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Author

Hyde, Melissa K, White, Katherine M

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Student and Community Perceptions about Organ Donors, Non-donors, and Transplant
Recipients

Melissa K. Hyde and Katherine M. White

Queensland University of Technology

Correspondence concerning this article should be addressed to Melissa K. Hyde, School of Psychology and Counselling, Queensland University of Technology, Brisbane, Queensland, 4034, Australia. Telephone: +61 7 3138 4881. Fax: +61 7 3138 4660.

Email: mk.hyde@qut.edu.au.

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Abstract

Despite efforts to encourage organ donation, low organ donation rates in Australia and other Western nations do not meet the demand for transplantable organs. One influence on organ donation decision-making yet to be fully explored is that of prototype perceptions about organ donors, non-donors, and transplant recipients. We conducted focus groups and interviews with 54 student and community participants to explore these perceptions of donors and non-donors in a living and posthumous context, as well as transplant recipients. Using content and thematic analysis, transcripts were analysed for consistently emerging themes. Donors were generally perceived positively as altruistic and giving and as ordinary people; however, some participants questioned the motives of living anonymous donors. Non-donors were commonly viewed negatively as self-absorbed and unaware, with living-related non-donors particularly perceived as cold-hearted and weak. Transplant recipients were generally viewed sympathetically (unfortunate and unwell); however, many participants also expressed negative views about transplant recipients as responsible for their predicament, depending upon the type of organ transplant needed. To encourage people's willingness to donate their organs, it is crucial to understand the extent to which these perceptions influence organ donation decisions.

Student and Community Perceptions about Organ Donors, Non-donors, and Transplant
Recipients

Introduction

In Australia, as in other Westernized nations, organ donation rates do not meet the demand for transplantable organs (Australian and New Zealand Organ Donor [ANZOD] Registry, 2006; Gabel, 2006). Australia has one of the lowest donation rates in the world (10 donors per million population) compared to other countries such as Spain (35.1 donors per million population), the United States (21.4 donors per million population) and the United Kingdom (10.7 donors per million population) (ANZOD Registry, 2006). Despite reported public support for organ donation and the availability of both living and posthumous organ sources, many people still die waiting for a transplant (approximately 20% of the 2000 Australians needing a transplant will die waiting) (Health Insurance Commission, 2005; Pfizer Australia, 2004).

Much research has examined the discrepancy between positive attitudes toward organ donation but low rates of donation and this gap between beliefs and action has been attributed to many factors. For instance, even if an individual wishes to donate their organs upon their death, only approximately 1% of the population will die in circumstances facilitating donation (ANZOD Registry, 2006). Further, many individuals have not discussed their donation wishes with family members who are consulted to give authority for organ donation and as a consequence family members may refuse consent to donate (Matthew, 2004; Rodrigue, Cornell, & Howard, 2006).

Donation decisions are also thought to be influenced by factors including: confusion about the concept of brain death (Siminoff, Burant, & Youngner, 2004), death anxiety (Robbins, 1990), fear of bodily mutilation, mistrust of the medical system and receiving inadequate medical care (Belk, 1990; Parisi & Katz, 1986), whether or not the donor is living or dead when donation

occurs (Boulware, Ratner, Sosa, Cooper, LaVeist, & Powe, 2002), the specific organs to be donated (Hayward & Madill, 2003), and the relationship between the donor and recipient (Crombie & Franklin, 2006; Skowronski, 1997). In a more predictive capacity, the influence of factors such as gender, age, ethnicity, religiosity, previous experience (Landolt et al., 2001; Radecki & Jaccard, 1997), knowledge (Horton & Horton, 1990), altruistic tendency (Morgan & Miller, 2002), and beliefs and attitudes (Boulware et al., 2002; Skowronski, 1997) on donation decisions have been examined. It is evident that there are a multitude of possible influences on donation decisions which vary across individuals, culture, and contexts. Although these factors go some way towards explaining organ donation decisions, they do not entirely account for why individuals choose or refuse to donate their organs, evidenced by the large amounts of unexplained variance in behaviour reported in quantitative studies (see Feeley, 2007; Radecki & Jaccard, 1997, for a review). As a result, further exploration of possible influences on donation decisions is still needed.

One possible influence on donation decisions, that has yet to be explored fully in the organ donation context, is that of prototype perceptions (from the prototype/willingness model, see Gibbons, Gerrard, & McCoy, 1995). Prototypes can be defined as an individual's social image (or perception) of the type of person who engages in a specified behaviour (e.g., the typical image of a smoker) (Gibbons, Gerrard, Blanton, & Russell, 1998). In the context of organ donation, judgements about the characteristics of the type of person who does and does not donate their organs, as well as judgements about the type of person benefiting from organ donation (i.e., an organ transplant recipient), may be influential in an individual's decision to donate their organs. Further, the individual's favourable or unfavourable evaluation of the image (prototype favourability) and judgement of the similarity of the image to themselves (prototype similarity) are thought to influence willingness to engage in behaviour (Gibbons, Gerrard, &

McCoy, 1995). In the context of organ donation, then, if an individual has a favourable image of the 'typical' person who donates their organs, and perceives themselves as similar to the 'typical' organ donor, they may be more willing to be an organ donor.

The importance of prototypes in the organ donation context is suggested by previous research investigating social representations of organ donors and non-donors (Lauri & Lauri, 2005), and organ allocation preferences (Browning & Thomas, 2001). Examining social representations of organ donors and non-donors, Lauri and Lauri (2005) found that the characteristics ascribed to organ donors were young, a public figure, and caring, whereas non-donors were described as conservative, uncaring, afraid, and uninformed. While there is a paucity of research about perceptions of posthumous organ donors and non-donors, to the authors' knowledge, there is also a distinct lack of research about perceptions of living donors and non-donors.

An examination of the literature also reveals that there is little research about perceptions of transplant recipients. Drawing on studies examining the organ allocation preferences of the general public, it is evident that many individuals have preconceived notions about recipients' deservingness of the organs allocated to them and that the perceived fairness of the organ allocation process impacts upon donation decisions (Morgan, Harrison, Afifi, Long, & Stephenson, 2008; Peters, Kittur, McGaw, First, & Nelson, 1996). Specifically, participants have expressed concern that their organs would be given to alcoholics, criminals, or undesirable people and believed that these recipients did not deserve their organs either because of their character or because they had brought their illness upon themselves. Lower priority for transplantation has also been allocated to individuals with a history of smoking (Sears, Marhefka, Rodrigue, & Campbell, 2000), alcoholism (Rodrigue, Hoffman, Park, & Sears, 1998), and drug or substance use (Neuberger, 1999) in ranking tasks for studies examining organ allocation decisions.

