows

for people with such convictions to opt out of organ donation and make it explicitly known that they are unwilling to yield their organs to others.

In countries such as the UK, USA and Australia the refusal of minority groups to donate organs on religious grounds may be insufficient to threaten transplant programme viability. The benefits of not threatening the security of religious minorities might be thought to outweigh the injustice of permitting free riders in the transplant system. For those with religious objections a policy that requires one to act against one's religious beliefs is no "easy" rescue at all (Chouhan and Draper 2003:160).

In the South African context cultural beliefs and superstitions are said to influence attitudes towards organ donation and transplantation thereby contributing to the low donation rate. One of the reasons given for being unwilling to donate their organs is the desire to be whole when buried, as described above. However in a small survey, seventy five percent of the black people interviewed indicated that they would be willing to donate their organs (Pike, Odell and Khan 1993:93). Therefore it would appear that traditional views may be changing on this subject as it is a relatively new concept.

It must be borne in mind that culture is not static, it evolves (Khumalo 2007:385). In an article entitled "Moral Education and Moral Reasoning in Traditional African Cultures," Ikuenobe describes the communitarian nature of traditional African moral reasoning. This reasoning, he asserts, is able to take further evidence into account in order to bring about change in the moral principles of a community both conceptually and practically

(Ikuenobe 1998:31). Khumalo (2007:385) believes that two questions should be asked when determining culture. These questions are whether the belief is important to a group of people and secondly whether it causes harm. Should the answers be 'yes' and 'no' respectively then there is no problem. However should there be any doubt, open and fearless debate is required. Debate may lead to modifications of beliefs thus limiting harm and providing a win-win situation. This type of approach could be extremely useful in the organ donation debate amongst the diversity of cultures comprising South African society.

This ability for a culture to evolve in their moral reasoning appears to be evident in this study as young black people were seen to be more willing to donate their organs than the older generations demonstrating a positive change in attitude towards the concept of organ donation (Pike, Odell and Kahn 1993:94). There have however, been strongly held views over the removal of organs from the dead for other purposes such as the making of "muti" (traditional medicine to ward off spells) and these views may adversely impact upon people's willingness to donate their organs after death (Pike, Odell and Khan 1993:93).

Even in some of those religious groups who have held firm beliefs regarding organ donation and who previously did not participate in organ donation there have been some changes in thinking about this subject over the last decade. A common theme of the Judeo-Christian ethic is the development of an unselfish concern for others and the act of altruistically donating organs would embody this ethic (Jotkowitz 2004:41).

Therefore, Rabbi Moshe Tendler from the Yeshiva University in Israel believes that saving any human life is halachically mandated and that Jews transgress the laws of the Torah if they are not willing to donate organs that would save another's life (The Jewish Voice 1996: December). According to the Rabbi saving a human life is the overriding value that permits the ordinarily forbidden desecration of the dead, in order to harvest the needed organs. A Jewish person's organs can be donated to a Jew or a non-Jew as Rabbi Tendler views all human life as identical.

At present due to beliefs about organ donation amongst most Jews there is marked shortage of organs in Israel, despite a high death rate from traffic accidents. Israel has an agreement with Cyprus whereby in exchange for organs from Cyprus the Israeli's will train Cypriot surgeons (The Jewish Voice 1996: December). This is clearly not a sustainable method of organ procurement and raises numerous ethical issues.

Although the King's fund report in the UK recommended that Muslim's and orthodox Jews should be "presumed objectors", both faiths subsequently endorsed organ donation. Therefore a desire to follow religious teachings does not preclude organ donation as most major religions positively encourage donation (English and Somerville 2003:148; Jotkowitz 2004:42). According to Netcare[6] many South African Moslems and Jews approve of donation provided that the donors have consented in writing in advance and provided that the organs are not stored but are transplanted immediately.

[6] More information describing the positions of a large number of religious groups towards organ donation is available on the Netcare website at www.transplant.netcare.co.za

5. Experiences of countries where an opt out approach has been implemented.

Both the positive and negative experiences of those countries who have adopted an opt out approach will be described. This chapter will mention the encouraging results obtained in twenty-two European countries and the less hopeful outcome in Brazil, a South American country.

5.1 European Countries

An opt out system for organ donation has existed for more than twenty years in some countries such as Belgium. In 1986 Belgium approved the law on presumed consent and was the first country to establish a computerized network that allows citizens to register their objections against or explicit consent to donating their organs and tissues after death (Roels, Vanrenterghem, Waer, Gruwez, Michaelsen 1990:2078). Interestingly less than 2% of the Belgian population have registered an objection to organ donation. Amongst the foreigners living in Belgium only 3,23% have opted out, which is still a relatively small number (Roels 1999:399). There is documented, convincing evidence that a change in the law from opting in to opting out led to a increase in organ donation of 55% within five years despite a concurrent decrease in the number of organs available from motor vehicle accidents (Michelsen 1995: 33).

