

Autonomy in organ donations v family consent: a South African legislative context

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SUMMARY

The lack of availability of transplantable donor organs remains the main obstacle to improving organ donation rates on a global level. The purpose of this article is to investigate the role of family consent in the donation process from a legal perspective. The question is posed whether family members should be approached to provide consent for deceased organ donation or whether the right to self-determination of the deceased should be honoured. The article analyses Chapter 8 of the National Health Act 61 of 2003 to determine the current legal position with regard to consent in the organ donation process. It is concluded that due to the continued stagnant state of the availability of donor organs in South Africa, at the very least appropriate, valid consent should not be nullified by a relative's objection.

1 Introduction

Due to the continued stagnant state of the availability of donor organs in South Africa, we are of opinion that at the very least appropriate, valid consent should not be nullified by a relative's objection. There is a desperate need for transplantable organs worldwide.¹ In South Africa, approximately 4300 people are waiting for an organ transplant.² In 2017³ only 371 solid organ transplantations were performed in the public and private sector.⁴ South Africa follows an "opt-in" procurement system meaning people must give consent for a donation before organs will be procured.⁵ This can be viewed as a scheme of "giving" as it is based on the idea that your right to self-determination implies the right

1 World Health Organization <https://www.who.int/bulletin/volumes/85/12/06-039370/en/> (accessed 2019-08-08).

2 Due to the fact that there is no national waiting list or national organ procurement organisation, the statistics with regard to organ donation in South Africa is not reliable.

3 The statistics for 2018 are not available as yet.

4 Statistics supplied by the South African Transplant Society. The Society educates healthcare professionals, public and patients on organ transplantation.

5 For a definition on "opt-in" see Delgado, Molina-Pérez, Shaw and Rodríguez-Arias "The role of the family in deceased organ procurement: a guide for clinicians and policymakers" 2019 *Transplantation* 113.

to make decisions about what happens to your body (even after death).⁶ Other countries like France and Belgium follows a system of “opt-out”. This means that every citizen is an organ donor unless he or she has registered an objection to a donate after death.⁷ Not opting out is considered presumed consent and can be labelled ‘taking’ as opposed to “giving”.⁸ The question is usually asked whether presumed consent automatically leads to more organs being available for transplantation. This is a presumption rather than based on scientific evidence.⁹ Recently, Wales, for example, have legalised presumed consent but this has not led to an increase in deceased organ donation.¹⁰ The question can be posed if presumed consent does not improve numbers what could then be done? The Norwegian Association for Organ Donation recommends the following:

“Spain,¹¹ is the leading country in organ donation. They have an opt-out system but in reality, it is the conversation with the relatives that counts – just as in Norway. If you look at Spain, it is clear that the opt-out system has little to say and the keys to their results are organization, sufficient resources and educated health staff at the hospitals.”¹²

It thus seems that legislation cannot by itself improve donor rates. Practices regarding family communication should be the focus to find a solution for the organ shortage. This is a hot debate as family members need to be approached in a time of grief. The question asked by Jensen and Larsen becomes applicable: “Is it desirable to image doctors and nurses wheeling a deceased patient to the operating theatre for organ procurement without asking the family – or worse, against the wishes of the family – families they have spent the last days and hours supporting and comforting?”¹³ It is the focus of this article to investigate the role of family consent in the donation process from a legal perspective. Should family members be asked for their consent for an organ donation after a loved one has died; or should the wishes of the deceased be honoured, and the family only asked to authorise a donation. Before the questions

6 Den Hartogh “Respect for autonomy in systems of postmortem organ procurement: a comment” 2019 *Bioethics* 550.

7 For a definition on “opt-out” see Delgado, Molina-Pérez, Shaw and Rodríguez-Arias 2019 *Transplantation* 113. See also Csillag “Brazil abolishes “presumed consent” in organ donation” 1998 *Lancet* 1367.

8 Jensen and Larsen “The public debate on organ donation and presumed consent in Denmark: Are the right issues being addressed?” 2019 *Scandinavian Journal of Public Health (Scand J Public Health)* 2.

9 See Jensen and Larsen 2019 *Scand J Public Health* 2.

10 Parsons “Welsh 2013 deemed consent legislation falls short of expectations” 2018 *Health Policy* 941; Albertsen “Deemed consent: assessing the new opt-out approach to organ procurement in Wales” 2018 *Journal of Medical Ethics (J Med Ethics)* 314.