As noted above, there are two key areas where there is a distinct lack of research. First, existing research has not explored perceptions of posthumous or living organ donors and non-donors in any depth. Awareness of the commonly held perceptions of organ donors and non-donors will increase our understanding of what comprises these perceptions and can provide insight into the degree to which these perceptions are favourable. This awareness may also provide an indication of whether or not individuals perceive themselves to be similar to donors and non-donors, an evaluation which may ultimately inform their willingness to donate their organs. Further, given that living donation is increasingly used as a method to supplement organ resources (Gruessner & Sutherland, 2002; NHMRC, 2006), it is important to understand perceptions of donors and non-donors in this context also. Second, the majority of research has examined organ allocation priorities rather than general perceptions of transplant recipients. Exploring such general perceptions is important to determine if the negative beliefs about transplant recipients perceived to be responsible for their illness are generated spontaneously and are still salient without using a scenario-based method or a pre-determined ranking exercise (as is currently the practice in research exploring organ allocation decisions). Further, such perceptions of transplant recipients have the potential to influence organ allocation policy, particularly if some individuals are viewed as more deserving of available organs than others (Browning & Thomas, 2001; Morgan et al., 2008; Ubel & Lowenstein, 1996).

The Current Study

Given that there is little research, particularly in Australia, about the perceptions of organ donors and non-donors in a living and posthumous context, and also transplant recipients, we chose a qualitative, focus group methodology to conduct a preliminary exploration of these perceptions. Focus group methodology was thought to be appropriate as it allows an initial, in-depth exploration of beliefs in areas where there has been little previous research conducted and

it encourages discussion of socially shared views (Krueger, 1994; Wilkinson, 1998). Focus group methodology was thought to be appropriate also as the aim was to elicit the common, salient words or images (i.e., prototypes) that first come to mind for participants rather than using a written method where individuals may be more likely to deliberate over or censor their thoughts. The findings of this preliminary investigation will inform the development of a prototype scale to be used in future quantitative research. The development of a prototype scale will allow us, within the framework of a predictive behavioural decision-making model, to determine the extent to which prototype perceptions ultimately influence donation decisions.

Drawing broadly upon the concept of prototypes, prototype similarity and prototype favourability outlined in the prototype/willingness model (Gibbons, Gerrard, & McCoy, 1995), we had four main research questions:

1. What are the commonly held perceptions of donors and non-donors in both posthumous and living (to a family member or close friend and to a stranger) donation situations?
2. Do these commonly held perceptions differ according to donation context (living or posthumous) and relationship (family or stranger) with the recipient?
3. What are the commonly held perceptions of the type of person needing a transplant (i.e., transplant recipient) and the commonly perceived reasons why a transplant may be needed according to organ type?
4. Are some prototype perceptions viewed favourably and others unfavourably and are participant perceptions of donors, non-donors, and recipients similar to perceptions of themselves?

Method

Participants

Participants were invited to take part in a discussion group involving “discussing your beliefs and opinions about living and posthumous (upon death) organ donation and your perceptions of organ donors and transplant recipients”. In an effort to obtain participants with both positive and negative views, we included a specific statement in the recruitment notice that we “would like to talk to people who have both negative and positive views about organ donation”. Recruitment was directed primarily by the availability of participants such that, although we initially recruited 4 to 6 participants for each of the focus groups, if only one participant attended a given focus group, then the group discussion became an interview.

We recruited 22 males and 32 females ($n = 54$), ranging in age from 17 to 66 years ($M = 31.17$ years; $SD = 13.22$ years) from student and general community samples. Most participants self-identified as Caucasian (96%). All of the student participants either had a university degree or were in the process of obtaining one and six of the community participants (25%) held a university degree. The majority of participants had registered either intent or consent to be an organ donor upon death ($n = 37$). Students ($n = 30$) were recruited from a large metropolitan university via university notice boards or online teaching websites and received either course credit or AUD\$10 for their time. Community participants ($n = 24$) were recruited from a local physiotherapy clinic or via snowball sampling using contacts of the first author and were compensated AUD\$10 for their time. Depending upon the number of participants in attendance on the day the particular focus group session was held, students and community members participated in either a 1 hour focus group ($n = 38$) or an interview ($n = 15$).

Materials

A semi-structured focus group discussion/interview guide based on the research questions was utilised involving a series of open-ended questions about perceptions of posthumous and living organ donors and non-donors, organ transplant recipients, and reasons why an organ

transplant may be needed and the type of person needing an organ transplant for each organ type. For instance, participants were first instructed to “think about what you imagine the type of person who donates their organs upon death would be like”. Participants were then asked to share and discuss their responses to the question: “What words or images can you think of that might describe a person who donates their organs upon death?”. Participants were asked to communicate words or images specifically, rather than using other techniques (e.g., photographs), as we were interested in constructing a donor and recipient prototype scale based on the verbal descriptions generated by participants. The discussion guide ensured consistency across groups/interviews, where each group of participants or interviewees were asked identical questions presented in the same order, allowing a comparison of responses across groups and interviews.

Procedure

Approval to conduct the study was granted from the University Human Research Ethics Committee (Project approval # 0600000470). All focus groups and interviews were audio recorded with both written and verbal consent obtained from participants at the time of recording. At the beginning of the focus group or interview session, each participant was provided with an information sheet explaining the voluntary nature of participation and the right to withdraw from the study at any time. The moderator informed participants that there were no right or wrong answers, encouraged them to respond honestly, and to respect the opinions of other group members. Participants were assured of the confidentiality of their responses and that no identifying information would be included in the resulting transcript. At the conclusion of each session, participants were able to raise any concerns they had about the topic or process of organ donation, allowing the moderator to debrief participants about a potentially sensitive topic. Based on concurrent analysis of the data and to ensure relatively equal numbers of male and female and

student and community participants, focus group sessions and interviews were continued until no new information about perceptions of donors, non-donors and recipients emerged and until a range of responses were obtained, indicating that we had reached theoretical saturation (Krueger, 1994; Morgan, 1997).