Non-donor registers exist in 22 European countries (Das and Lerner 2007: 726) among them Austria, Switzerland, Sweden, France, Norway and the Netherlands. A recent analysis across the 22 countries over 10 years has shown that here has been a 25 -30% increase in organ supply attributable to presumed consent when controlling for the legal system, religious belief and the number of motor vehicle accidents and cerebrovascular accidents in each population (Abadie and Gay 2006: 599).

In France anyone over the age of thirteen who is willing to donate his organs is urged to inform his relatives and to carry a donor's card (Dorozynski 1998:234). The age at which someone may consent or object to organ donation differs from one country to another as does the role of the deceased's nearest of kin. The family's permission is not required for organ harvesting with the Belgian system but they may oppose the donation (Michielsen 1996:663). In Austria organs may be removed irrespective of the views of the deceased's relatives (WHO 1994: 278).

Michielsen (1996:665) points out that the organ retrieval rate in a specific country depends on a large number of contributing contextual factors such as the density of the population, the age stratification, the number of motor vehicle accidents, the number of intensive care units and the social security system. Ensuring an enabling legal environment, in order to maximize the number of potential donors, is only one of the necessary requirements to increase the number of successful organ transplants.

5.2 American Countries.

The differences in the structural elements of various countries may assist our understanding of why the implementation of presumed consent for human organ donation appears to have been well received in a number of European countries and yet other continents have been slow to adopt this method. In South America when Brazil enacted a presumed consent law during 1997, many Brazilians responded by forming long lines in civil registry offices to register their desire to opt out. The Brazilian Medical Association and the Federal Council of Medicine had criticized the process as doctors were unwilling to remove organs without family consent. Other constraints to the implementation of the law were the lack of infrastructure to keep a register of those awaiting organs and the ability to notify them when an organ became available (Csillag 1998: 1367). The law was repealed in 1998 (Jacob 2006: 296) and doctors once more obtain permission from family members for organ retrieval.

Moustarah (1998:231) has argued for presumed consent to be adopted in Canada while acknowledging that this would be a "radical change in policy". Canadians have not been ready to embrace this change as yet and families are still approached for final consent. It is of concern however, that in Canada where the opt in system for cadaver donation currently exists, there are not only insufficient numbers in the current pool of donors but there is an emerging two tier system of organ procurement from living donors (Giles 2005: 189). This two tier system is inequitable as it differentiates between those who have social and financial capital and those who do not. It is possible that a similar

situation of moral hazard could readily arise in the South African context where a black market in organs could potentially flourish (Satyapal 2003: 845).

Thus far in the discussion, it is apparent that there is no easy solution to the persistent problem of severe organ donor shortages (Erin and Harris 2003:137). However it is clear that in the light of the overwhelmingly positive quality of life benefits for organ recipients (Laupacis *et al* 1996:235) we are compelled to critically examine presumed consent as a reasonable method of ensuring a morally defensible method of increasing organs for transplantation.

6. Legal basis of research.

In this section the principles of the World Health Organisation regarding organ donation will be examined briefly. The Constitution of South Africa may be seen as epitomizing the values and ideology of the people of this country and will be reflected upon from this view. In addition, South African law will be scrutinized in order to ascertain whether the current laws and regulations allow for the introduction of an opt out policy for organ donation or whether legislative changes would be required and what these changes might be.

6.1 The World Health Organisation.

The guiding principles issued by the World Health Organisation (WHO) in 1991 state that organs may be removed from the body of a dead person if: *(a)* any consents required

by law are obtained; and *(b)* there is no reason to believe that in the absence of any formal consent given during life the dead person would have objected to such removal.

On examination of these broad principles it is evident that each country is required to draw up legislation concerning organ donation and that these laws should state the type of consent that is required and the nature of the parties who may give this consent. It is incumbent upon the society in each country to determine an approach to organ donation that will best suit the needs of the inhabitants of that country, taking into account that society's culture and values. Presumed consent is permissible according to the above principles of the World Health Organisation provided that each member of society has been given the opportunity to record their objection to organ donation while alive.

6.2 The South African Constitution.

The South African Constitution of the Republic of South Africa[7] will be drawn upon as a fundamental source of South African values in order to inform the discussion on presumed consent. This legal document enshrines the rights of all South African citizens including their health care rights, freedom of expression and freedom of religion, belief and opinion (section 15 of the Constitution).

Can this highly esteemed document provide guidance for the development of a moral framework for adopting an opt out system for organ donation in South Africa?

