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Author

Hyde, Melissa K, White, Katherine M

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RUNNING HEAD: Donors' perceptions about transplant recipients

A Comparison of Registered and Unregistered Organ Donors' Perceptions about Transplant
Recipients

Melissa K. Hyde and Katherine M. White

School of Psychology and Counselling, Queensland University of Technology, Brisbane, 4059,
Australia.

Correspondence concerning this article should be addressed to Dr Melissa Hyde, School of
Psychology and Counselling, Queensland University of Technology, Victoria Park Road, Kelvin
Grove, Queensland, 4059, Australia. Telephone: +61 7 3138 4887. Fax: +61 7 3138 0486.

Email: mk.hyde@qut.edu.au

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3 Tables, 1 Appendix.

Abstract

Background: We examined whether registered and unregistered donors' perceptions about transplant recipients' previous behavior (e.g., substance use) and responsibility for illness differed based on their deceased organ donor registration decisions.

Methods: Students and community members from Queensland, Australia were surveyed about their perceptions of transplant recipients.

Results: Respondents ($N = 465$) were grouped based on their organ donor registration status to determine if their perceptions about transplant recipients differed. Compared to registered respondents, a higher proportion of unregistered respondents held more negative and less favorable perceptions of recipients. Multivariate analysis of variance confirmed statistically that unregistered respondents evaluated recipients more negatively than registered respondents, $F(6,449) = 5.33, p < .001$. Unregistered respondents were more likely to view recipients as a smoker, substance user, or alcohol dependent and as undeserving of a transplant, blameworthy, and responsible for their illness.

Conclusion: Potential donors' perceptions of transplant recipients' behavior and responsibility for illness differ according to their registration status. Future interventions should challenge negative perceptions about recipients' deservingness and responsibility and promote the perspective that people from all walks of life need transplants in the aim of ultimately encouraging an increase in donor registration.

Keywords: transplant recipient, responsibility for illness, deservingness, substance use, organ donation.

The discrepancy between positive organ donation attitudes but low rates of consent for deceased donation has been attributed to numerous factors (e.g., communication of donation wishes, confusion about the concept of brain death, knowledge, general willingness) (1). One influence common to all individuals' decisions to donate organs upon death which has received less research attention is the type of person benefiting from a transplant (2). Research suggests that people have preconceived notions about transplant recipients' behavior prior to transplantation and express concern that their organs may be given to alcoholics, drug users, smokers, criminals, or other undesirable people (3-4). These negative perceptions manifest as a judgment about recipients' worthiness or deservingness of the organs allocated to them either because their behavior is socially undesirable or because they are perceived to be responsible for their own illness (5).

Members of the general public have been less willing to distribute organs to intravenous drug users, perceiving them as unworthy candidates, even if they had better transplant outcomes than other recipients (6). Similarly, respondents' preferences for a potential liver transplant recipient whose need for a transplant arose from a naturally occurring medical condition rather than from their own behavior (i.e., excessive consumption of alcohol) has been demonstrated (7). Respondents in previous studies have allocated lower priority for transplantation to individuals with a history of smoking (8), alcoholism (9), and drug/substance use (10). These perceptions about transplant recipients' behavior and responsibility for their illness have the potential to influence both organ allocation policy and organ donation decisions (3,5,8-9), particularly if some individuals are viewed as more deserving of the scarce available organs than others (11-12). To extend the existing literature, we explored whether people who have and have not registered their commitment to donate differ in their perceptions about transplant recipients.

Materials and Methods

Questionnaire

University Human Research Ethics Committee approval was obtained prior to conducting the study. A questionnaire was constructed to assess individual difference variables including age, gender, ethnicity, religious denomination, relationship status, education, registration status, knowledge, and previous experience with organ donation, as well as questions related to perceptions about organ transplant recipients. Self-reported knowledge was assessed using one item (Overall, how would you rate your knowledge of the topic of organ donation?), rated on a 7-point Likert scale from *poor* (1) to *excellent* (7). Respondents were instructed to think about the type of person who needs an organ transplant, and to rate their opinion of the type of person who needs an organ transplant on six bipolar descriptor items on six accompanying response scales from 1 to 7 (e.g., What is your opinion of the type of person who needs an organ transplant? 1 *blameworthy* to 7 *unfortunate*; 1 *deserving of organs* to 7 *undeserving of organs*; see Appendix 1). These items were based on earlier pilot work (13). In accordance with the research questions, we were interested primarily in respondents' perceptions about transplant recipients' behavior and their evaluation of recipients' deservingness or responsibility for their illness. The six bipolar descriptor items were: *non-smoker/smoker*, *substance user/not a substance user*, *blameworthy/unfortunate*, *deserving of organs/undeserving of organs*, *responsible for their illness/not responsible for their illness*, and *alcohol dependent/not alcohol dependent*.