11 See Matesanz and Miranda “A decade of continuous improvement in cadaveric organ donation: the Spanish model” 2002 *Journal of Nephrology (J Nephrol)* 22-28; Rodríguez-Arias, Wright and Paredes “Success factors and ethical challenges of the Spanish Model of organ donation” 2010 *Lancet* 1109-1112.

12 Jensen and Larsen 2019 *Scand J Public Health* 4.

13 Jensen and Larsen 2019 *Scand J Public Health* 5.

can be answered it is necessary to analyse legislation regarding organ donation and transplantation in South Africa.

2 The National Health Act 61 of 2003

South Africa does not have a specific piece of legislation dealing with solid organ donation and transplantation.¹⁴ The legislative requirements for valid donations and transplantation are covered in Chapter 8 of the National Health Act 61 of 2003 (NHA). The relevant section in the Act concerning the donation of organs is section 62, entitled “Donation of human bodies and tissue of deceased persons”. The title addresses “tissue” but according to the definitions in the Act, tissue includes an organ.

“Section 62 states the following:

62(1)(a) 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 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 purpose provided for in this Act.

(b) ...

(c) ...

(d) ...

- (2) In the absence (own emphasis) 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 ...”

The section thus determines that an adult person of sound mind can decide while still alive whether he or she wants to be an organ donor after death. According to testamentary law, a competent person of 16 years of age can draw up a legally valid will.¹⁵ The problem with donating your organs in a will or final testament is that after death the will or testament

14 Countries like Canada, India, New Zealand, Singapore, United Kingdom and the United States have separate pieces of legislation regulating organ donation. Previously, South Africa had a separate Act concerning organ and tissue donation and transplantation, the Human Tissue Act 65 of 1983. This Act was repealed in total in 2012 when the Regulations to Chapter 8 of the NHA was promulgated. Currently organ donation and transplantation are only addressed in Chapter 8 of the NHA and the regulations in terms of the Act.

15 This section poses a further discrepancy with the Children’s Act 38 of 2005 which states in section 129 that a child over the age of 12 with sufficient maturity is allowed to consent to surgical operations if duly assisted by his or her parent or guardian.

must be validated by the Master of the High Court. This process takes days and seems futile as time is of the essence in organ transplantations. The second requirement, that you as a living person can donate your organs after death by stating your wish in a document signed in the presence of two competent witnesses (14 years or older), seems the best solution and will be elaborated on below, before that is done, the third possible way of donating an organ should be addressed. The Act states that you can donate your organs by way of an oral statement but in front of witnesses. This could be very controversial as who will attest to that and how would it be proved. This requirement thus also seems futile. The only stipulation in the Act worth exploring is thus the second one of a written statement.

This statement should be distinguished from a living will. A living will have no legal status in South African law¹⁶ but because the NHA specifically states that a donation may be made in a document signed by the donor and two competent witnesses, the Act creates a legally valid document. Unfortunately, this requirement is ignored by organisations involved with donor awareness. The Organ Donor Foundation (ODF) for example, requires registration as a donor. This can be done online or manually by filling in a form. There is no space for two signatures of witnesses and therefore it does not comply with the legal requirement. The registration process with the ODF is merely for statistical purposes. This is unfortunate, because if the ODF made it compulsory for donor registration to have the signatures of two competent witness, with the signature of the donor, it would have been a legally valid document and a valid reflection of the donor's wishes. Because this does not happen the registration as an organ donor practically serves no purpose other than indicating to the family that the deceased wanted to be a donor.

The sticker on a driver's license is also just an indication of the deceased wishes but not legally binding. The same goes for the donor card distributed by the ODF to be kept in a purse. The general practice in hospitals in South Africa is thus that the default position is followed in all instances of a possible organ donation. The family of the deceased is approached for consent to remove organs from the deceased body. Although the Act specifically states that "in the absence of ..." an indication that the person wanted to be an organ donor, all indications are ignored, and the family must consent. This general practice in hospitals has proven unsuccessful as there are never enough donations to supply in the demand. Family members who are grieving about the death of their loved one, most of the time do not want to consent to organ donations for various reasons that will be discussed below. If the deceased had indicated he or she wanted to be a donor after death, it makes the decision of the family easier, although many families still refuse, based on their views about organ donations. It is our belief that if the law is followed, meaning the deceased drew up a document while still

16 Skeen "Living Wills and Advance Directives in South African Law" *Medicine and Law* 2004 937-43. See *Clarke v Hurst NO* 1992 (4) SA 630 (D).

alive and signed it with two competent witnesses, it should be enough proof of his or her wishes as it is stipulated in an Act. Therefore, the hospital staff should respect the wish and act accordingly by removing viable organs for transplantation purposes.¹⁷ The family should not be ignored, but their authorisation is all that will be required, not their consent.

