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Exploring Donation Decisions: Beliefs and Preferences for Organ Donation in Australia

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Abstract

We explored common beliefs and preferences for posthumous and living organ donation in Australia where organ donation rates are low and little research exists. Content analysis of discussions revealed the advantage of prolonging/saving life whereas disadvantages differed according to donation context. A range of people/groups perceived to approve and disapprove of donation were identified. Barriers for posthumous donation included a family's objection, with the type of organ needed important for living donation. Motivators included knowledge about potential organ recipients. Donation preferences favored loved ones, with weaker preferences for recipients who were perceived as morally questionable or responsible for their illness.

Keywords: posthumous organ donation, living organ donation, transplant recipient, beliefs

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As in other Westernized nations, posthumous organ donation rates in Australia (9.4 donors per million population) do not meet the demand for transplantable organs, despite reported public support for organ donation (Excell, Hee, & Russ, 2008). The organ shortage in Australia, and internationally, has resulted in an increasing reliance on the supply of organs (e.g., kidney, liver, pancreas, and lung¹) from living donors who are either related (i.e., relative) or unrelated (i.e., friend, stranger) to the recipient (National Health and Medical Research Council [NHMRC], 2007). Although there is a substantial body of literature reporting beliefs about posthumous organ donation (e.g., Gallup Organization, 1993; Mandell et al., 2006), an understanding of the beliefs influencing living donation is crucial also given the increasing use of this type of donation. An examination of posthumous and living organ donation beliefs is particularly important in Australia, where organ donation rates are one of the lowest in the world, and few recent investigations of current organ donation beliefs have been conducted. Identifying the common beliefs and preferences for both types of organ donation will allow us to explore the similarities and differences across donation contexts to inform strategies designed to increase the available supply of organs

Previous organ donation research conducted primarily in the USA (e.g., Gallup Organization, 1993; Manninen & Evans, 1985) and UK (e.g., Ahmed, Harris, & Brown, 1999) suggests that there are a wide variety of beliefs and attitudes associated with organ donation. Common reasons for organ donation center on altruistic motivations of helping others, saving another person's life, or improving the quality of another person's life (e.g., Morgan & Miller, 2001) and the personal feeling of satisfaction felt by the donor in the case of living donation (e.g., Cotler et al., 2001). Beliefs thought to discourage posthumous donation relate to the fear of

death being declared prematurely for the purpose of extracting organs if the individual is a donor match (e.g., Nijkamp, Hollestelle, Zeegers, van den Borne, & Reubsaet, 2008), fear of mutilation and the body not being whole after death (e.g., Bilgel et al., 1991), and lack of knowledge about organ donation (e.g., Horton & Horton, 1990). Similar beliefs discouraging living donation include concerns about the surgical donation procedure, uncertainty about the possibility of sustaining a normal life after donation, fear of pain, and lack of knowledge about the procedure (e.g., Landolt et al., 2003).

In addition to recognizing the underlying benefits and barriers related to organ donation, the literature has focused on perceptions of the potential recipients of organs as another factor influencing donation decisions (e.g., Ubel et al., 2001). For posthumous donation, this focus involves issues of deservingness and concerns that organs will go to undesirable recipients who are perceived to be responsible for causing their illness (e.g., recipients with a history of smoking, alcohol, or substance use; Neuberger, 1999). For living donation, recipient preferences manifest as an increased willingness to donate organs to a known recipient, such as family members or close friends, rather than to an unknown recipient (Spital, 2001). Most research exploring preferences for organ recipients, however, has used hypothetical organ allocation scenarios (e.g., Wilmot & Ratcliffe, 2002) or tasks requiring ranking of specific organ recipients (e.g., Ubel et al., 2001). It is, therefore, important to determine if these recipient preferences are expressed when people are not forced to consider specific scenarios or choose between predetermined options, particularly for the living context where donation to a known recipient may occur.

Considering the limitations outlined above, the present article contributes to the existing organ donation literature by providing a current comparison of Australian beliefs about

posthumous and living donation and preferences for the recipients of organ transplants. In addition to exploring organ recipient preferences and the perceived advantages and disadvantages of posthumous and living donation, we consider whether the opinions of other people or groups may impact on individuals' donation beliefs, and we examine the perceived factors that may prevent (i.e., barriers) and encourage (i.e., motivators) people's organ donation for both types of donation. We used focus groups to facilitate discussion of socially shared views about organ donation (Wilkinson, 1998) and qualitative content analysis (Joffe & Yardley, 2004) to explore commonly held organ donation beliefs.