Questionnaires ($N = 1800$) were distributed to community members via their mailbox (with an accompanying letter of invitation and reply paid envelope) in various areas of South East Queensland, Australia, and university students in-class time across 3 university campuses in South East Queensland during the period of March to August 2007. University students received course credit and the opportunity to win one of four AUD\$30 music vouchers for their participation and community members were given the opportunity to win one of four AUD\$50

department store vouchers. In total, 465 questionnaires were returned, representing a response rate of 25.8%.

Statistical Analysis

Descriptive analyses were conducted to determine differences in the demographic profile of respondents using chi-square analysis (which tests whether two categorical variables are related, 14) and Analysis of Variance (ANOVA; which uses the F statistic to test whether the mean of two groups differs significantly, 14) (Table 1). A dichotomous independent variable was created to distinguish between respondents who had registered their donation wishes (*registered respondents* $N = 259$; coded as 1 for analyses) and those who had not (*unregistered respondents* $N = 206$; coded as 0 for analyses). Initially, the percentage of registered and unregistered respondents harboring negative perceptions about transplant recipients was examined (Table 2). Multivariate Analysis of Variance (MANOVA, which tests whether the means of two groups differ significantly when there are multiple outcome/dependent variables, 14) was then conducted to explore the statistically significant differences in scores on perceptions about transplant recipients between those who had and had not registered their donation decision (Table 3).

Results

Descriptive Analysis of the Demographic Profile

Respondents were university students ($n = 283$) and community members ($n = 182$), ranging in age from 17 to 65 years ($M = 30.6$ years). Of the total sample, approximately half (55.8%) had registered their organ donation decision on a donor register or other method (e.g., driver license). The majority of respondents was Caucasian (88%), female (74%), highly educated (79%), and single (51%). Most respondents considered themselves to belong to a religious denomination (63%). Some respondents had previous experience with organ donation

having either known an organ donor (16%) or known someone waiting for a transplant (11%). See Table 1 for the specific demographic profiles for registered and unregistered respondents.

Differences in the Demographic Profile of Respondents

Chi-square analyses revealed differences between unregistered and registered respondents on the individual difference variables of ethnicity, $\chi^2(1, N = 461) = 22.04, p < .001$, education, $\chi^2(1, N = 465) = 33.84, p < .001$, relationship status, $\chi^2(1, N = 455) = 18.90, p < .001$, and religious denomination, $\chi^2(1, N = 465) = 11.61, p = .001$. ANOVA also revealed differences between unregistered and registered respondents in age, $F(1, 463) = 67.11, p < .001$, and self-reported knowledge about organ donation, $F(1, 460) = 31.12, p < .001$. These differences are likely due to the higher proportion of respondents who were Caucasian, educated, and students, and the higher proportion of registered respondents who were married and did not state a religious preference. Given that registered respondents self-reported higher levels of knowledge about organ donation than unregistered respondents, bivariate correlations (i.e., which show the strength of the relationship between two variables, 14) were examined to determine if there was a relationship between knowledge and the items reflecting perceptions about transplant recipients. For both registered and unregistered participants, no statistically significant correlations emerged between the knowledge and perceptions about recipients items (with the exception that self-reported knowledge and perceptions about transplant recipients as not being substance users had a small but significant positive correlation for registered respondents only, $r(256) = .17, p = .006$).

Insert Table 1 about here

Prevalence of Registered and Unregistered Respondents Negative Perceptions about Recipients

Initially, the percentages of registered and unregistered respondents endorsing negative perceptions were examined in a descriptive manner. Unregistered respondents consistently held more negative and less positive perceptions about transplant recipients (Table 2). This trend was

particularly evident with the items relating to perceptions of recipients as a smoker, substance user, and responsible for their illness. It is noteworthy also that a large proportion of both registered and unregistered respondents chose the middle response option rather than endorsing solely positive or negative perceptions.

Differences in Registered and Unregistered Respondents Perceptions about Recipients

To establish if these differences in perceptions were statistically significant, a MANOVA was conducted with registration status (*registered vs. unregistered*) as the independent variable and the transplant recipient perception items as the dependent variables. This analysis indicated there were differences between registered and unregistered respondents' perceptions about transplant recipients, $F(6,449) = 5.33, p < .001, \eta^2 = .07$. To further explore the identified differences between registered and unregistered respondents' perceptions, the transplant recipient perception items were examined at the univariate level with appropriate adjustment of the alpha cut off to control for Type I error (i.e., when a statistically significant effect is found but in reality there is no effect, 14) (Table 3). These analyses revealed that unregistered respondents overall had more negative evaluations of transplant recipients compared to registered respondents. Specifically, unregistered respondents were more likely to perceive the typical transplant recipient as a smoker, a substance user, blameworthy, undeserving, responsible for their illness, and alcohol dependent, than registered respondents.