The ideal situation could be that an organisation is established to distribute donor documents which should then be signed by the donor and two competent witnesses. This document should be filed as a legally valid document. The personal information of the donor, for example, his or her identification number should then be electronically recorded on an application for a smartphone. If the person should then die in a manner that his or her organs could be used for transplantation, the medical staff in the intensive care unit should utilise the application, using the deceased identification number to verify whether he or she was a valid organ donor according to the Act.¹⁸ If it is the case, the hospital should respect his or her wishes and take the organs to be used for transplantation. The family of the deceased could be informed of the process and their authorisation towards the donation could be recorded, but they will not be expected or required to give consent. Should there be a scenario where the family members are unhappy about the process, the hospital staff should explain to them the validity of the donation according to the stipulations in the NHA.¹⁹ If the family should still institute legal action,²⁰ it should be clear that a court of law will determine whether there is in fact a legally signed document in existence and if that is the case, then the family will have no cause for action. In any event, more good follows from a process of organ retrieval and 8 lives could be saved than overruling the donor's wish by the preconceived views of the family.

17 This is also underscored by the Regulations Regarding the General Control of Human Bodies, Tissue, Blood, Blood Products and Gametes R380 in GG 35099 issued in terms of the National Health Act 61 of 2003 dated 2 March 2012, s 14(3) "If a person who have died has in her or his will or in a document donated tissue of her or his body, a medical practitioner may act upon that will or document if on the face of it appears to be legally valid."

18 Currently, neither transplant coordinators nor transplant centres have access to the registered organ donors database.

19 The NHA and the regulations in terms of the Act have been discussed, unfortunately there is no case law in South Africa on the topic of family consent in organ donations.

20 May, Aulisio and DeVita "Patients, families and organ donation: Who should decide?" 2000 *The Milbank Quarterly (Milbank Q)* 333 the authors refer to the anecdotal statements of organ-procurement coordinators: "dead patients don't sue, but live families do." In fact, "fear of being sued" was cited as among the common reasons for ignoring a valid donor card and, instead, seeking consent from family.

3 Personal autonomy v family consent

The Constitution of the Republic of South Africa, 1996 guarantees the right to self-determination.²¹ This right translates in the right to personal autonomy. It is more in line with respect for autonomy to adhere to the wishes of the deceased than to ask relatives at the time of death.²² Giving the relatives decision power with regards to the removal of organs from a deceased body will have to be weighed against possible violations of the respect for the deceased's autonomy²³ to determine a better way forward. According to us, respect for personal autonomy is the only moral consideration worth fighting for in the organ shortage debate.

Rosenblum *et al.*²⁴ states that the involvement of the family in deceased organ procurement worldwide is unclear. They investigated 54 nations that either has an opt-in or opt-out procurement system,²⁵ concerning the involvement of family members in the organ donation process. They found that the family of the deceased in the organ procurement process were involved with the decision making in most nations, regardless of the consent principle and whether the deceased has expressed a wish to donate or not – “[t]he next-of-kin have a considerable influence on the organ procurement process in both presumed and explicit consent nations”.²⁶ After a death the relatives when approached for organ donation can do the following: (a) they can inform the hospital staff that they are aware of the deceased's wishes and would like them to act accordingly, or (b) the relatives can indicate they have no idea what the wishes of the deceased was, and therefore they would rather not donate,²⁷ or (c) they can indicate they know the wishes of the deceased but would like to *veto* or overrule it²⁸ because of their own preferences or (d) they can consent to a donation even though they do not know the express will of the deceased.²⁹

21 S 12 of the Constitution of the Republic of South Africa, 1996.

22 Den Hartogh 2019 *Bioethics* 553.

23 Den Hartogh 2019 *Bioethics* 554.

24 Rosenblum *et al.*, “The authority of next-of-kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations” 2012 *Nephrology Dialysis Transplantation (Nephrol Dial Transplant)* 2533-2546.

25 Rosenblum *et al.*, 2012 *Nephrol Dial Transplant* 2533.

26 Rosenblum *et al.*, 2012 *Nephrol Dial Transplant* 2533.

27 See Sque *et al.*, “Bereaved donor families’ experiences of organ and tissue donation, and perceived influencers on their decision-making” 2018 *Journal of Critical Care (J Crit Care)* 82-89.