The Bill of Rights applies to all citizens of South Africa affirming the democratic values of human dignity, equality and freedom. These are absolute, non-derogable rights. In section 27 of the South African Constitution a detailed set of socio-economic rights that promise access to housing, education, water, social security, food and health care to everyone are set out (Liebenberg and Goldblatt 2007: 337). The important distinguishing feature applicable to the socioeconomic rights is that they are subject to limitations and are therefore derogable[8] rights. All socioeconomic rights are subject to progressive realization and resource availability. Thus it is clear, that limitations can be imposed in certain circumstances, even when considering fundamental human rights[9].

These limitations are not unique to the South African situation but accord with the approach adopted by the United Nations Committee on Economic, Social and Cultural Rights (Bilchitz 2003:12) and as such have been accepted by the South African community and the world in general. Constitutions adopted after 1989 have increasingly recognized socio-economic rights as justicable rights. This is in contrast to the United States of America and many European countries where citizens are unable to directly derive any socio-economic rights from their laws (Rijlaarsdam 2004: 219).

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[7] The Constitution of the Republic of South Africa, Act 108 of 1996.
[8] Derogable means to be able to take a part away from, to detract from a right.
[9] The Government has an obligation to fulfill the rights described in the Constitution and the Constitutional Court has had a series of cases where it has had the opportunity to adjudicate claims based on socio-economic rights (Bilchitz 2003:1). It has affirmed that both the negative and positive duties imposed by these rights are justiciable (Liebenberg and Goldblatt 2007:352).

Central to the Constitutional courts decision making in each case is the concept of reasonableness as the legislation states in Act 108 of 1996 section 26 (2) and 27 (2) that "the state must take reasonable legislative and other measures within it's available resources to achieve the progressive realization of each of these rights."

It is clear from the above statement that the intent of such socio-economic rights is that the government should strive to provide a certain minimum level of health care or housing while at the same time taking reasonable measures to qualitatively increase these services in the future as resources become available (Bilchitz 2003:12). This, argues Bilchitz (2003:11), is the true intention of the progressive realization of these rights. However, it is important to acknowledge that these rights will essentially only be realized in the long term (if ever) (De Vos 2001: 262).

Implicit in the understanding of these rights and their limitations is the acceptance that there is a requirement to balance the needs of an individual with those of society as a whole. The case of *Soobromoney v Minister of Health, Kwazulu Natal*[10] exemplifies this principal. In *Soobramoney* the applicant sought an order compelling the KwaZulu-Natal health department to provide him with expensive dialysis treatment. This occurred at a time when primary health care services were inadequate for many of the indigent people residing in that province (De Vos 2001: 259). The Court upheld the decision of the KwaZulu-Natal department of health to ration access to dialysis according to evidence

[10] Soobramoney versus the Minister of Health, Kwazulu Natal. 1998 (1) SA 765 (CC)

based clinical entry criteria[11] and taking into account a finite budget and staff allocation for renal dialysis in that province. This is in contrast to the ruling in the case of the *Minister of Health v Treatment Action Campaign*[12] where a different perspective and balance was provided. In this case the Court ordered that the state should provide widespread access to the drug Nevirapine to prevent the transmission of the Human Immunodeficiency virus (HIV) to thousands of infants[13] born to HIV positive mothers. The fact that the prevention of Mother to Child Transmission (MTCT) of HIV could be achieved in a cost-effective manner in most health care settings including primary health care clinics, allowed this decision to further the development of the idea of the progressive realization of the right to health care for many (Klaaren 2003: 118).

Furthermore, given the finite nature of state budgets and the multitude of possible areas of valid expenditure in order to realize at least the minimum level of the socio-economic rights allocation decisions are required to balance society's needs (Pieterse 2004: 393). These allocation decisions will necessarily limit some members of society's rights while choosing to assist other disadvantaged groups at that particular time. In the case of *Government of the Republic of South Africa v Grootboom*[14] the court was required to assess the reasonableness of the budget priorities of the government, including the degree of importance given to competing social needs and the temporal order chosen to meet those needs (Klaaren 2003: 459).

[11] Evidence-based medicine describes the systematic and rigorous use of methods that have already been tried and tested when treating individual patients. It is a basis for decision making in which the best available data are used to assist in selecting a treatment.
[12] Minister of Health v Treatment Action Campaign. 2002 (5) SA 721 (CC)
[13] Approximately 70 000 children are infected with HIV through mother to child transmission annually.
[14] The Grootboom case concerned the (socioeconomic) right to housing. Government of the RSA v Grootboom 2001 (1) SA 46 CC

Similiarly, the law introduces limitations to citizen's rights and their autonomy for the greater benefit and protection of society with conscription to the armed forces, mandatory vaccination, taxation and mandatory post mortem in the case of unnatural deaths. These coercive practices are widely accepted now but were undoubtedly unpopular when they were first introduced into society (Spital 2003: 172).