Data Analysis

All focus group discussions and interviews were transcribed verbatim upon completion of each session. Transcripts were then analyzed and coded using content and thematic analysis (Hsieh & Shannon, 2005; Joffe & Yardley, 2004). Initially, broad concepts were identified for each organ donation context and coded according to the pre-determined semi-structured interview questions (e.g., perceptions of the type of person who is a posthumous organ donor). Each broad concept was further refined to incorporate the themes arising from patterns in the data (e.g., aware or community minded) (Hsieh & Shannon, 2005; Joffe & Yardley, 2004). These refined themes consisted of groupings of descriptions used to communicate participants' perceptions (e.g., knowledgeable, educated, informed, organised, thinks ahead, were descriptions that made up the theme of aware). As new themes emerged from focus group discussions and interviews, transcripts were recoded to incorporate these themes and this process continued until no new themes emerged. Each authors' coding assignments corresponded so that coding consistency was achieved before we proceeded with data analysis.

Findings and Interpretations

To answer the research questions we first looked for the consistent descriptions generated by participants about donors and non-donors and transplant recipients. We were interested in the number of times a description fitting into an identified theme was raised across individuals to gain an understanding of the common words or images (i.e., prototype) used to describe donors, non-donors and recipients to inform the scale construction. The full list of descriptions generated

by participants about donors and non-donors are presented in Appendix A and descriptions of transplant recipients and the reasons why organs are needed is shown in Appendix B.

Once the common descriptions were identified we then compared them to see if they differed according to context (living or posthumous) and relationship with the potential recipient (family or stranger). We also searched for evidence of participants' favourability or unfavourability towards an image (prototype favourability) as well as evidence of the perceived similarity of an image to participants' images of themselves (prototype similarity).

Perceptions of Organ Donors

As shown in Appendix A, regardless of the donation context or relationship, the most common descriptions of donors included selfless, helps others, and generous, caring, kind, and unselfish comprising the main theme of *altruistic and giving*. These perceptions are in line with Lauri and Lauri's (2005) findings of donors as caring and reflect the general social acceptability of organ donation (Moloney & Walker, 2002) and the positive evaluation of donors in the media (Feeley & Vincent, 2007) and in society as people who 'give the gift of life' (Sque, Payne, & Clark, 2006). Participants' discussions of living-related and living anonymous organ donors also included descriptions of donors as extremely self-sacrificing, brave and strong, represented by the theme of *courageous*. In general, living donors, particularly living anonymous donors, were held in very high regard by participants. As one participant noted: "You'd have to be some sort of a saint to just waltz into the hospital and say you know I'm happy to donate this to the next person that may well need one".

Other perceptions commonly raised by a small number of participants for posthumous and living-related donors were average, normal, ordinary person and someone who has responsibilities such as a family or children, represented by the themes of *ordinary person* and *family-oriented*. As one participant noted for posthumous donation: "I think of everyday people,

because to me it's nothing spectacular you know it's not like you need them [organs]". While the following quote about living-related donation reflects that donors are ordinary people, it also reflects the fact that such decision making in this context is often automatic, with little thought given to the decision to donate because it is viewed as 'the right thing to do' (Shanteau & Skowronski, 1990).

This may sound strange but my gut reaction was who wouldn't? Like if your family member was ill and you could donate something to help them who wouldn't?...So my opinion is everybody would do that.

Participants also raised perceptions that were unique to the specific organ donation context and relationship with the recipient. Posthumous organ donors were perceived by some participants as someone who does not have any religious beliefs and is not overly spiritual, represented by the theme of *non-religious*. Other participants described posthumous organ donors as public spirited or community-oriented captured by the theme of *community minded*. For example: "I have a picture of the type of person who is very community oriented, someone who is probably not overly involved in what's going on in the world but someone who is aware of it and aware of people". Perceptions of posthumous organ donors also included the belief that they were informed about organ donation, viewed organ donation in a practical way, and were younger in age, represented by the themes of *aware*, *pragmatic*, and *young*. For instance:

I think your typical organ donor would be younger rather than older...the older people are the less likely they are to have come to grips with the idea of organ donation whereas younger generations have probably grown up with the concept of transplant operations and the ability to do that sort of thing a little bit more.

In the case of living anonymous donors, although some participants viewed these donors as altruistic, other participants characterised these donors as irrational, as "either incredibly selfless or incredibly stupid" and "obviously extremely kind hearted I suppose...on the edge of insanity. I don't know!". These notions about living anonymous donors were represented by the

themes of *foolish* and *strange*. In accordance with this idea, two participants expressed uncertainty about living anonymous donors' (and also living related donors') motives for donating, suggesting that this type of donation would only occur if money was involved in the equation. As one participant noted:

You know I would really be doubtful if they were completely disconnected from the person that they are donating to in that situation [living anonymous]. If somebody suddenly said 'oh we need a kidney for a patient over in Western Australia' and you said 'oh I'll give you a kidney', I'd think 'well what's in it, there's something not quite right about that'. So I'd be very doubtful. I'd be very doubting of that person.

Such perceptions of living anonymous donors reflect the reluctance reported in previous research (e.g., Boulware et al., 2005; Landolt et al., 2001) to accept donations from these donors on account of their perceived psychological instability (Boulware et al., 2005), spontaneous, irrational thinking (Landolt et al., 2001) and scepticism about the donors' reasons for giving an organ to someone unknown to them.

Consistent with previous literature documenting the perceived obligation to donate to family members while living (e.g., Franklin & Crombie, 2003), participants' discussions highlighted the perceived expectation that if a family member is in need of an organ then another family member will volunteer to donate. This perception was represented by the theme of *obligated*. A small number of participants also raised the belief that living-related donors would see donation to a family member as the right thing to do and would need to be very certain about their decision. These additional beliefs are illustrated by the themes of *committed* and *emotionally attached* to the recipient. As one participant noted:

I just don't think it's logical [not to donate]...I couldn't understand anyone who could let their brother or their sister or their mother, father...continue to suffer or even possibly die when it's within their means to help them. As far as I can see when you love someone that's what you do.

