


Ethics of organ procurement from the unrepresented patient population

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Received 20 May 2019

Revised 22 August 2019

Accepted 26 August 2019

Published Online First

10 September 2019



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To cite: Raho JA, Brown-Saltzman K, Korenman SG, et al. *J Med Ethics* 2019;45:751–754.

ABSTRACT

The shortage of organs for transplantation by its nature prompts ethical dilemmas. For example, although there is an imperative to save human life and reduce suffering by maximising the supply of vital organs, there is an equally important obligation to ensure that the process by which we increase the supply respects the rights of all stakeholders. In a relatively unexamined practice in the USA, organs are procured from unrepresented decedents without their express consent. Unrepresented decedents have no known healthcare wishes or advance care planning document; they also lack a surrogate. The Revised Uniform Anatomical Gift Act (RUAGA) of 2006 sends a mixed message about the procurement of organs from this patient population and there are hospitals that authorise donation. In addition, in adopting the RUAGA, some states included provisions that clearly allow organ procurement from unrepresented decedents. An important unanswered question is whether this practice meets the canons of ethical permissibility. The current Brief Report presents two principled approaches to the topic as a way of highlighting some of the complexities involved. Concluding remarks offer suggestions for future research and discussion.

INTRODUCTION

With more than 113 000 persons in the USA currently on the organ transplantation waiting list, many will die—roughly 6500 in 2017—before receiving an organ.¹ Various strategies have been considered to increase donation rates, from improving ways to maximise donor registrations,² removing financial disincentives to donation,³ to shifts in public policy (eg, from ‘opt-in’ to ‘opt-out’ models).^{4–6} A less examined practice in the USA involves procuring organs from deceased unrepresented patients—that is, individuals who have no known healthcare wishes or advance care planning document, and lack a surrogate decision-maker.⁷

Because of controversies over the procurement of organs or tissues without consent by decedents or their families, the Revised Uniform Anatomical Gift Act (RUAGA)⁸ of 2006 was designed to curtail the retrieval of organs in the absence of consent. However, the RUAGA left some room for anatomical gifts from unrepresented decedents. When family members are not available, procurement may be authorised by ‘any other person having the

authority to dispose of the decedent’s body.’¹ Moreover, in adopting the RUAGA, some states (eg, California⁹ and New Jersey¹⁰) included provisions that encourage organ procurement from unrepresented patients. In California, for example, hospital administrators, coroners and medical examiners may approve retrieval of organs if the decedent had not registered a prior refusal to make an anatomical gift, and no other decision-maker (eg, healthcare agent, family member, friend, or guardian) is reasonably available after diligent search efforts have been made within a circumscribed period of time.¹¹ Other states allow for different individuals to authorise organ retrieval in these circumstances.¹² In addition to these provisions, analysis of data from the United Network for Organ Sharing reveals a number of non-donor consent mechanisms for organ recovery. In these instances, authorisation was provided by, among others, the state police, the Organ Procurement Organization (OPO), funeral homes and via court order.¹³

ⁱSee section 9, ‘Who May Make Anatomical Gift of Decedent’s Body or Part,’ of the RUAGA.⁸ Forty-five states include verbatim or similar language. The five states that do not are Florida, Kentucky, Missouri, Rhode Island and West Virginia. In Missouri, only a public official, not ‘any other person,’ may have the authority to do so.

ⁱⁱSee section 7150.40 of California’s Revised Uniform Anatomical Gift Act.⁹ Regarding what constitutes a ‘reasonable’ search effort, section 7150.40(10)(B) states the following: ‘Except in the case where the useful life of the part does not permit, a reasonable effort shall be deemed to have been made when a search for the persons has been underway for at least 12 hours. The search shall include a check of local police missing persons records, examination of personal effects, and the questioning of any persons visiting the decedent before his or her death or in the hospital, accompanying the decedent’s body, or reporting the death, in order to obtain information that might lead to the location of any persons listed.’⁹

ⁱⁱⁱFor example, a court-appointed or court-authorized ad litem guardian or representative (Florida, Georgia, Maryland and Virginia), a ‘public ward custodian’ and ‘mental health facility personnel, or foster parents’ (Michigan), licensed funeral director (Ohio) and wardens or directors of correctional facilities (Delaware and Pennsylvania).