Consideration of section 11 and 12 of the Constitution of South Africa is warranted in respect of the responsibilities of the state and the need for individual consent for bodily procedures. Section 11 states that everyone has a right to life. It is the duty of the state to respect, protect, promote and fulfil the rights in the Bill of Rights[15]. It is therefore incumbent upon the state to advance the right to life and health. In terms of the organ shortage one could argue that it is the positive duty of the state to ensure that the rules/laws governing organ donation are those that would assist in making organs more widely available. Doing so would increase the likelihood of many chronically ill people once more being given a right to life. The opt out approach would help to achieve the promotion and fulfillment of the right to life for the thousands who are dying of organ failure.

Section 12 describes the right to freedom and security of the person. This section establishes the need for an individual to give their consent for medical treatment and

[15] Chapter 2, Section 7 (2) of the Constitution of the Republic of South Africa.

procedures[16]. One interpretation of this right is that it would preclude legalizing presumed consent. In this view, presumed consent would directly infringe the right as one would be required to relinquish control over one's body. However it is debatable whether the intention of this right includes rights after death and whether citizens have a right to make decisions about their bodies after death?

I would argue strongly that the need to balance the right to life outweighs any possible dubious posthumous rights to bodily control. It is my contention that as it is the responsibility of the state to promote and fulfil the right to life, this would include enacting enabling legislation to optimise the number of organs available for transplantation. The opt out approach would be an appropriate means of achieving this.

3.4.3 The Human Tissue Act.

The Human Tissue Act, 1983 (Act 65 of 1983) provides for the donation or making available of human bodies or tissue for the purposes of medical and dental training, research or therapy or the advancement of medicine and dentistry in general. Under this Act the term human tissue includes any flesh, bone, organ, gland or body fluid but excludes any blood or gamete.

[16] Section 12 (2) states that everyone has the right to bodily and psychological integrity, which includes the right – (b) to security in and control over their body.

The Act provides that for donation of human bodies or tissue of deceased persons

(1) Any person who is competent to make a will may in his will or in a document signed by him and at least two competent witnesses, or in an oral statement made in the presence of at least two competent witnesses-

(a) donate his body or any specific tissue thereof to be used after his death for any of the purposes referred to in section 4(1); or

(2) In the absence of a donation under subsection (1) by a person and of a contrary direction given by that person-

(a) his spouse, major child, parent, guardian, major brother or major sister may after his death donate his body or any specific tissue thereof to an institution or person referred to in section 3 (1) to be used for any of the purposes referred to in section 4(1); and

(b) the Director-General or any person specially authorized by him for this purpose or the holder of a specific office authorized as such may after the death of the person concerned, if none of the persons referred to in paragraph (a) can be traced and the Director-General or such authorized person or holder of an office is satisfied that all reasonable steps have been taken to locate those persons, donate any specific tissue of the body of that person referred to in section 3 (1) to be used for any of the purposes referred to in section 4(1).

[Para. (b) substituted by s.2 of Act 51 of 1989.]

Section 4(1) of Act 65 of 1983 describes legally acceptable purposes of donation as including medical and dental training, research, the advancement of medicine or dentistry, or therapy, including the use of tissue concerned in any living person or persons or for the production of a therapeutic, diagnostic or prophylactic substance.

It is evident that under the Human Tissue Act the opt out approach would not be permissible as explicit consent is required either by the donor, specific family members or the Director-General or his designates.

However the Human Tissue Act 65 of 1983 has been repealed by section 93(1) of the National Health Act 61 of 2003. The National Health Act came into force on the 2nd of May 2005 except for chapter eight which deals with the control of human blood and tissue. The Human Tissue Act therefore continues to govern organ donation and transplantation until this section of the Act is repealed. Will the National Health Act allow for a policy change to presumed consent for organ donation?

6.4 The National Health Act.

The National Health Act incorporates many of the provisions of the Human Tissue Act and stipulates *inter alia* that no tissue,[17] blood, a blood product or gametes may be removed from the body of a living person for prescribed medical or dental purposes without their written consent. The Act provides that only a registered medical or dental

[17] "Tissue" is defined in section 1 of the Act as "human tissue and includes flesh, bone, a gland, an organ, skin, bone marrow or body fluid, but excludes blood or a gamete."

practitioner may remove any tissue from a living person including tissue to be transplanted into another living person. Only those older than 18 years of age may consent to the removal and or donation tissue that is non-replaceable by natural processes. This provision does not apply to blood that is quickly replaced thereby allowing children above the age of 16 to donate blood without the permission of a parent or legal guardian.

Further examination of chapter eight of the National Health Act, where the control of the use of blood, blood products, tissue and gametes in humans is covered, is warranted.