Perceptions of Organ Non-Donors

Common perceptions of people who do not donate their organs, regardless of context or relationship, focussed on two themes which represented non-donors as *self-absorbed* and *unaware*. The theme of self-absorbed was comprised of descriptions of non-donors as selfish, self-centred, or ego-centric whereas the theme of unaware was encapsulated by descriptions such as ignorant, less knowledgeable, uneducated or uninformed and views organ donation in an irrational way. As one participant commented about posthumous organ non-donors:

Selfish is the key one...selfish and self-centred and thinking that, it actually irritates the hell out of me to be honest. People think that they are beyond helping others and what they came with to this world is what they get to take out of this world without leaving it behind when they can actually save somebody's life.

Regardless of donation context or relationship, some participants commonly perceived non-donors as normal, average, everyday people represented by the theme of *ordinary person*. This perception was particularly evident for living anonymous non-donors, with many participants commenting that not donating to a stranger while living was very different to not donating to a family member or close friend while living. In general, participants raised less negative perceptions of living anonymous non-donors, with the majority of participants describing these donors as 'just like me'. The perception of living anonymous non-donors as similar to the self directly parallels participants' perceptions of living anonymous donors as someone apart from the self, as saint-like, and unusual. Indeed, many participants expressed amazement that anyone would willingly risk their own health and donate their organ to someone they didn't even know for 'no reason' other than to help another person.

Consistent with Lauri and Lauri's (2005) research, non-donors in all contexts were also commonly perceived as scared or fearful and undecided about organ donation, represented by the themes of *uncertain* and *anxious*. These negative perceptions were directed particularly at living-related non-donors with some participants also describing them as a coward, weak, vindictive,

and cold-hearted suggesting that choosing not to donate while living to a family member is unacceptable (e.g., Cotler et al., 2001). For example:

If it's just like Tom, Dick, and Harry, and they're just out there and they don't know nothing about it, then I'd say they're just normal. But if like their Mum's dying and they've got a kidney to give them but they're like 'nuh, you can't have it' I think that's a totally different story. I wouldn't think very highly of them.

Other descriptors of the typical posthumous organ non-donor and living-related non-donor raised by participants focussed on explanations or reasons for why a person does not donate, including having religious beliefs or being a 'religious person' and being sick or having health issues. These explanations are exemplified by the themes of *religious* and *medically unable to donate*. For posthumous organ non-donors particularly, having an old-fashioned mindset, not really caring or thinking about organ donation, and being possessive of their organs or not wanting to be cut up were descriptions communicated about non-donors. Such descriptions are captured by the themes of *conservative*, *indifferent*, and *needing a whole body for burial*. One participant, who did not want to be an organ donor themselves, described a posthumous non-donor as:

Someone that maybe they just can't live with the fact that knowing that their organs may possibly be living in someone else's body...I just can't comprehend the whole fact that someone would want to do that, donate any organs upon their death. It seems to me to be an absolutely bizarre thing!

This participant reflected not only on the desire to have a whole body for burial (a desire which may stem from various beliefs about how the person defines death, the meanings of organs and religious beliefs; Hayward & Madill, 2003), but the belief that a person retains ownership of their organs once they die and organs will carry the qualities of the donor when donated to another individual (e.g., Kaba, Thompson, Burnard, Edwards, & Theodosopoulou, 2005). It is also interesting to contrast this perception with the belief of participants who perceived posthumous donors to be practical and pragmatic and objectified or detached themselves from

their body by referring to their body and organs as ‘bits’, ‘parts’, or ‘hunks of meat’ (see Sanner, 2001).

For living anonymous non-donors, some participants believed that there was no obligation to donate to strangers while living and that they were not responsible for doing so, represented by the theme of *not obligated*. In line with the perceived lack of responsibility and obligation, and exemplified by the themes of *sensible* and *acceptable*, many participants indicated that they were less willing to judge living anonymous non-donors because they could understand why they did not want to donate to a stranger and felt that it was not logical to give away an organ when there was no urgent reason to do so.

Overall, findings of the study suggest that there are commonly held perceptions of donors and non-donors regardless of type of context (living or posthumous) or relationship (relative or stranger). Some perceptions; however, also differed according to the specific context and relationship with the recipient. Such discrepancies are consistent with the literature demonstrating differences in willingness to give while living and upon death (Sanner, 1998) and also differences in willingness to give to a relative and a stranger (Shanteau & Skowronski, 1990). The consistencies and differences in perceptions suggest the importance of future research investigating the perceptions and evaluations of donors and non-donors that are most influential and also the extent to which they influence decisions based on donation context and relationship with the recipient.

Perceptions of Organ Transplant Recipients

As shown in Appendix B, across participant descriptions, a division in perceptions emerged. On the one hand, most participants commonly held perceptions of the typical transplant recipient as someone who is sick or in pain, vulnerable, unfortunate or a victim, and desperate to

receive a transplant. These descriptions are represented by the themes of *unwell*, *helpless*, *desperate*, and *unfortunate* and can be demonstrated by the following quote:

I suppose most people who would require a transplant would...I assume would have physical signs like sickness and stuff...you know illness to the point of hospital bound, straight bed-ridden or something like that. You don't sort of see too many people running around who require a new lung.

On the other hand, some participants perceived the typical transplant recipient as responsible for their own predicament, a substance user, and regretting their own choices, reflected by the theme of *responsible*. These perceptions were particularly evident when specific organ types such as the liver and lungs were discussed. These participants also communicated very negative views about transplant recipients, reflected in one participant's quote below about transplant recipients as being an:

Alcoholic, possible drug abuser, and you gotta wonder whether they should be at the top of the list because that is in fact self-done. No one makes you drink alcohol, no one makes you take drugs, and yet they get a transplant before a 15 year old who's got the rest of their life ahead of them and needs it just as much...but they're on the head of the list. I think if it's self induced they should be behind everyone else.

It is also interesting to note that many participants offered contrasting views in that the same participants who viewed transplant recipients in a sympathetic way also perceived transplant recipients as bringing their situation upon themselves. This conflict in perceptions is communicated by the following participant's quote:

It depends whether you came into the world and needed one [a transplant] to survive, which I think they're very unfortunate and they deserve a chance and hopefully they'll get one...but then you've got on the other hand the people that have abused it and they've got themselves there [needing a transplant] and they're waiting for someone else to pick up the pieces that they weren't responsible enough to look after.