Insert Tables 2 and 3 about here

Discussion

Summary of Findings

Our preliminary examination suggests that, consistent with previous research (2-4,6,11), potential donors' perceptions about transplant recipients' behavior prior to transplantation and evaluations of their deservingness or responsibility for illness may impact upon their donation

registration decisions. Unregistered respondents had less favorable evaluations of transplant recipients believing that they were more likely to be a smoker, substance user or alcohol dependent and to perceive recipients as undeserving, blameworthy and responsible for their illness. These perceptions are concerning as they may reflect a conviction that potential recipients perceived as responsible for their illness should not receive equal priority for transplantation (3,6,8,9,11), which may ultimately impact on a person's decision to donate their own or other's organs for transplantation (9). It should be noted, however, that given a large proportion of both registered and unregistered respondents chose the middle response option rather than endorsing solely positive or negative perceptions, extreme responses, therefore, were not recorded on average by either group. Statistically significant differences between the mean values for unregistered and registered participants, however, were observed.

Implications of the Research

The findings suggest several areas for future research. First, it is important to understand how these perceptions about transplant recipients eventuate and the beliefs and sources of information that may potentially inform these perceptions. It is possible that such perceptions (e.g., evaluations of responsibility) may be perpetuated by the media (15-16) or by the prevalence of associations between particular organs and unhealthy behaviors such as the assumption that a lung transplant is needed because the patient is a smoker (17). Future research should employ both qualitative methods to allow an in-depth exploration of the reasoning behind these perceptions and quantitative methods (e.g., statistical modeling) to determine at what stage in the decision-making process these perceptions may impact on people's donation beliefs and actions.

In addition, it is important to address the negative evaluations of transplant recipients and to inform people about the numerous reasons why transplants are needed to encourage the idea that people from all walks of life need transplants (13). While education to target the lack of

knowledge about the process of organ donation has been widely advocated (18), 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 ultimately donation rates) could examine whether increased knowledge about reasons for organ transplantation has a positive impact on organ donation decisions (13).

Finally, it is noteworthy that many individuals differentiate transplant recipients' deservingness for organs on the basis of their perceived responsibility for their illness as a result of past behavior. Such perceptions can be considered contrary to the altruistic context and spirit in which organs are given as organ donation is often represented as the ultimate gift which may save or improve the quality of another human being's life (19). Like any other life enhancing or life saving medical treatment, many argue that access to organ donation should not be based on personal responsibility for past behavior or actions that have led the potential recipient to their need for medical assistance (20-23). The concept that all recipients need organs regardless of past actions could be promoted and the altruistic spirit of giving on the basis of need and community benefit, and not perceived responsibility for current health status, could be encouraged strongly in donor registration promotion initiatives.

Study Limitations

Results should be interpreted in light of study limitations, including the higher proportion of Caucasian and female participants. The low response rate, likely due to the data collection method employed, is a major limitation of the present study leading to a cautious interpretation of the results obtained. The lack of comparison between responders and non-responders is also a limitation of the present research. Future efforts to gain a community wide response may benefit from the use of interviewing of individual households to increase response rate, and, in addition, individual interviewing would allow for a comparison between community members who do and

do not wish to participate. A final limitation relates to the need to potentially consider other variables (e.g., general deceased donation attitudes, social influences, and self-efficacy, 24-25) that may be relevant to people's donation decisions.

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Appendix 1

Questionnaire Items Related to Perceptions about Organ Transplant Recipients

Think about the typical person who needs an organ transplant. What is your opinion of the type of person who needs an organ transplant? Please circle a number on each line.

Example:

a	Bad	1	2	3	4	5	6	7	Good
a	Non-smoker	1	2	3	4	5	6	7	Smoker
b	Substance user	1	2	3	4	5	6	7	Not a Substance user
c	Blameworthy	1	2	3	4	5	6	7	Unfortunate
d	Deserving of organs	1	2	3	4	5	6	7	Undeserving of organs
e	Responsible for their illness	1	2	3	4	5	6	7	Not responsible for their illness
f	Alcohol dependent	1	2	3	4	5	6	7	Not Alcohol dependent

Note. The response options available to participants were comprised only of the two endpoints stated above for each item (i.e., there were no descriptors accompanying values 2 through 6). A lower value on an item (e.g., 1 through 3) represented a more negative perception about recipients (e.g., smoker, substance user etc.). A higher value on an item (e.g., 5 through 7) represented more positive perceptions about recipients (e.g., deserving of organs, not responsible for their illness etc.). The middle value (i.e. 4) represented neither positive nor negative perceptions about recipients.