Method

Participants

Fifty four participants comprising students ($n = 30$) and community members ($n = 24$) participated in focus group or individual discussions about organ donation during the period of August 2006 to January 2007. A total of 15 focus groups (8 student groups, 7 community groups) and 15 interviews (7 students, 8 community members) were conducted. Students were recruited from a large metropolitan university via in-class announcements and received course credit or AUD\$10 for their time. Community members were recruited from a local health clinic ($n = 8$) or via contacts of the first author ($n = 16$) and were compensated AUD\$10 for their time. Participants were mostly Caucasian (96%), highly educated, males ($n = 22$) and females ($n = 32$), aged 17 to 66 years ($M = 31.17$ years; $SD = 13.22$ years). Over half of the participants (68.5%) had registered their intent or consent for donation on the Australian Organ Donor Register or driver license.

Procedure

Approval to conduct the study was granted from the University Human Research Ethics

Committee. All focus groups and interviews were audio recorded with consent obtained at the time of recording. Participants were provided with an information sheet explaining the anonymous, confidential, and voluntary nature of participation. Initially, participants identified the organs they believed could be donated upon death and while living and then were provided with a list of donatable organs to ensure equivalent awareness. Participants then discussed their beliefs related to posthumous and living donation, as well as preferences for the recipients to whom they were willing to donate their organs. At the conclusion of each session, participants were given the opportunity to raise any concerns they had about the topic or process of organ donation, allowing an opportunity to debrief participants about a potentially sensitive topic.

Data Analysis

Although we recruited up to 6 participants per focus group, if only one person attended the scheduled session, the focus group became an interview. As such, participants attended either a focus group ($n = 38$) or an interview ($n = 15$) with no differences identified in the content of beliefs based on the data collection method. Discussions were transcribed verbatim (see Appendix 1 for focus group/interview questions). Transcripts were coded initially by grouping responses about each donation type according to beliefs about the advantages and disadvantages of donation, the important people or groups perceived to approve and disapprove of donation, and the barriers preventing donation and motivators encouraging donation. Each set of beliefs (e.g., advantages of posthumous donation) was further refined to incorporate the specific beliefs (e.g., “avoiding the waste of healthy organs”) commonly discussed by participants. The results of the content analysis reported below represent the beliefs participants most commonly reported. Frequencies for a belief (n) are the total number of times a belief was discussed across all of the focus groups/interviews. If the same belief was discussed multiple times by a single participant it

was only counted once. The abbreviations *PD* and *LD* refer to posthumous and living donation, respectively.

Results

Advantages and Disadvantages of Posthumous and Living Donation

The most common advantage for posthumous and living donation focused on saving, prolonging, or improving the quality of someone's life (*PD*: $n = 46$, *LD*: $n = 33$). Feeling good about being a donor (*PD*: $n = 6$, *LD*: $n = 8$) was also raised as an advantage in both contexts. Helping was perceived to have more personal significance for living donation as participants would be able to physically see or know about the benefits of their donation while they were still alive (*LD*: $n = 15$). Some participants viewed the advantages of organ donation in a more practical (e.g., "I'm not using them, why not donate?") or detached way (e.g., referring to organs as "stuff" or as akin to "spare car parts"). These beliefs encapsulated advantages such as avoiding the waste of healthy organs if they are no longer needed (*PD*: $n = 23$) and increasing the availability of organs (*LD*: $n = 4$).

For posthumous organ donation particularly, some participants believed that being an organ donor upon death may help their loved ones to cope with their death (*PD*: $n = 6$). As one participant noted: "The family of the donor could feel some sense of worth, that the death of their loved one wasn't just a waste" (*PD*). In contrast, many participants believed that a disadvantage of posthumous donation would be creating distress for family members or loved ones (*PD*: $n = 17$) who had to think about their loved one undergoing surgical procedures. As one participant noted: "At the same time they [family members] are grieving having lost someone...having to deal with the fact that that person they have lost is going to be cut up and things taken from them even if that may be the wishes of the person who's passed away" (*PD*). Participants' concern for

others was extended to feelings of responsibility for the quality of their donated organs and concern that they may inadvertently cause the death of the recipient if their organ is rejected (*PD: n = 7*).