The division in participants' perceptions of transplant recipients was also evident in descriptions of the reasons why a particular organ may be needed which indicated either responsibility or blamelessness for their illness. For instance, participants most commonly

associated the liver and lungs with the words alcohol or alcoholic (for the liver) and smoking or smoker (for the lungs) whereas participants readily associated bone marrow with the word children and skin tissue with the description of burns victim.

The negative perceptions of transplant recipients highlighted above are consistent with studies indicating participants' reluctance to donate to those perceived as responsible for their own illness (Neuberger, 1999; Rodrigue et al., 1998; Sears et al., 2000), and also participants' concern that their organs would go to undesirable people or undeserving recipients (Morgan et al., in press). Such perceptions, however, do not occur without being influenced by the information most readily available to the individual, including popular media such as television, magazines, and newspapers (Garcia, Goldani, & Neumann, 1997; Quick et al., 2006).

Accordingly, it is difficult to determine if these perceptions are truly representative of participants' own personal views about the type of person receiving organ transplants or merely a reflection of the latest media coverage about organ donation which often sensationalises cases that can be detrimental to positive organ donation beliefs (e.g., alcoholics who become liver transplant recipients and continue to drink alcohol, the sale of organs on the black market, or organ allocation on the basis of economic or racial criteria; see Garcia et al. for a discussion). Further, given the conflicting perceptions of transplant recipients as unfortunate, but also responsible, it is important for future research to determine which of these perceptions about transplant recipients (if any) are more salient when making organ donation decisions and the extent to which these perceptions influence actual donation decisions.

It is also important to highlight the finding that, while some participants were able to suggest reasons for a liver, lung, skin tissue or bone marrow transplant, many participants indicated that they did not know why a kidney, pancreas, heart, or cornea transplant may be needed. In addition, participants were rarely able to describe specific organ-related diseases, and,

instead, specified reasons for a transplant in general terms for each organ such as: cancer, complications, a genetic problem, or some kind of accident and indicated that the organ was damaged, diseased, or had failed. The lack of awareness about the range of circumstances under which transplants are needed may inhibit some individuals from donating as they do not understand or know about the reasons why transplants are needed and, therefore, may be unable to make an informed donation decision. While the lack of knowledge about the process of organ donation is an issue that has been widely addressed in the literature (e.g., Horton & Horton, 1990), knowledge deficits about the reasons why transplants are needed, both in general and according to specific organ type, have not been addressed. Strategies to increase organ donor registration and donation rates should focus on these knowledge deficits and future research should examine the impact of increased knowledge about reasons for organ transplantation on organ donation decisions.

Favourability and Similarity of Donor, Non-Donor and Recipient Perceptions

We also examined participants' evaluations of their perceptions about donors, non-donors, and recipients to establish whether these perceptions were viewed generally as favourable or unfavourable. In addition, we searched for evidence of participants' beliefs about the similarity of these prototype perceptions to perceptions of themselves (that is, whether or not participants view donors, non-donors, and transplant recipients as similar to themselves). In general, organ donors were perceived favourably and positively as altruistic and giving people and this was particularly the case for living-anonymous donors (e.g., saint). In contrast, non-donors in general were perceived unfavourably. The negative perceptions were directed particularly at posthumous organ non-donors (e.g., selfish) and living related non-donors (e.g., coward, cold hearted) but were somewhat qualified for living anonymous non-donors (e.g., no obligation, sensible). For prototype perception similarity, some participants viewed posthumous and living-related *donors*

as ordinary people, suggesting that the typical donor may be considered to be similar to the self and, therefore, *donation* in these circumstances is something that the individual may choose for themselves. In contrast, participants also perceived living anonymous *non-donors* as someone who is very much like themselves, suggesting that individuals may be more likely *not* to donate while living to a stranger.

In general, participants had a sympathetic and favourable view of transplant recipients (e.g., unfortunate, unwell, helpless); however, some participants also viewed transplant recipients unfavourably and negatively as responsible for their own illness. These contrasting favourable and unfavourable perceptions were also continued in participants' discussions of the reasons why a transplant may be needed for each organ type. Participants cited reasons for needing a transplant associated with responsibility or blame (e.g., substance use or abuse), but also with being not at fault (e.g., genetic predisposition). It is interesting to note, however, that while the description of 'ordinary' or 'normal' person was raised frequently for donors and non-donors, it was not used to describe transplant recipients in any focus group or interview. This anomaly may simply communicate participants' perceptions that transplant recipients are very different to themselves as they are unwell and are in a situation that most of us do not perceive to be relevant to ourselves or our future (i.e., 'optimistic bias'; see Weinstein, 1980). Alternatively, the tendency to perceive others as more at risk than oneself (and therefore different to the self) may be a function of the use of mass media campaigns to communicate the need for organs. As research testing the impersonal impact hypothesis (Tyler & Cook, 1984) suggests, mass media campaigns have been shown to increase perceptions of risk for others rather than perceptions of personal risk (see also Morton & Duck, 2001). Future research could explore this optimistic bias further and assess the impact of mass media campaigns on perceptions of personal risk for needing an organ transplant.

On the other hand, this difference is also concerning as the need for transplants in Australia (and in other western nations) outweighs organ availability and many of us are more likely to need a transplant in our lifetime than to donate an organ while living or upon death (Hoffman, 2006). If participants do not see themselves as similar to transplant recipients and do not evaluate them favourably, then they may be less willing to donate to transplant recipients or to consider the need for organs for transplantation. Further, if positive information about potential organ transplant recipients can increase willingness to donate organs (Singh, Katz, Beauchamp, & Hannon, 2002); then, it follows that negative perceptions about transplant recipients may also decrease willingness to donate organs. Incorporating measures of prototype perceptions, prototype favourability and prototype similarity in future quantitative research (for example by a series of semantic differential scales reflecting the images described alike, such as caring/uncaring and deserving/undeserving) will enable us to understand further the influence of these perceptions about donors and recipients on actual organ donation decision-making.