28 See Shaw *et al.*, “Family over rules? An ethical analysis of allowing families to overrule donation intentions” 2017 *Transplantation* 482-487; Cay “Contemporary issues in law and ethics: Exploring the family veto for organ donation” 2019 *Journal of Perioperative Practice* 1-7.

29 For a more in-depth discussion of the possible roles of the family in organ donation see Delgado, Molina-Pérez, Shaw and Rodriguez-Arias 2019 *Transplantation* 114-115.

Shaw *et al.*³⁰ list six arguments in favour of the right of family members to overrule a donor's wish: it reduces families' distress; it minimises stress for healthcare staff; a donation cannot proceed without information being provided by the family; families might have new information about a patient's refusal to donate; going against the wishes of the family may weaken trust in the donation process and by adhering to the wishes of the donor too much emphasis is placed on individualism.³¹ They have only five arguments against family overrule: firstly, it violates the wishes of the deceased; it takes away the burden of decision making from families; it guards against a regret for overruling a deceased's wishes; it helps patients waiting for an organ and it is more in line with laws guiding donations in nearly all jurisdictions that make it clear that the patient's wishes should be respected.³²

May *et al.*³³ states there is a significant discrepancy between an individual willing to donate and their family's willingness to give consent after his or her death. They refer to a study by the United Network for Organ Sharing (UNOS) in the United States of America that found that 35 of 36 organ procurement organisations (OPO's) they studied, will never recover organs or tissue from a patient with a signed donor card against family wishes.³⁴ They also refer to the Centre for Organ Recovery and Education (CORE) an OPO operating in the regions of New York, Pennsylvania³⁵ and West Virginia that adopted a 'controversial' policy of acting on the documented wishes of individuals to donate, independent of family consent. Families are informed of the organ procurement process instead of asking their consent for it. "CORE has discovered that families rarely oppose donation when they are *informed* about it, rather than when they are asked to consent".³⁶ We agree with the authors that the practice adopted by CORE is justified and morally required.

When someone has died, there is immense grief and sometimes even unresolved issues. It is a fact that the family remaining behind is suffering and sensitivity to their grief is a profoundly and important part of ethical and humane healthcare practices. However, it must be balanced against the respect for the rights of patients.³⁷ The deceased wish should therefore be established and if he or she wanted to be an organ donor it should be respected. An advance directive is a form of guidance for the family but if the deceased executed his or her will to be an organ donor in the way and according to the NHA³⁸ as discussed above, it should take

30 Shaw *et al.*, 2017 *Transplantation* 482-487.

31 Shaw *et al.*, 2017 *Transplantation* 484.

32 Shaw *et al.*, 2017 *Transplantation* 485-486.

33 May, Aulisio and DeVita 2000 *Milbank Q* 323-336.

34 May, Aulisio and DeVita 2000 *Milbank Q* 323.

35 Pennsylvania Act 102 (1994) explicitly upholds the validity of a properly executed donor card, Pennsylvania driver's licence, or living will indicating a wish to donate.

36 May, Aulisio and DeVita 2000 *Milbank Q* 324.

37 May, Aulisio and DeVita 2000 *Milbank Q* 326.

38 S 62(1)(a)(ii) of the National Health Act 61 of 2003.

precedence over family wishes. Such a directive should be both definitive and directly applicable.

“The assumed conditional clause (“If I am dead...”) in a directive for organ donation is not uncertain. The medical state of the donor is death: he or she is not ‘probably’ dead or ‘likely to be’ dead. Therefore, subsequent instruction must be applied unless it is illegal, impossible or unethical. Similarly, the directive (“I consent to organ donation”) is not ambiguous and requires no interpretation about intent or meaning. Because there is no uncertainty about intent, diagnosis, or instruction in the scenario of organ donation from a dead potential donor, it is a more powerful document than an advance directive.”³⁹

This argument by May et al, makes perfectly sense and underlines personal autonomy as every individual should have the right to decide for him or herself what should happen with his or her body after death. This is whole point of drawing up a document and signing it in the presence of two competent witnesses. An adult person of sound mind should be viewed as being a master of his or her own body and be able to take a decision what should happen with it after death. The whole idea also of a written signed document, is to take the pressure off family members to decide during an uncomfortable time. The decision has been made while the deceased were still living, all that is required of the family members and the hospital staff is to respect the wishes indicated in a document.