Section 62 (1) (a) of the Act provides that a person who is competent to make a will may-

(i) in the will;

(ii) in a document signed by him or her and at least two competent witnesses; or

(iii) in an oral statement made in the presence of at least two competent witnesses, donate his or her body or any specified tissue thereof to be used after his or her death, or give consent to the post mortem examination of his or her body, for any purposes provided for in this Act.

(b) A person who makes a donation as contemplated in paragraph (a) must nominate an institution or a person contemplated in section 63 as donee.

(c) If no donee is nominated in terms of paragraph 9(b), the donation is null and void.

(2) In the absence of a donation under subsection (1)(a) or of a contrary direction given by a person whilst alive, the spouse, partner, major child, parent, guardian, major brother

or major sister of that person in the specific order mentioned, may, after that person's death, donate the body or any specific tissue of that person to an institution or a person contemplated in section 63.

(3)(a) The Director-General may, after the death of a person and if none of the persons contemplated in subsections (2) be located, donate any specific tissue of that person to an institution or a person contemplated in section 63.

(b) The Director-General may only donate the specific tissue if all the prescribed steps have been taken to locate the persons contemplated in subsection (2).

The Act is clear regarding reimbursement for human tissue, blood, blood products and gametes. It is an offence to for a person who had donated human tissue, blood, a blood product or a gamete to receive any form of financial or other reward for such a donation, except if he or she is reimbursed to cover reasonable costs incurred in the provision of such donation.[18] The Act also prohibits the selling or trading in human tissue, gametes, blood and blood products.[19]

When comparing the Human Tissue Act, currently in force, and the National Health Act with respect to the donation of organs in South Africa it is appears that there have been very few material changes to the laws governing consent to donation. There are no clauses in chapter eight of the current National Health Act that would facilitate the change from an explicit opt in approach to organ donation to that of a well considered opt

[18] S 60(4)(a) of The National Health Act
[19] S 60(4)(b) of The National Health Act

out policy. Should an opt out policy for organ donation be desired by the South African nation, enabling legislative changes will need to be made to allow for this.

At the time of writing the Human Tissue Act is still in force. The draft regulations regarding the general control of human bodies, tissue and organs for transplantation were circulated for comments in the first quarter of 2008[20]. Comments have been received by the Department of Health. Enactment of the regulations is anticipated to occur in the near future.

However the current system is impractical and cumbersome in a third world society as relatives are frequently difficult to locate and may be impossible to contact in the more rural areas. This is in complete contrast to the experience of the developed world where members of the medical staff often develop a relationship with the relatives of patients while they are being cared for in the intensive care unit. In the latter setting the provisions of the Act regarding contacting the patient's family, may be easier to fulfill.

7. Synthesis and Conclusion.

In this, the final chapter the main threads of both the ethical and legal arguments are drawn together. Consideration is given to certain issues unique to the South African situation. Recommendations for a possible way forward are made and a conclusion as to the suitability of the opt out method of organ donation for South Africa is drawn.

7.1 Presumed Consent in South Africa

In the South African context where there is a co-existence of cultures in a pluralistic society (Ross 2008:384), it may be more relevant to argue for the promotion of a communitarian approach to organ donation where personal appeals to individuals have failed. This communitarian approach could shift the moral culture towards encouraging citizens within a nation to feel that it is their social responsibility to become organ donors argues Amitai Etzioni (2003:5). This approach may be more acceptable to many South African citizens due to an established moral culture of assisting your neighbour and members of the wider community.

This moral culture is captured in an African proverb *umuntu ngumuntu ngabantu*[21] and embraces the concept of social solidarity. The concept of self in African societies is seen to be 'relational' and therefore differs from the Western perception of autonomy. In the African culture selfhood is not an individualistic view with independent decision making but requires ongoing participation in the community with full awareness of one's responsibilities and obligations to that community (Mkhize 2006: 28). Because of this fundamental difference in the application of the concept of autonomy attempts to implement first person consent have met with problems, particularly in rural communities with a dominantly communitarian conception of self (Kuczewski and McCruden 2001: 35). Mkhize (2006: 28) suggests that in such cultural communities informed consent is a

[20] National Health Act Act 61 2003, Government Gazette, 7 March 2008.
[21] Roughly translated this means, a human being becomes a human being through participation in a community of other human selves.

semiotic[22] process where various stakeholders negotiate the processes and procedures necessary to obtain such consent.

It is likely that there will be those who will argue that further time, effort and money ought not to be spent on developing systems to ensure the procurement of additional organs for transplant when there are more pressing health care challenges in South Africa. Benatar (2004:291) argues that the current organ donation debate around various proposed methods to increase the number of available organs is myopic and individualistic and fails to consider the many people who are dying due to lack of access to the most basic health care. Benatar argues this way because costs associated with organ donation can seem prohibitively high when faced with so many other health care needs and with limited resources particularly in a developing country setting. Clearly the cost-effectiveness[23] of organ transplantation would need to be evaluated and assessed against all other competing interests in the same way that all other expensive treatments are evaluated and rationed.