Strengths and Limitations

This research has several strengths. First, recruitment of a sample of Australian participants provides a current depiction of perceptions about donors, non-donors and transplant recipients in a context where there is a paucity of research examining such perceptions. Second, the use of qualitative focus group methodology allowed insight into perceptions of donors and non-donors in both a living and posthumous context. This method also allowed an examination of the general perceptions of transplant recipients without using a scenario or ranking exercise. Finally, the use of qualitative methods enabled us to determine the commonly held, salient, perceptions of donors, non-donors and recipients to inform the future development of a prototype perception scale. The development of the prototype perception scale for use in quantitative

research will allow us to determine the extent to which donor, non-donor, and recipient prototypes influence organ donation decisions.

There are, however, some limitations warranting consideration. First, the use of the chosen method of asking participants to discuss words or images used to describe the 'typical' donor, non-donor and recipient to elicit perceptions may have been difficult for some participants. Two participants indicated that they had not previously thought about words or images to describe donors and recipients and one participant stated that they were having difficulty verbalising their thoughts about donors and recipients. Another method, such as the use of photographs or other images (e.g., Lauri & Lauri, 2005), may have facilitated participant's discussions of their perceptions. The verbal description method, however, was chosen to elicit the words or descriptions that first come to mind (i.e., the salient perceptions) and to avoid influencing participant perceptions through the provision of visual information. Second, the use of convenience sampling for recruitment of a proportion of the community sample may have resulted in community participants with similar perceptions. Sampling for maximum variability may have provided a broader representation of perceptions. Third, the sample contained a large proportion of individuals who had registered intent or consent to donate their organs upon death which may potentially have contributed to more positive perceptions of donors. The positive perceptions attributed to donors, however, are consistent with previous research and, in addition, there were no differences detected in registered and non-registered participants' perceptions about organ donors. Fourth, a large proportion of the sample either held, or were in the process of obtaining, a university degree. The high level of education of the sample is likely due to the fact that half of the participants are students. Future research should aim to obtain a broader representation of educational levels within the population under study; however, students are still

an important population to study in this context given that over half of Australian donors with a known occupation are identified as students (ANZOD Registry, 2006).

Finally, it should be noted that the majority of participants in this study were Caucasian. Much organ donation research (e.g., Fahrenwald & Stabnow, 2005; Molzahn, Starzomski, McDonald, & O'Loughlin, 2006) has highlighted the importance of culture in beliefs and attitudes about organ donation. As such, although not feasible in the current study, future research in an Australian context should explore the beliefs and perceptions related to living and posthumous organ donation of Indigenous Australians. Such research is particularly important given that Indigenous Australians are over-represented in the population of Australians requiring treatment for end-stage renal disease (Cass et al., 2004) but are less likely to receive a kidney transplant (McDonald, 2004) compared to the Australian population in general.

Conclusion

To gain greater insight into the perceptions influencing organ donation decisions, we conducted focus groups and interviews enabling an exploration of the salient, commonly held prototype perceptions about posthumous and living organ donors, posthumous and living organ non-donors, and transplant recipients. In addition, we also explored participants' beliefs about the reasons why a transplant is needed and the descriptions of the type of person needing a transplant for each organ/tissue type. Findings revealed that some perceptions of donors and non-donors differed according to the donation context and the relationship with the recipient; however, in general, donors were viewed favourably as altruistic and giving and non-donors were viewed negatively as self absorbed. Perceptions about transplant recipients, on the one hand, focussed on recipients as unfortunate but, on the other hand, as responsible. These contrasting perceptions related to donors, non-donors and recipients could be used effectively in future research to assess the extent to which prototype perceptions, prototype similarity and prototype favourability,

influence the decision to donate organs. Understanding of these perceptions is crucial to encourage positive perceptions and increase willingness to donate organs to those relying on the altruism of others to improve the quality of their lives.

References

- Australia and New Zealand Organ Donation Registry. (2006). *ANZOD Registry 2006 report*. Adelaide, South Australia: Australia and New Zealand Organ Donor Registry.
- Belk, R. W. (1990). Me and thee versus mine and thine: How perceptions of the body influence organ donation and transplantation. In J. Shanteau & R. Harris (Eds.), *Organ donation and transplantation: Psychological and behavioral factors* (pp. 139-149). Washington, DC: American Psychological Association.
- Boulware, L. E., Ratner, L. E., Sosa, J. A., Cooper, L. A., LaVeist, T. A., & Powe, N. R. (2002). Determinants of willingness to donate living related and cadaveric organs: identifying opportunities for intervention. *Transplantation, 73*, 1683-1691.
- Boulware, L. E., Ratner, L. E., Troll, M. U., Chaudron, A., Yeung, E., Chen, S., et al. (2005). Attitudes, psychology, and risk taking of potential live kidney donors: Strangers, relatives, and the general public. *American Journal of Transplantation, 5*, 1671-1680.
- Browning, C. J., & Thomas, S. A. (2001). Community values and preferences in transplantation organ allocation decisions. *Social Science and Medicine, 52*, 853-861.
- Cass, A., Devitt, J., Preece, C., Cunningham, J., Anderson, K., Snelling, P., et al. (2004). Barriers to access by Indigenous Australians to kidney transplantation: The IMPAKT study. *Nephrology, 9*, s144-s146.
- Cotler, S. J., McNutt, R., Patil, R., Banaad-Omiotek, G., Morrissey, M., Abrams, R., et al. (2001). Adult living donor liver transplantation: Preferences about donation outside the medical community. *Liver Transplantation, 7*, 335-340.
- Crombie, A. K., & Franklin, P. M. (2006). Family issues implicit in living donation. *Mortality, 11*, 196-210.