A survey among healthcare professionals in 1996 found that 98 percent of respondents believed that a conflict between a deceased’s wishes to be a donor and family refusal should be resolved by accepting the deceased’s directive.⁴⁰ It is also a stress reliever for them should there be such a legally valid document indicating the deceased’s wish.

A current problem with advanced directives which could be cancelled out if a document is specific and signed by the donor and witnesses is the vagueness of consent. Shaw⁴¹ in an article addressing the vagueness of consent to organ donation states that a sticker on a driver’s licence, a donor card, or even a tattoo or wrist band indicating the person is a donor is too vague to be legally binding. He states that under normal circumstances if a person must consent to a medical intervention three criteria must be met. The patient must be adequately informed about the treatment and potential benefits and risks or side-effects of the treatment, as well as the consequences of not receiving the treatment. Secondly, the patient must have the mental capacity to decide and thirdly, the patient must be free from coercion. But, registering as a donor is very simple, with no checks on whether any of these criteria are met.⁴² The patient will be dead and thus permission must be given for

39 May, Aulisio and DeVita 2000 *Milbank Q* 327.

40 Spielman and Verhulst “Discussing organ donations with patients” 1996 *Journal of Family Medicine (J Family Med)* 698-701.

41 Shaw “The consequences of vagueness in consent to organ donation” 2017 *Bioethics* 424-431.

42 Shaw 2017 *Bioethics* 425.

something that will happen after death. It is our submission that if the NHA⁴³ is followed the document that the donor should sign could be drawn up in such a way that he or she can indicate there is no coercion, that he or she is an adult of sound mind and that he or she understand what organ and tissue donations entails. The fact that the person consenting signs the document in front of two competent witnesses attesting to the fact that the donor is of sound mind and filled in the form him or herself should counter the argument of Shaw and exclude vagueness. Shaw, and we agree with his sentiments, concludes his arguments for less vagueness in the consent process by saying that the creation of a new consent system may discourage some people from donating, but it would increase the chances that the wishes of someone who does want to donate will be respected. This could substantially increase health professionals' and families' confidence in the consent of donors and also reduce the distress caused to both families and healthcare staff.⁴⁴

South Africa could learn from the Human Tissue Authority (HTA) defined in the Human Tissue Act 2004 of the United Kingdom (UK). The UK has a separate piece of legislation for human tissue, whereas South Africa only have a chapter in the NHA addressing organ donations and transplantation.⁴⁵ The HTA has a Code of Practice for donation of solid organs and tissue for transplantation.⁴⁶ This Code addresses living and deceased donations. Section 117 states concerning deceased donors that “[t]here is no legal right for anyone in a qualifying relationship to revoke a legally valid decision to give or withhold consent.” In section 120 it is stated; “[a] relative’s objection does not nullify appropriate, valid consent from the prospective donor.” The Code gives the following example:

“A prospective donor has given valid consent to the donation of her organs for transplantation. Her son does not want the donation to proceed because he does not want organ retrieval to take place during a traumatic time for the wider family. The donor’s consent is still valid, and retrieval should proceed. The son should be sensitively encouraged to support his mother’s wishes.”⁴⁷

Section 121 states that the appropriate, valid consent permits an activity to proceed, but does not mandate that it must. The final decision about whether to proceed with the activity rests with the medical practitioner.

43 S 62(1)(a)(ii) of the National Health Act 61 of 2003.

44 Shaw 2017 *Bioethics* 31(6): 431.

45 See Slabbert “The law as an obstacle in solid organ donations and transplantations” 2018 THRHR 70-84.

46 HTA (F) Donation of solid organs and tissue for transplantation: Code of Practice, published 3 April 2017 <https://www.hta.gov.uk/code-practice-2-donation-solid-organs-transplantation>. (Accessed 2019-07-17).

47 HTA (F) Donation of solid organs and tissue for transplantation: Code of Practice, published 3 April 2017 <https://www.hta.gov.uk/code-practice-2-donation-solid-organs-transplantation>. (Accessed on 2019-07-17).

4 Conclusion

This article sought to investigate the role of family consent in the donation process from a legal perspective. The question was posed whether family members should be asked for consent for deceased organ donation or whether the wishes of the deceased should be honoured. Due to the continued stagnant state of the availability of donor organs in South Africa, we are of opinion that at the very least appropriate, valid consent should not be nullified by a relative's objection. Section 62 of the NHA already makes a provision for a valid donation to occur by means of a document attested by two witnesses. It is merely a case of implementing valid legal measures into the organ donor registration process. By implementing this procedure, the right to autonomy as guaranteed by the Constitution will be truly upheld and respected.