Participants were also concerned about the risk to their own well-being as a result of medical interventions; however, the reasons for this concern differed according to the donation context. For posthumous donation, participants focused on risk to themselves because they were afraid that life saving measures would not be implemented by medical staff if they were an organ match for a potential transplant recipient (*PD: n = 7*). Many participants also raised disadvantages related to their body not being whole after death such as: being cut up, needing burial of the whole body, and the desire for an open casket funeral (*PD: n = 20*). For example: “I don’t think it’s natural. I’m not a religious person but I actually believe you come into this world whole and you should leave the same way. I really have, I think, a problem with it. Other people have said “Oh, that’s ridiculous”, but that’s just a personal feeling” (*PD*). For living donation, participants were concerned about risk to themselves as a result of voluntarily undergoing a medical procedure (*LD: n = 19*). These disadvantages included reducing the quality and length of their life (*LD: n = 20*), complications, recovery time, invasiveness, and experiencing pain or discomfort (*LD: n = 19*) as a result of undergoing an operation. Participants also worried about losing their “spare” organ as a backup if they need it in the future (*LD: n = 19*). The concerns associated with the loss of an organ after surgery included shortening the life span, being on medication for the remainder of life, and the risk that something will happen to the remaining organ.

Important People/Groups Approving and Disapproving of Posthumous and Living Donation

Physicians and researchers or government agencies (*PD: n = 25, LD: n = 14*), transplant

recipients (*PD: n = 18, LD: n = 13*), family members and friends of the donor (*PD: n = 24, LD: n = 18*), family members of the recipient (*PD: n = 15, LD: n = 8*), and religious groups or people (*PD: n = 6, LD: n = 6*) were the common people or groups of people perceived to approve of posthumous and living donation. The general community was also an important influence approving of posthumous donation (*PD: n = 5*). In addition to approving of donation, family members of the donor (*PD: n = 10, LD: n = 17*) and people/groups with strong religious beliefs (both specific religious groups such as Jehovah's Witnesses and all religious denominations generally) (*PD: n = 37, LD: n = 25*) were also perceived to disapprove of posthumous and living donation. Family members were thought to disapprove of posthumous donation because they did not want their loved one to be mutilated upon death, with several participants noting that such family disapproval would factor into their decision making. For living donation, participants believed that family members would disapprove of the potential health risk to the donor. Participants could not explain why they believed religious groups generally would be opposed to donation and were uncertain about the accuracy of their beliefs.

Barriers Preventing and Motivators Encouraging Posthumous and Living Organ Donation

In general, participants did not consider many factors that would prevent or discourage them from posthumous donation, believing that if they had registered their intent or consent to donate that this indication of their wishes was enough to ensure organ donation occurred. Some participants, however, reported that their family's objection to donation was the major barrier to posthumous donation (*PD: n = 17*) as family members may try to overturn their decision. A belief perceived similarly by participants as a barrier in both donation contexts was a lack of knowledge about what the process of organ donation entails and what happens to their own body or the body of their family member (*PD: n = 12, LD: n = 4*): "I would be very concerned about

how they would treat my family member... whether they treat them with respect or just use them like a butcher's table" (*PD*). Participants believed also that the medical suitability of their organs and their health would prevent them from being able to donate (*PD*: $n = 9$, *LD*: $n = 4$).

Participants raised additional barriers to living organ donation, including the costs involved with donation and transplantation and the financial burden this would have for them (*LD*: $n = 3$), as well as the impact living donation would have on their own health, such as the possibility of premature death (*LD*: $n = 8$). The decision to donate while living is something that participants would consider carefully and would also be dependent on which particular organ or tissue was needed by the recipient, with participants more willing to donate organs/part of an organ that regenerates (*LD*: $n = 10$). For example, "whether or not the thing [organs] would grow back to normal... [if] I could just wait a week and it's good again, I'd be happy to give it away. Something that's a more permanent lifestyle change and might inhibit me from doing things I'd be a bit more hesitant about" (*LD*).

In contrast to the various barriers believed to prevent donation, only two motivators encouraging posthumous and living donation were discussed. One motivation was whether a family member or loved one were sick and needed an organ (*PD*: $n = 13$, *LD*: $n = 29$); a motivation particularly important for encouraging living donation because many people stated their unwillingness to donate unless they had a connection with the recipient. For example, "It would be the relationship with the person who needed the organ...a family member or very close friend that you wanted to help for selfish reasons as much as for altruistic reasons" (*LD*).