In the case of renal transplants it has been shown in several studies that a renal transplant is significantly more cost-effective than long-term peritoneal dialysis or haemodialysis (Laupacis 1996: 235; Kaminoto 2001:100). The National Institute for Clinical Excellence in the United Kingdom has estimated that the average annual cost of treating a patient on haemodialysis at a satellite renal unit is £21 000 (NICE 2002:24). Transplantation costs

[22] Semiotic is used here in the sense of 'meaning making' process

are approximately the same as haemodialysis costs in the first year, which includes surgery, the costs of the immunosuppressant drugs, regular consultations and treatment. However the cost of a treating a transplant recipient reduces in the subsequent years, making transplantation the most clinically and cost effective form of treatment for chronic renal failure (Winkelmayer et al. 2002:423). These costs do not take into account the considerable benefit patients experience from a significantly improved quality of life.

It is evident that even in the case where more organs are available for transplant in South Africa rationing of organ transplantation will take place. National guidelines have been developed detailing who is eligible for organ transplantation. These guidelines are based on maximizing aggregate benefit and quality of life thereby assisting in micro allocation decisions between patients (Lockwood 2006: 454). The case of Soobramoney[24] raised the awareness of the public to the issue of rationing of resources for renal dialysis and to eligibility criteria for renal transplant. This may have been an ideal time to launch a major educational campaign to encourage members of the public to consider organ donation.

Chapter 8 of the National Health Act 61 of 2003[25] that is yet to be enacted, includes regulations regarding the allocation of organs and states that organs should be allocated purely on the clinical needs of the intended recipient and may not take into account race, religious beliefs, political affiliation, culture, language or any other aspect of the

[23] Cost-effectiveness analysis is a method of comparing alternative treatments in which the costs and consequences of the treatments vary. The outcomes of the alternative treatments are measured in the same non-monetary unit e.g. life years gained in order to facilitate accurate comparison.
[24] Soobramoney v Min of Health, Kwazulu Natal 1998
[25] Government Gazette, 7 March 2008.

deceased person's life that has no bearing on the physical state or quality of the tissue in question. Thus the allocation of organs should be fair, transparent and morally defensible as defined clinical parameters are used to establish a hierarchy of need amongst those on the transplant list.

A survey of attitudes of South African citizens was undertaken between December 1987 and November 1990 and included eight hundred and twenty six urban blacks, one thousand two hundred and ninety nine urban whites and six hundred and twenty five rural blacks. The questions were added to existing market research questionnaires and the samples were therefore dependant on the particular product being researched. The results of the survey are positive with eighty nine percent of whites, eighty four percent of rural blacks and seventy six percent of urban blacks prepared to donate their organs. All groups are slightly less willing to donate the organs of relatives due to the belief that the decision should have been made by the person before death (Pike, Odell and Khan 1993:91).

It is important to bear in mind society's interest in organ donations and in having an effective health care system that cares for all South Africans. The probability exists that in many cases organ transplants will enable members of society to become more functional individuals, with both a positive capacity to contribute to South African society, and who will no longer be a drain on the extremely limited resources available to public health care. The South African constitution grants individuals many rights, and

imposes burdens on the state to realize many of these rights. While individuals may contribute to society in many ways organ donation is an extremely democratic contribution, requiring no special skills, and this affirms the membership even of the marginalized in South African society.

This view is shared by Glannon (2003: 153) who emphasises that donation is a form of returning something to a community from which one has benefited over the course of one's life. In this situation one could be perceived as having an obligation to society as opposed to making a gift of one's organs from an altruistic motive. The sense of obligation to bequeath one's organs for donation is generated from the belief that one share's common interests, needs and values with other individuals in a community. This is a morally preferable model to a rights-based model that would coercively transfer organs from the deceased without their previous consent.

7.2 Recommendations

1) Effective public education campaigns.

Notwithstanding the apparent willingness of the public to donate organs as indicated by the results in the study by Pike, Odell and Khan, there remains a dire need for effective public education campaigns. These will increase public awareness regarding the urgent need for organs and should be used to dispel any myths or misunderstandings regarding organ donation. Further education needs to occur about age of donors and the types of

tissues that can be used other than solid organs for example sclera and bone. All the literature and media needs to be persuasive and overtly pro-donation with the legitimate intention of inclining in favour of donation all but those with the strongest objections (Chouhan and Draper 2003:161).