- Fahrenwald, N. L., & Stabnow, W. (2005). Sociocultural perspective on organ and tissue donation among reservation-dwelling American Indian adults. *Ethnicity and Health, 10*, 341-354.
- Feeley, T. H. (2007). College students' knowledge, attitudes, and behaviors regarding organ donation: An integrated review of the literature. *Journal of Applied Social Psychology, 37*, 243-271.
- Feeley, T. H., & Vincent, D. (2007). How organ donation is represented in newspaper articles in the United States. *Health Communication, 21*, 125-131.
- Franklin, P. M., & Crombie, A. K. (2003). Live related renal transplantation: Psychological, social and cultural issues. *Transplantation, 76*, 1247-1252.
- Gabel, H. (2006). Organ donor registers. *Current Opinion in Organ Transplantation, 11*, 187-193.
- Garcia, V. D., Goldani, J. C., & Neumann, J. (1997). Mass media and organ donation. *Transplantation Proceedings, 29*, 1618-1621.
- Gibbons, F. X., Gerrard, M., Blanton, H., & Russell, D. W. (1998). Reasoned action and social reaction: Willingness and intention as independent predictors of health risk. *Journal of Personality and Social Psychology, 74*, 1164-1180.
- Gibbons, F. X., Gerrard, M., & McCoy, S. B. (1995). Prototype perception predicts (lack of) pregnancy prevention. *Personality and Social Psychology Bulletin, 21*, 85-93.
- Gruessner, R. W. G., & Sutherland, D. E. R. (2002). Living donor pancreas transplantation. *Transplantation Reviews, 16*, 108-119.
- Hayward, C., & Madill, A. (2003). The meanings of organ donation: Muslims of Pakistani origin and white English nationals living in north England. *Social Science and Medicine, 57*, 389-401.

Health Insurance Commission (2005). Australian Organ Donor Register Online. Available:

<http://www.hic.gov.au/ourservices/aaodr.htm>

Hoffman, L. (2006, 18-19 February). Organ donors increase, but ill die waiting. *The Weekend Australian*, p. 22.

Horton, R. L., & Horton, P. J. (1990). Knowledge regarding organ donation: Identifying and overcoming barriers to organ donation. *Social Science and Medicine*, 31, 791-800.

Hsieh, H., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15, 1277-1288.

Joffe, H., & Yardley, L. (2004). Content and thematic analysis. In D. F. Marks & L. Yardley (Eds.), *Research methods for clinical health psychology* (pp. 56-68). London, UK: Sage Publications.

Kaba, E., Thompson, D. R., Burnard, P., Edwards, D., & Theodosopoulou, E. (2005). Somebody Else's Heart Inside Me: A Descriptive Study of Psychological Problems after a Heart Transplantation. *Issues in Mental Health Nursing*, 26, 611-625.

Krueger, R. A. (1994). *Focus groups: A practical guide for applied research*. Thousand Oaks, California: Sage Publications.

Landolt, M. A., Henderson, A. J. Z., Barrable, W. M., Greenwood, S. D., McDonald, M. F., Soos, J. G., et al. (2001). Living anonymous kidney donation. *Transplantation*, 71, 1690-1696.

Lauri, M. A., & Lauri, J. (2005). Social representations of organ donors and non-donors. *Journal of Community and Applied Social Psychology*, 15, 108-119.

Mathew, T. (2004). The Australian experience in organ donation - 2003. *Annals of Transplantation*, 9, 28-30.

McDonald, S. (2004). Indigenous transplant outcomes in Australia: What the ANZDATA really tells us. *Nephrology*, 9, s138-s143.

- Moloney, G., & Walker, I. (2002). Talking about transplants: Social representations and the dialectical, dilemmatic nature of organ donation and transplantation. *The British Journal of Social Psychology, 41*, 299-320.
- Molzahn, A. E., Starzomski, R., McDonald, M., & O'Loughlin, C. (2005). Chinese Canadian Beliefs Toward Organ Donation. *Qualitative Health Research, 15*, 82-98.
- Morgan, D. L. (1997). *Focus groups as qualitative research* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Morgan, S. E., Harrison, T. R., Afifi, W. A., Long, S. D., & Stephenson, M. T. (2008). In their own words: The reasons why people will (not) sign an organ donor card. *Health Communication, 23*, 23-33.
- Morgan, S. E. & Miller, J. K. (2002). Communicating about the gifts of life: The effect of knowledge, attitudes, and altruism on behavior and behavioral intentions regarding organ donation. *Journal of Applied Communication Research, 30*, 163-178.
- Morton, T. A. & Duck, J. A. (2001). Communication and health beliefs: Mass and interpersonal influences on perceptions of risk to self and others. *Communication Research, 28*, 602-626.
- National Health and Medical Research Council (NHMRC). (2006). *Making a decision about living organ and tissue donation: Consultation draft - August 2006*. Retrieved 20th January, 2007, from http://www.nhmrc.gov.au/publications/_files/decorgantissue.pdf
- Neuberger, J. (1999). Allocating livers to substance and alcohol misusers. *Addiction Biology, 4*, 385-390.
- Parisi, N., & Katz, I. (1986). Attitudes toward posthumous organ donation and commitment to donate. *Health Psychology, 5*, 565-580.
- Peters, T. G., Kittur, D. S., McGaw, L. J., First, M. R., & Nelson, E. W. (1996). Organ donors

- and non-donors: An American dilemma. *Archives of Internal Medicine*, 156, 2419-2424.
- Pfizer Australia (2004). Poll shows Australians accept animal organ transplants but under informed. Available: <http://www.pfizer.com.au/Media/Transplants.appx>
- Quick, B. L., Meyer, K. R., Kim, D. K., Taylor, D., Kline, J., Apple, T., et al. (2007). Examining the association between media coverage of organ donation and organ transplantation rates. *Clinical Transplantation*, 21, 219-223.
- Radecki, C. & Jaccard, J. (1997). Psychological aspects of organ donation: A critical review and synthesis of individual and next-of-kin donation decisions. *Health Psychology*, 16, 183-195.
- Robbins, R. (1990). Signing an organ donor card: Psychological factors. *Death Studies*, 14, 219-229.
- Rodrigue, J. R., Cornell, D. L., & Howard, R. J. (2006). Organ donation decision: comparison of donor and nondonor families. *American Journal Of Transplantation: Official Journal Of The American Society Of Transplantation And The American Society Of Transplant Surgeons*, 6, 190-198.
- Rodrigue, J. R., Hoffman, S. J., Park, T. L., & Sears, S. F. Jr. (1998). Perceptions of liver transplant candidates with or without an alcohol use history. *Journal of Clinical Psychology in Medical Settings*, 5, 199-211.
- Sanner, M. A. (1998). Giving and taking--to whom and from whom? People's attitudes toward transplantation of organs and tissue from different sources. *Clinical Transplantation*, 12, 530-537.
- Sanner, M. A. (2001). People's feelings and ideas about receiving transplants from three different origins - questions of life and death, identity and nature's border. *Clinical Transplantation*, 15, 19-27.