Some participants stated that knowing the potential recipients of their organs and if their organs would be looked after would be another motivator for them (*PD*: $n = 9$, *LD*: $n = 14$). Participants did not desire a personal relationship with the recipient, but rather wanted to know

details about their health status, history (e.g., substance abuse), or demographic details. Some participants also indicated that television commercials, movies, and stories of others benefiting from organ donation would encourage them to consider donation (*PD*: $n = 7$, *LD*: $n = 3$): “When I see ads for young children that need organs to keep them alive, I could happily donate an organ even alive” (*PD*). Given the lack of awareness about the process of organ donation, some participants suggested that information about the process of posthumous donation would be another factor that could motivate them to consider donation (e.g., what happens to organs after death) (*PD*: $n = 5$).

Recipients to Whom Participants Preferred to Donate

Although a small number of people refused to state their preference, most participants specified the particular people to whom or circumstances in which they would be more or less likely to donate, if they were given a choice. For both types of donation, participants indicated they would be more likely to donate to a recipient they knew personally such as a partner, family member, or close friend (*PD*: $n = 18$, *LD*: $n = 35$), and, for living donation, a recipient they knew publicly, such as specific cases publicized by the media (*LD*: $n = 5$). For example: “I think people who need transplants, the ones that get publicized in the media, people feel more inclined to help them out because they think if they are putting them in the paper or the news they must really need it” (*LD*). Participants also indicated a preference for donation to children or younger people (*PD*: $n = 16$, *LD*: $n = 14$) because these recipients had not had a chance to live their life, a preference common to both types of donation. In addition to this preference, some participants preferred to donate to people who they believed were not responsible for their illness (i.e., it was not their “fault” they needed a transplant) such as people who were genetically predisposed to an illness and needed a transplant as a direct result of their illness (*PD*: $n = 10$), and those who

needed the transplant the most or were the “sickest” candidates (*PD*: $n = 6$, *LD*: $n = 4$). In the living context specifically, some participants indicated that they would be more likely to donate to someone with responsibilities (e.g., children, mortgages to pay), or who would appreciate their organ; what some participants perceived as a “worthy” person (*LD*: $n = 7$).

In line with the organ recipient preferences outlined above, participants were less likely to consider posthumous donation for people of an older age (*PD*: $n = 5$) and living donation to strangers or acquaintances (*LD*: $n = 9$). Participants consistently discussed also that they would be less inclined to donate to people perceived to be responsible for their illness (i.e., people who used or abused substances such as alcohol, drugs, or smoked) or people who were not going to look after their organ (*PD*: $n = 21$, *LD*: $n = 20$). As one participant commented: “If it’s a medical reason beyond their control then I’m fine with that...but you worry it’s going to go to someone that still might ruin it and abuse it again” (*PD*). Further, participants in both donation contexts communicated that they would be less likely to donate to someone who had engaged in acts that society sanctioned as morally wrong (e.g., a person with a criminal conviction) (*PD*: $n = 9$, *LD*: $n = 9$). These participants believed that those who had committed criminal acts, such as murder or rape, and violated the rights of others, had forfeited their own right to receive life saving measures such as organ transplantation.

Discussion

In its recruitment of a sample of Australian participants, this study provides a current comparison of similar and dissimilar beliefs about posthumous and living donation, as well as preferences for the recipients of organ donation, in a country with one of the lowest organ donation rates in the world where little recent research about organ donation beliefs has been conducted. Using qualitative content analysis (Joffe & Yardley, 2004), we identified the most

commonly occurring beliefs about the advantages and disadvantages, important people or groups, barriers and motivators influencing organ donation in each context.

One advantage common to both types of organ donation was prolonging or saving someone's life. Advantages raised by participants that were dependent on the donation context included avoiding the waste of healthy organs (posthumous donation) and seeing the benefits of helping someone else (living donation). Disadvantages differed also according to the donation context. Preventing the body from being whole after death and creating distress for the family were important disadvantages of posthumous donation and both various risks to one's health and pain as a result of undergoing a surgical procedure were key disadvantages raised for living donation. Despite the associated disadvantages, most participants viewed both posthumous and living organ donation positively, and as behaviors approved of by others who are important to them and more broadly by society.