^{iv}The requested data were in regard to mechanisms of consent for deceased donors recovered in the USA between 1 January 1998 and 30 April 2019. The vast majority of donors had consented via donor card, driver’s license, donor registry, advance directive, or durable power of attorney/healthcare proxy. However, the data revealed 273

Retrieving organs from unrepresented patients raises ethical issues that have not been widely discussed in the academic literature.^v For example, is it defensible to depart from the standard approach to organ donation in the USA (express consent) and make an exception for one of society's most vulnerable populations? If so, on what basis? Is a hospital administrator, coroner, or medical examiner an appropriate individual to authorise these decisions, or should some kind of external body—for example, an ethics committee—decide?

This Brief Report does not attempt to answer all of these questions, but instead presents two principled approaches to the topic as a way of highlighting some of the challenges in this context. Concluding remarks offer suggestions for future research and discussion.

POSITION 1: PROCUREMENT FROM THE UNREPRESENTED IS ETHICALLY PERMISSIBLE

This perspective endorses the view that retrieval of organs from the unrepresented patient population is morally permissible for the following reasons.

First, the law allows the practice. In those states in which organ procurement from the unrepresented is permitted, consent is obtained from an authority figure, which in some instances is an elected or appointed position (eg, coroner). Individual transplantation centres have the option of not participating or placing additional safeguards on the practice (eg, mandating a longer waiting period; requiring review of the case by a clinical ethics consultant, hospital ethics committee, or judge). However, because the decision about whether to procure organs is 'extremely time sensitive'⁸ (p 35), institutional policy needs to strike a balance between appropriate oversight and ensuring organ viability.

Second, in light of strong public support for organ donation, it is not unreasonable to presume consent from unrepresented patients. Currently, 54% of the US adult population has registered to be a donor.¹¹ In a national US survey of organ donation attitudes¹² (p 1), 94.9% of the study's 3200 US adults supported or strongly supported donation.^{vi} In the same survey¹² (p 2), many individuals who stated that they were unsure of their loved one's wishes regarding the issue indicated that they would authorise procurement if asked (75.6%). In the case of the unrepresented population, anecdotal evidence suggests that, after a diligent search by the healthcare team has been made and the patient's family is identified, a majority of surrogates ultimately authorise organ transplantation. Thus, one could argue that procurement should proceed based on the presumption that the deceased (if asked while alive) or their family (if found) would authorise donation. This presumption could be rebutted in a particular case if it became clear that the unrepresented

instances of non-donor consent mechanisms being invoked for organ recovery. Statistical analysis of these data is forthcoming.

^vAfter extensive literature review, we identified only one law review article¹⁷ that addressed this topic, although in the context of a discussion of presumed consent policies to organ donation. A letter to the editor in 2004²¹ raised the possibility of procurement from unrepresented decedents in Nevada, and proposed legislation to permit this to occur. Recently, the topic was highlighted in an original article that examined organ retrieval from the homeless patient population in Hawaii¹⁶; in this study, however, all seven homeless decedents had next of kin who authorised procurement. Finally, in the lay press, the *Houston Chronicle* published an article²² in 2016 about the procurement of organs from a man presumed to be homeless, after an emergency petition was granted by the County Civil Court.

^{vi}This corresponds to more than 145 million registered adults.

patient held religious and/or spiritual beliefs that would prohibit procurement. Yet, this concern may be unfounded, since many religions support organ transplantation and few religions have specific prohibitions against it¹³ (pp 1–27).¹⁴

Third, it is not clear how the unrepresented could be harmed or wronged by organ retrieval. For example, a corpse cannot be harmed by the action of removing organs because the concept of harm requires a living subject. Moreover, since their organs cannot be used to support their own life, the unrepresented are not deprived by having their organs removed.