Table 1

Demographic Profile of Unregistered and Registered Respondents

		<i>Unregistered</i>	<i>Registered</i>
		<i>n = 206 (%)</i>	<i>n = 259 (%)</i>
Age in years (SD)		24.94 ± 11.73	35.17 ± 14.55
Gender	Male	56 (27.2)	65 (25.1)
	Female	150 (72.8)	194 (74.9)
Ethnicity	Caucasian	166 (81.8)	246 (95.3)
	Non Caucasian	37 (18.2)	12 (4.7)
Religion	Religious denomination	147 (71.4)	145 (56.0)
	No religious denomination	59 (28.6)	114 (44.0)
Education	High school and below	10 (5.0)	46 (17.8)
	Diploma/trade certificate	8 (4.0)	34 (13.1)
	University degree	188 (91.0)	179 (69.1)
Relationship status	Single	139 (69.2)	100 (39.4)
	Married/de-facto	57 (28.4)	123 (48.4)
	Separated/divorced	4 (1.9)	25 (9.8)
	Widowed	1 (0.5)	6 (2.4)
Previous experience	Knew an organ donor	35 (17.0)	41 (15.8)
	Knows recipient on waiting list	24 (11.7)	28 (10.8)
Organ donation knowledge (1 = <i>very poor</i> to 7 = <i>excellent</i>) (SD)		3.57 ± 1.45	4.31 ± 1.40

Table 2

Frequency (%) of Registered and Unregistered Respondents Perceptions about Transplant Recipients

What is your opinion of the type of person who needs an organ transplant?	Unregistered <i>n</i> = 204	Registered <i>n</i> = 257
<hr/>		
Substance user/Not a substance user		
<i>(Substance user)</i> 1 to 3	43 (21.1)	29 (11.3)
4	109 (53.4)	138 (54.0)
<i>(Not a substance user)</i> 5 to 7	52 (25.5)	89 (34.7)
<hr/>		
Blameworthy/Unfortunate		
<i>(Blameworthy)</i> 1 to 3	12 (5.9)	6 (2.4)
4	72 (35.5)	82 (32.0)
<i>(Unfortunate)</i> 5 to 7	119 (58.6)	168 (65.6)
<hr/>		
Responsible for their illness/Not responsible for their illness		
<i>(Responsible for their illness)</i> 1 to 3	25 (12.3)	17 (6.6)
4	108 (52.9)	106 (41.2)
<i>(Not responsible for their illness)</i> 5 to 7	71 (34.8)	134 (52.2)
<hr/>		
Smoker/Non-smoker		
<i>(Smoker)</i> 1 to 3	69 (34.0)	52 (20.3)
4	105 (51.7)	154 (59.9)
<i>(Non-smoker)</i> 5 to 7	29 (14.3)	51 (19.8)
<hr/>		
Alcohol dependent/Not alcohol dependent		
<i>(Alcohol dependent)</i> 1 to 3	21 (10.3)	16 (6.2)

	4	130 (63.7)	150 (58.4)
	(<i>Not alcohol dependent</i>) 5 to 7	53 (26.0)	91 (35.4)
<hr/>			
Undeserving/Deserving			
	(<i>Undeserving</i>) 1 to 3	12 (6.0)	10 (4.0)
	4	76 (37.4)	77 (30.0)
	(<i>Deserving</i>) 5 to 7	115 (56.6)	169 (66.0)

Note. Response options were originally based on 7-point bipolar descriptor scales ranging from 1 to 7. Responses have been condensed into three response categories for the purposes of presentation (1 to 3, 4, 5 to 7) with scale anchors are presented in brackets. Lower values (1 to 3) represent more negative perceptions and higher values (5 to 7) represent more positive perceptions about transplant recipients. The middle value (4) represents neither positive nor negative perceptions about transplant recipients.

Table 3

Mean Differences in Unregistered and Registered Respondents' Perceptions about Transplant Recipients

	Unregistered	Registered
Perceptions of Transplant Recipients	<i>n</i> = 202	<i>n</i> = 254
Smoker/Non-smoker	3.73	4.17***
Substance user/Not a substance user	4.13	4.53**
Blameworthy/Unfortunate	5.21	5.55**
Undeserving/Deserving	5.04	5.48***
Responsible for their illness/Not responsible for their illness	4.50	5.06***
Alcohol dependent/Not alcohol dependent	4.38	4.74**

*** $p < .001$, ** $p < .008$

Note. Mean scores are based on 7-point bipolar descriptor scales ranging from 1 to 7. A lower value on an item corresponds to a more negative perception about recipients (e.g., smoker, substance user etc.). A higher value on an item corresponds to more positive perceptions about recipients (e.g., deserving of organs, not responsible for their illness etc.).