- Sears, S. F., Marhefka, S., Rodrigue, J. R., & Campbell, C. (2000). The role of patients' ability to pay, gender, and smoking history on public attitudes toward cardiac transplant allocation: An experimental investigation. *Health Psychology, 19*, 192-196.
- Shanteau, J., & Skowronski, J. (1990). The decision to donate organs: An informational-integration analysis. In J. Shanteau & R. Harris (Eds.), *Organ donation and transplantation: Psychological and behavioral factors* (pp. 59-67). Washington, DC: American Psychological Association.
- Siminoff, L. A., Burant, C., & Youngner, S. J. (2004). Death and organ procurement: Public beliefs and attitudes. *Social Science & Medicine, 59*, 2325-2334.
- Singh, M., Katz, R. C., Beauchamp, K., & Hannon, R. (2002). Effects of anonymous information about potential organ transplant recipients on attitudes toward organ transplantation and the willingness to donate organs. *Journal of Behavioral Medicine, 25*, 469-476.
- Skowronski, J. J. (1997). On the psychology of organ donation: Attitudinal and situational factors related to the willingness to be an organ donor. *Basic and Applied Social Psychology, 19*, 427-456.
- Sque, M., Payne, S. A., & Clark, J. M. (2006). Gift of life or sacrifice?: Key discourses to understanding organ donor families' decision-making. *Mortality, 11*, 117-132.
- Tyler, T. R. & Cook, F. L. (1984). The mass media and judgments of risk: Distinguishing impact on personal and societal level judgment. *Journal of Personality and Social Psychology, 47*, 693-708.
- Ubel, P. A. & Loewenstein, G. (1996). Distributing scarce livers: The moral reasoning of the general public. *Social Science and Medicine, 42*, 1049-1055.
- Weinstein, N. D. (1980). Unrealistic optimism about future life events. *Journal of Personality and Social Psychology, 39*, 806-820.

Wilkinson, S. (1998). Focus group methodology: A review. *International Journal of Social Research Methodology*, 1, 181-203.

Appendix A - *Groupings of Descriptions of Posthumous, Living Related and Living Anonymous Donors and Non-Donors*

Donation context/ relationship	Description Groupings
<i>Donors</i>	
Posthumous	Giving, generous, caring, kind, thoughtful, loving, considerate, respectful, compassionate; Altruistic, selfless, unselfish, helps others; Community oriented, community minded, public spirited; Knowledgeable, educated, informed; Non-religious; Practical, logical; An ordinary person; Open minded; Organised, thinks ahead; Down to earth; Younger; Family oriented
Living Related	Giving, generous, caring, kind, thoughtful, loving, considerate, compassionate; Altruistic, selfless, unselfish, self sacrificing, helps others; Brave, strong, courageous; An ordinary person, average, normal; Deserving, good person; Emotionally attached, related; Committed; Family oriented; Informed, educated; Remunerated
Living Anonymous	Altruistic, selfless, unselfish, self sacrificing, saint; Giving, generous, caring, kind, thoughtful, loving, considerate, compassionate; Brave, strong, courageous, heroic, have faith; Strange, weird, wonder what motivation is; Foolish, stupid; Loner, no family, nothing to lose; Remunerated
<i>Non-Donors</i>	
Posthumous	Ignorant, less educated, less knowledgeable, irrational; Selfish, self-centred, ego-centric, mean; Religious, religious beliefs; Scared, undecided, uncertain; Possessive of own organs, need a whole body for burial, don't like being cut up; Conservative, introverted; Lazy, disorganised, complacent; An ordinary person, common; Medical condition, physically unable to donate
Living Related	Selfish, ego-centric, self absorbed; Scared, undecided, uncertain, fearful, coward, weak; Uneducated, uninformed; Normal, someone like me; Vindictive, cold hearted; Illogical, irrational, stupid; Medical condition, physically unable to donate; Religious; Poor/lacking family relationship, not a close relation
Living Anonymous	Normal, average, everyday person, just like me; Selfish, self absorbed, ego-centric; Sensible, acceptable; Ignorant, uneducated; Not responsible for doing it, no obligation; Scared

Appendix B - *Groupings of Descriptions of Transplant Recipients and Organ Type*

	Description Groupings
Transplant recipients	Sick, dying, terminal, in pain; Needy, helpless, vulnerable, reliant on someone else; Desperate; Grateful, hopeful; Responsible for their own predicament, substance user, regret their own choices; Unlucky, unfortunate, victim; Scared, worried, depressed; Waiting, patient; Frail, weak; Disadvantaged, limited; Trying to accept their own death/mortality
<i>Organ/Tissue type</i>	
Liver	Substance use or abuse: alcohol, alcoholism, alcoholic, heavy drinker and drugs, medication; Liver disease, infection, failure; Hepatitis; Cancer; Genetic, born with it; Cirrhosis; Accident; Yellow
Kidney	Kidney disease, infection, failure; Don't know; Dialysis; Genetic, born with it; Substance use/abuse; Diabetes; Cancer; Accident, injury; Hepatitis
Lung	Smoking, smoker; Exposure to environmental pollutants or chemicals (e.g., asbestos, dust); Cystic fibrosis; Respiratory problems, asthma; Cancer; Genetic, born with it; Accident, injury; Lung diseases, deformity, scarring, degenerative; Tuberculosis; Emphysema
Heart	Lifestyle factors (e.g., diet, overweight, smokes, drinks); Heart disease, infection, failure, weakness; Genetic, born with it; Heart defects - valve, heart murmur, hole in the heart; Heart attack, arrhythmia, cardiomyopathy, arteriosclerosis; Older, old age; Accident, injury; Cancer
Pancreas	Don't know; Diabetes, insulin, sugar; Cancer; Genetic, born with it; Pancreatic disease, infection, failure; Accident, injury; Pancreatitis
Cornea	Blind, poor vision, cataracts; Accident, injury, damage; Don't know; Older, old age; Genetic, born with it; Disease, degenerative condition; Glaucoma
Bone marrow	Leukaemia; Cancer; Children; Genetic; Blood related disease; Don't know
Skin	Burns victim (chemical or fire); Accident, injury, trauma, damaged, scarring; Cancer; Infection, diseased skin; Genetic, deformity