Could the unrepresented nevertheless be wronged by procurement? One might argue that the unrepresented would be wronged if they, while alive, had firm wishes against organ retrieval (eg, expressed in writing) and those wishes were disregarded following their deaths. But this is not the context under discussion. Unrepresented decedents did not establish clear preferences regarding disposition of the body while alive and their wishes on the matter cannot be known. We do know, however, that they did not register an objection when they could have. Because the situation is not a clear instance of refusal to authorise donation, one could argue that their prior silence on the matter could be construed as non-dissent to the retrieval of their organs postmortem.

Finally, there is an ethical mandate to save human life, especially when it is possible to do so and the benefits of the action are not offset by disproportionate burdens. Organ transplantation is a public good that saves and improves human life. The Health Resources and Services Administration reports¹¹ that one organ donor can save up to eight lives.^{vii} Although the dead are beyond harm with respect to procurement, those who suffer from organ failure face impending doom on a daily basis. In the USA, one person is added to the waiting list every 10 minutes and 20 people die each day while awaiting an organ.¹¹ Procurement of organs from unrepresented patients could increase the supply of available organs, reduce transplantation waiting times and extend and improve the quality of life of individuals who receive the organs.^{viii} By extension, not taking organs from unrepresented patients could result in death for those patients who otherwise might have benefitted from use of the organ.

POSITION 2: PROCUREMENT FROM THE UNREPRESENTED IS ETHICALLY IMPERMISSIBLE

Although legally permitted, this perspective contends that the practice is not morally justified for the following reasons.

First, despite all of the arguments advanced in the previous section, Position 2 begins from a powerful sentiment: procuring organs from the unrepresented simply feels wrong and morally deficient. The practice violates many of our moral intuitions about how a good society ought to treat the most vulnerable among us. It also fails to respect the dead, denying their essential humanity and reducing them to a mere means.

Second, donating one's organs remains supererogatory. Vital solid organs are not considered to be common resources

^{vii}That is, if each of the deceased's organs (heart, two lungs, liver, pancreas, two kidneys, intestines) goes to one recipient.

^{viii}A letter to the editor²¹ (p 793) notes that, in a 1-year period, there were seven out of eight deceased unrepresented individuals who would have met criteria for organ procurement. Had the practice been permitted, these individuals 'could have been multiorgan donors' which, in their procurement location, would have resulted in 'a 26% increase in the number of cadaveric organ donors for that year.'

in the USA, nor is there any societal expectation that individuals donate. As the etymology of the word donation (Latin *donum* (gift)) suggests, organ procurement should respect the gifted, charitable nature of the act. Failure to do so in the case of unrepresented decedents represents a stark departure from this paradigm of gifting.^{ix}

Third, based on the ethical principle of respect for persons, the accepted basis for the recovery of organs in the USA is express consent—that is, consent from the donor or a valid surrogate decision-maker. Indeed, the models of routine retrieval and presumed consent have been consistently rejected in the USA in favour of voluntary donation. As the Institute of Medicine reminds us, ‘The default option, in the absence of express consent, is nondonation’¹⁵ (p 9).

When a person has indicated a clear preference regarding donation, there is a strong ethical mandate for respecting that wish. If the deceased had not made a decision regarding organ donation, a surrogate must decide—based on the deceased individual’s prior expressed wishes or a substituted judgment. In order for a valid authorisation to occur, the surrogate needs some reason to believe that the now deceased patient, if asked while alive, would have wanted to donate.

It is this aspect of surrogate decision-making in the absence of any direct knowledge of unrepresented decedents that makes procuring their organs problematic. On the one hand, although consent is technically obtained by someone who has the legal authority to dispose of the body, the authorisation is not based on any direct knowledge of the former person. Because no information about the deceased individual’s wishes or values is available, the decision to procure organs lacks moral authority.