Religious leaders should be included in the education campaigns as they are in a powerful position to convey the theologically based support of organ donation while dispelling inaccurate religious assumptions (Rumsey et al 2003: 2849). Some churches in the USA have started to specifically educate members about the need for organs and are dispelling myths surrounding organ donation (Sodeke 2004: 48). Community leaders should be willing to show their commitment publicly and to reinforce the idea that it is not just a matter of giving organs but that they are giving them back to the community they owe something for the common good (Glannon 2003:153)

2) Further research.

Undoubtedly further current research regarding attitudes to human organ donation in South Africa amongst all ethnic and religious groups is required. This research should seek to clarify general beliefs about organ donation and more specifically it should aim to determine attitudes towards an opt out approach for organ donation.

This research should also ask specific questions regarding the suitability of different methods of establishing whether members of society wish to opt out as it is important to

minimize the burden of exercising one's right to opt out (Robertson 2004: 47). Facilitating the process of opting out may be an important consideration in increasing the likelihood of the acceptability of the concept and to prevent the possibility of some members of society being marginalized.

3) Changes in legislation.

Should the research, alluded to above, show positive results regarding attitudes to organ donation in general and to the concept of presumed consent more specifically, then enabling legislation for the opt out approach will be a necessity. The legislation will be required to stipulate that a register must be created and continuously updated to reflect all those citizens of South Africa that have made an express wish not to donate their organs upon their demise. In addition this register will need to be available to all hospitals in order to facilitate the immediate harvesting of the vital organs.

It might be prudent for South Africa to enact weak presumed consent legislation, at least initially, to ensure that the illiterate and marginalized are not at a disadvantage. Weak presumed consent laws do not require that consent is obtained from a relative but should an objection be raised by a close relative this is upheld. Both Norway and Tunisia have weak presumed consent systems (Blackbeard 2003: 55). Introducing a weak presumed consent system may provide some reassurance to those who are concerned that there is a risk that organs may be removed against the deceased's wishes.

4) Consultation with the Physician Associations.

In the United Kingdom and the United States of America the medical associations have had ongoing discussions over many decades, regarding the type of organ donation system that they believe balances ethical behaviour while increasing the number of organs available for transplantation. In the year 2000, the British Medical Association recommended that Great Britain moved to a soft presumed consent policy (British Medical Association Medical Ethics Committee 2000). The government in the United Kingdom is seriously considering this proposal.

The Brazilian experience reinforces the need to ensure that the medical practitioners of a particular country are in agreement with the proposed method of consent for organ donation as the responsibility of organ harvesting and transplantation ultimately rests with the clinicians. The introduction of presumed consent is said to have failed in Brazil for several reasons. One of the main reasons is that Brazilian doctors were unwilling to remove organs from the deceased without the consent of the family, despite what the new Brazilian law proclaimed (Lancet 1998: 1367). It is therefore imperative that there is meaningful engagement and debate with all relevant parties before considering the introduction of an opt out approach in South Africa. The South African Medical Association (SAMA) would need to be consulted and all other relevant physician societies including adult and paediatric nephrologists and the society of transplant surgeons.

7.3 Conclusion

The major ethical and legal arguments, discussed earlier in the text, are summarized here revealing the undeniable similarities in reasoning found in the disciplines of ethics and law. These common threads lead one to a robust conclusion providing evidence that the concept of presumed consent deserves greater consideration in the quest for the right to health in South Africa.

A survey of public attitudes to organ donation in South Africa has been conducted by Pike, Odell and Khan (1993:94). The results of this survey are very encouraging as they indicated that the majority of South Africans are willing to donate their own organs (82%) and those of their relatives (78%). The opinions of South African citizens regarding an opt out approach has not been assessed as yet. In view of the high percentages in favour of donating their organs an opt out approach appears to be the most efficient means to increase the number of organs available for transplantation in this country. Evidently this method has yielded encouraging results in those countries where it has been legislated and there is no reason to suspect that similar positive effects could not be experienced in South Africa.

Having discussed the concept of the opt out system of organ donation with family, friends and work colleagues the majority agreed that this sounds like a very reasonable approach. This may be because many of them acknowledged that they would be willing

to donate their organs for transplantation but have failed to make their wishes known to their families and do not carry an organ donor card. The system of presumed consent would ensure that the unexpressed wishes of many members of society are fulfilled and that precious life- giving organs are not squandered.

It is apparent that there are two main areas of ethical discussion that arise in the context of presumed consent for human organ donation, namely the autonomy centred view and the beneficence centred view (Savalescu 2003:128). Autonomy refers to being able to choose freely in order to control our lives and encompasses giving consent for procedures to be carried out on one's body. Once one has ceased living one loses human choice, will and life and therefore, it can be argued one lacks any ability to exert individual autonomy. Although autonomy is one of the major principles of bioethics it can be overridden by competing moral considerations (Beauchamp and Childress 1994: 126).

One might agree with Chadwick and Schuklenk (1998:396) who state that "perhaps we should realize the weakness of the interest in controlling our own dead bodies and move toward an opting out scheme."