The findings of this study suggest the need for future strategies designed to promote organ donation to consider the role of important people or groups such as family members and friends of the donor, transplant recipients, religious groups, or the general community (for posthumous donation only) as sources of influence who may potentially impact on people's decision making. Participants identified two key influences (i.e., family members and friends of the donor and religious groups/people), who, despite their perceived approval, were also thought to disapprove of donation in some circumstances. To overcome the concerns of family and friends of potential donors about organ donation, people should be encouraged to engage in a dialogue about the benefits and costs of organ donation with the important people in their life. This approach would allow people to determine what the actual concerns of family members and friends are and if these concerns can be overcome by a consideration of the benefits of donation and the provision

of accurate donation information. Furthermore, participants' expressed uncertainty about the views of religious denominations. Although some participants were accurate in their assumption that other people may not wish to donate because they hold beliefs that organ donation is equivalent to desecration of the body or believe organs are needed for the afterlife or resurrection, the majority of participants were not. Most participants either incorrectly assumed that particular religions, such as Jehovah's Witnesses, Christianity, or Catholicism, opposed donation (while admitting that they did not know if their assumption was true) or could not identify the specific religious denominations that may oppose donation and, instead, believed that merely having strong religious beliefs prevented donation. This finding suggests that, for those who value their religious beliefs or belong to a culture with strong ties to a particular religion or spiritual belief system (e.g., indigenous populations), the approval and support of religious affiliations for organ donation and for individual choice in making organ donation decisions could be emphasized (Elliot, 1999).

Key barriers for posthumous donation included a family's objection to donation whereas the specific organ donated emerged as important for living donation, with participants unwilling to donate organs which may result in the loss of a backup organ or inhibit their long-term lifestyle. Family members needing an organ and knowledge about organ recipients were acknowledged by participants as motivators to encourage donation in each context. The barriers of a lack of knowledge about both donation types and family objection to posthumous donation highlights the continuing need to educate the general public about the process of organ donation and encourage communication of the donation decision to family members to ensure donation wishes are carried out. Potential strategies may be to first acknowledge the perceived difficulties people face when communicating their donation wishes to family members and to follow this

acknowledgement with suggestions detailing how to make people's expression of their organ donation decision easier and more effective (Waldrop, Tamburlin, Thompson, & Simon, 2004).

Participants stated clear donation preferences for individuals to whom they were more (i.e., family, friends, and children) or less (i.e., recipients perceived as morally questionable or responsible for their illness) likely to donate their organs. Although Australian legislation prevents direct contact between the deceased donor's family and the transplant recipient to protect the anonymity of both parties, the findings of this study point to the potential benefits of providing some non-identifying demographic information (e.g., gender, age) about the potential organ recipients prior to donation. This approach may appease the desire of potential donors and donor families to know some information about who recipients are and therefore encourage them to consider donation (see Singh, Katz, Beauchamp, & Hannon, 2002). Providing non-identifying details about potential organ recipients when the request for donation is made may serve to humanize the process for family members of potential donors.

This study, in its recruitment of a sample of Australian participants, provides a current depiction of beliefs about living and posthumous donation in a context where little recent research has been conducted. Some limitations of this study, however, should be considered. These limitations include the recruitment of contacts of the researcher as part of the community sample which may have resulted in similar beliefs identified; however, variation across community beliefs was evident. In addition, the sample included registered participants who may have more positive donation beliefs; however, many registered participants offered beliefs about the disadvantages of and barriers preventing donation. Despite its limitations, this study has identified a range of influences that may affect Australians' beliefs about organ donation, an important endeavor considering Australia's low donation rates. Exploring the beliefs about

posthumous and living organ donation in Australia and internationally is a crucial step in understanding donation decisions and increasing the likelihood that organ donation may occur, ultimately alleviating the suffering of those recipients waiting to benefit from organ donation decisions.

Footnotes

¹ Approximately 40% of kidney transplants performed in Australia are from living donors, the majority of whom are related to the recipient. Only one transplant of a liver lobe from a living donor has been performed in Australia (in 2003) and transplantation of a lung lobe from a living donor has yet to occur; however, the increasing use of these transplant procedures overseas suggests they may occur more frequently in the future (NHMRC, 2007).

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Appendix 1

Questions Discussed in Focus Groups and Interviews

1. Can you tell me which organs or tissue (or part of an organ) can be donated [upon death/ while living] that you know of?
2. What are the advantages that come to mind about organ donation [upon death/ while living]?
3. What are the disadvantages that come to mind about organ donation [upon death/ while living]?
4. Who are the individuals or groups that would approve of organ donation [upon death/ while living]?
5. Who are the individuals or groups that would disapprove of organ donation [upon death/ while living]?
6. What are the factors that would prevent/discourage you from donating your organs [upon death/ while living]?
7. What are the factors that would motivate/encourage you to donate your organs [upon death/ while living]?
8. If you could specify, are there particular people you would be more likely to donate to [upon death/ while living]?
9. If you could specify, are there particular people you would be less likely to donate to [upon death/ while living]?