On the other hand, one cannot discount the potential for conflicts of interest. Hospital administrators, coroners and medical examiners have relationships to transplantation centres and OPOs that are not disinterested.^x Financial conflicts of interest could occur if the administrator who authorises procurement worked for a hospital that had a transplant programme.¹⁶ Finally, transplant centres have incentives to maximise the number of organs that they contribute to the donor pool—especially if they are in receipt of organs that have been obtained at other centres from the unrepresented patient population.

Fourth, although it is not stated as such in the law, the purported ethical rationale for organ retrieval in this patient population is presumed consent. Presumed consent policies can be justified morally—in general, when there is ‘extensive and effective public education’ regarding the issue and there are ‘clear, easy, non-onerous, and reliable ways for individuals to register their refusal’¹⁵ (pp 226–227). However, such policies remain questionable when applied to the unrepresented population. For example, the issue has neither been debated publicly nor discussed in the scholarly literature, and there have been no attempts to educate the public on the matter, including surveying members of the affected population. Although in principle unrepresented patients who do not wish to make an anatomical gift can take steps to register their refusal, in practice there are significant barriers to doing so—viz

limited literacy, diminished decision-making capacity,^{xi} lack of advance directive completion, no way to opt out of the online registration system^{xii} and mistrust.^{xiii}

Finally, procuring organs from the unrepresented violates our standards of fairness. Consider in this regard the evolution of the Uniform Anatomical Gift Act (UAGA) and state anatomical gift acts¹⁷ (pp 304–308). Under the 1987 version of the UAGA and many state laws, coroners or medical examiners could authorise organ or tissue donations from decedents under their custody in the absence of known objections by the decedents or their surrogates. But there were major controversies over the exercise of this presumed consent authority—even for corneas—when families later found out about the donations.^{xiv} This led to a substantial curtailment of presumed consent in the 2006 Revised UAGA (RUAGA). Under the RUAGA, anatomical gifts are permissible without consent only from unrepresented decedents; if family members are not available, an anatomical gift may be made by ‘any other person having the authority to dispose of the decedent’s body’⁸ (p 33). It is unclear whether the RUAGA includes organ transplants as a permissible anatomical gift by ‘any other person.’ On one hand, the comments to the RUAGA indicate that the ‘any other person’ provision is triggered ‘if no other persons are reasonably available’⁸ (p 34). On the other hand, the comments also observe that by the time the ‘other person’ would assume authority to dispose of the body, ‘it is most unlikely that the decedent’s organs [would] be medically suitable for transplantation’⁸ (p 34). Rather, there might be donation of tissues that remain viable for an extended period of time after the decedent’s death or for anatomical gifts related to research or education. Most states have adopted the ‘any other person’ provision, and there are hospitals that rely on the provision to approve organ retrieval. Moreover, when some states, including California and New Jersey,^{xv} revised their anatomical gift acts, they expressly authorised hospital administrators to consent to organ procurement from unrepresented decedents for transplantation if the decedents had not objected while alive.

This history highlights one aspect of the fairness problems. In response to the concerns of family members, the drafters of the RUAGA protected represented decedents from procurement in the absence of consent. But the drafters still left unrepresented decedents at risk for tissue, and possibly organ, procurement without consent. And several states have contributed to the ongoing controversy by explicitly allowing for unconsented organ retrieval. If it was clear that presumed consent was not acceptable for decedents who have families or surrogates able to represent them, it is problematic to permit presumed consent for decedents who do not have such individuals to represent their interests.^{xvi}

^{xi} Particularly in those unrepresented patients who have conditions (eg, psychiatric illness, substance dependence) that could impair their ability to decide regarding anatomical donation.

^{xii} One must opt out via advance directive or testament.