The principles relevant to the beneficence centred view are the 'benefit to others' and the 'harm' principle. The latter principle states that there may be situations where it is morally justifiable for a government to interfere with a citizen's behaviour in order to protect other citizens. The 'benefit to others' principle holds that it is morally legitimate to restrict an individual's liberty or autonomy to produce some benefit for other persons.

The two principles mentioned above support the opt out approach to organ donation, both by preventing substantial harm to those awaiting organs and by fulfilling the requirement of providing benefit to others. The case for limiting liberty can be strengthened if the benefit to others can be achieved with very little effort by the individual and is called the duty of easy rescue (Savalescu 2003: 129). Presumed consent fulfills both conditions of easy rescue, as firstly the act of donation makes a great difference to another and secondly the act does not incur great risks for the donor. Thus the motivation for restricting a deceased individual's liberty is that of the duty of easy rescue which is a rather weak expression of beneficence.

All South African citizens should be encouraged to explicitly choose to maximize the recovery of organs due to the ethical principal of beneficence even if it does bring about a restriction in an individual's liberty for the greater good of society. When asked to sign an organ donor card one is confronted with both the need and the opportunity and this provides each one of us with a *pro tanto* duty to be organ givers (Nelson 2004:29).

As a society we need to prioritize what is most important to us particularly where there are competing goals and it is clear that we cannot have everything that we wish to (Spital 2003: 170). Thus far in South Africa we have chosen to respect individual and family autonomy and have been unable to realize a reasonable supply of organs for transplantation. Perhaps it is time for our individualistic society to reflect on the meaning of reciprocity, justice and inter-dependance and to agree with Rackoff who says "… like

it or not, we all live embedded in the larger community" (Jacoby 2004: 16; Rackoff 2002: 10).

In the case for presumed consent the principal that the good of society takes precedence over the individual's interests is explicit. However the opt out approach does allow those members of society who do not wish to donate their organs to make a declaration stating this and thereby allowing citizens to retain a degree of autonomy. The limitations imposed by the opt out approach should therefore not be seen as too onerous.

Examination of the South African Constitution revealed that even in the case of human rights, particularly socio-economic rights, it has been necessary to introduce limitations to such rights. It is notable that these limitations have been imposed for analogous reasons to those that have been argued for in the ethical debate about the opt out approach to organ donation.

Limitations on rights are required in situations where there are a finite number of resources and a large pool of possible beneficiaries. In these circumstances an individual's rights are weighed up against those of greater society. The case of *Soobramoney v Minister of Health* exemplifies this principle. However in the TAC case for the prevention of HIV transmission from mother to child, the decision of the court was in favour of greater society. In this case it was the large number of newborns who could have access to a cost-effective intervention that would prevent them acquiring HIV

and ultimately provide the newborn children with the realization of a right to health care and the right to life.

I have argued that in terms of Section 11 of the Constitution of the Republic of South Africa, the right to life imposes a positive duty on the state to ensure that the laws regulating organ donation are those that would promote greater availability of human organs for transplantation. In the interpretation of Section 12 of the Constitution, I contend that the intention of this right includes only the living and therefore precludes the need for formal written consent for the removal of organs from the deceased's body. It would therefore be possible to introduce presumed consent in South Africa without infringing on this right.

The balance certainly appears to sway towards the right to life, in Section 11, and away from any possible dubious posthumous rights to bodily control that one might attempt to ascribe to from Section 12. The responsibility of the state to promote and fulfil the right to life therefore includes enacting enabling legislation to maximise the number of organs available for transplantation. The opt out approach would be an appropriate and efficient means of achieving this.

In conclusion a sensitive, secure and robust opt out system could be introduced. This should be preceded by a reasonable period of education, notice and publicity to facilitate understanding by the public and allow objections to be registered by those who are opposed to the system. A change in the law to an opt out system would achieve the dual

effect of increasing the supply of organs and at the same time lessening the distress of relatives who are usually left to make this complex decision (Kennedy et al 1998:1651).

Radical action is needed if politicians and society want to reduce the organ shortfall experienced both here and abroad. Strategies to amend and improve the current opt in system will not suffice. In the interim perhaps South Africa can learn from the Spanish model where transplant coordinators are charged not merely with gaining consent from relatives for organ donation. Rather they are explicitly required to attempt to persuade relatives to donate by stressing the generosity of the gift, the life altering benefits to the recipients and the importance of social solidarity (Chouhan and Draper 2003: 161).

Encouraging people to donate their organs to fellow members of humankind while allowing them to opt out of doing so maintains respect for individual autonomy. Furthermore this approach can engender and maintain trust among the public for the medical profession and all involved in the procurement and transplantation of these vital organs (Glannon 2003:156).

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