^{xiii} On this last point, one should bear in mind that many unrepresented patients are undomiciled, who may have higher levels of distrust of healthcare professionals than other patient groups. One study²⁴ (p 5) found that such individuals ‘are often disappointed because they are not treated equally and feel disparaged by professionals.’

^{xiv} See endnote x.

^{xv} Cal Health & Safety Code § 7150.40(a)(10)(A); NJ Stat § 26:6-85(a)(1)(h).

^{xvi} Accordingly, a few states eliminated the ‘any other person’ authority entirely in their revised anatomical gift acts. Ky Rev Stat § 311.1925(1); RI Gen Laws § 23-18.6.1-9; W Va Code § 16-19-9(a).

^{ix} Indeed, the practice seems to place a unique burden on the unrepresented population, since the default approach (‘opt-in’) becomes one of ‘forced procurement’—a situation that does not arise for decedents who have representation.

^x One high-profile exposé revealed conflicts of interest at a coroner’s office that involved taking corneas without consent.²³

The other dimension of the fairness issue centres on the type of patient population under consideration. The unrepresented, one of society's most vulnerable groups, come disproportionately from marginalised backgrounds (eg, the undomiciled, the mentally ill, those who are substance dependent and individuals who have been estranged from their families). Predictably, some unrepresented individuals with end-stage disease would have better health outcomes if they received an organ transplant (eg, long-term dialysis patients). Yet, lack of social support¹⁸ (p 1147),¹⁹ (p 3),²⁰ (p 8), evidence of psychiatric or psychological conditions that render one unable to cooperate or remain adherent post-transplant¹⁹ (p 3) and substance dependence¹⁸ (p 1147),¹⁹ (p 4),²⁰ (p 4) frequently are taken to be excluding criteria for receiving an organ. A social arrangement that effectively bars this population from access to organs, yet sanctions them to be used as a 'source' of organs for persons with adequate psychosocial support, compounds the injustice.

CONCLUSIONS

Organ donation is a public good. In the absence of an adequate supply of organs, many individuals experience severely compromised health outcomes or death. Failure to use otherwise available organs denies scarce, life-saving resources to persons whose lives depend on them. On the other hand, obtaining organs from the deceased unrepresented population without express consent presents legitimate ethical concerns. Awareness of this policy could diminish public trust in organ donation if the practice were interpreted as violating a vulnerable minority.

How should society reconcile these issues? Given the ethical implications of this practice, we believe further collaborative research is warranted to enable patients, clinicians, administrators and policymakers to consider all the relevant aspects of this complex issue. Future avenues for research include: reports that document the frequency and types of organs that are procured from unrepresented patients; a study that compares the socioeconomic demographic of organ donors (including unrepresented donors) and recipients; a survey of the attitudes of those who are authorised to provide consent; a review of institutional policies that either permit or exclude the practice; proposals for oversight; a survey of a diverse number of unrepresented patients regarding their attitudes towards organ transplantation in general and a policy of routine procurement in the absence of a registered objection; and a survey of the perceptions of an equally diverse public.

Acknowledgements Many of the ideas presented in this article were inspired by discussions that occurred during the meetings of the UCLA Health Ethics Committee. A subcommittee was created to study this issue; this discussion paper represents its key findings. We wish to thank Valerye Milleson, PhD, MS (former UCLA senior clinical ethics fellow and subcommittee member), whose comments and insights enriched this manuscript. The authors also thank the two peer reviewers for helpful comments.

Contributors JAR, KBS and SGK conceived the article. JAR drafted, edited and approved the final paper. JAL made inquiries to UNOS for data on the practice. DO drafted key sections of the paper with regard to the Revised Uniform Anatomical Gift Act. All authors participated in discussions of the topic, assisted in revision of the manuscript, gave final approval of the version to be published and are accountable for all aspects of the work.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Disclaimer The ideas expressed should not be understood to represent the views of UCLA, the UCLA Health System, or the Ethics Committee.

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

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