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OPEN

Organ Donation Attitudes Among Individuals With Stage 5 Chronic Kidney Disease

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Background. The need for transplantable organs drastically outweighs the supply. Misconceptions are a barrier to increasing the rate of donor registration. Individuals with stage 5 chronic kidney disease (CKD) may incorrectly believe they are unable to be donors; however, their attitudes have not been studied. This study aims to explore beliefs of individuals with stage 5 CKD about their ability to donate and test the validity of an organ donation scale. **Methods.** We examined the psychometric properties of a new 25-item organ donation scale among 554 patients with stage 5 CKD at 12 dialysis units in southeast Michigan. Patients completed surveys during dialysis treatment with assistance from a program coordinator or social worker. **Results.** Two subscales with good psychometric properties were identified: general benefits ($\alpha = 0.86$) and general barriers ($\alpha = 0.80$). For both subscales, more positive attitudes were associated with higher intent to sign up on the donor registry, suggesting validity of the scale. **Conclusions.** Patients who were older than 60 years, white, or of higher education status reported more positive attitudes. Misconceptions about the ability of patients with stage 5 CKD to donate are common and highlight a need for education about donor eligibility. Individuals with stage 5 CKD may be able to donate organs and tissues.

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Over 115 000 individuals are on the organ transplant waitlist, based on the Organ Procurement and Transplantation Network data as of December 28, 2017. This number has increased over the past decade, coinciding with increased prevalence of chronic health conditions, such as diabetes and stage 5 chronic kidney disease (CKD).¹ Nearly 14 000 individuals are currently waiting for a liver on the transplant waitlist; this group comprises 12% of the waitlist. According to Organ Procurement and Transplantation Network data, in 2016 over 33 500 transplants were

performed, an increase of 19.8% since 2012; however, this number is still far from meeting the current need.

In response to the increasing need, various approaches have been used to increase organ donation including educating older adults,²⁻⁴ approaching individuals in hospice,⁵ and educating minority populations.⁶ The use of livers from extended criteria donors is being recognized as a viable method of increasing the number of transplants.^{7,8} From 2004 to 2008, 35% of liver-alone donors in Michigan had stage 5 CKD.⁹ This shift presents an increased opportunity for older adults and those with chronic conditions to become organ

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and tissue donors. People with chronic health conditions, such as stage 5 CKD, however, may believe that they are unable to donate their organs after death. Although individuals with stage 5 CKD cannot donate their kidneys, they can donate other organs and tissues.

Although several studies have looked at attitudes of individuals with CKD toward receiving a living kidney donor transplant,¹⁰⁻¹² no research has been conducted on the attitudes of individuals with stage 5 CKD on being deceased organ and tissue donors themselves. The purpose of the study is to understand the attitudes of persons with stage 5 CKD toward being a deceased organ donor through development of a validated tool to assess the beliefs. In addition, we aimed to understand the uses of the instrument and the role/implications of the tool in increasing awareness of the potential for deceased donation among those on dialysis and thus increasing organ donation rates.

Our research group developed an organ donation scale that addressed specific barriers of individuals on dialysis to donating organs and other common benefits and barriers to donation. The latter 2 parts of this scale were used in prior studies, funded by the Health Resources and Services Administration (HRSA), Healthcare Systems Bureau, Division of Transplantation, among African Americans.¹³⁻¹⁶ In the current study, we added dialysis-specific items to an adapted survey instrument that was administered to patients with stage 5 CKD at dialysis units in southeast Michigan.¹⁵ The purpose of the study was to test the psychometric properties and correlates of this adapted measure of organ donation attitudes and practices for individuals on dialysis.

MATERIALS AND METHODS

This study was part of a larger organ donation intervention trial that tested the effectiveness of using lay health advisors (termed “peer mentors”) to discuss organ donation with individuals on dialysis to increase enrollment in the Michigan Organ Donor Registry. The larger trial used a cluster randomized, pre-post design with a comparison group. Data for the current study was collected from the baseline survey instrument, which was completed by 554 participants from 12 dialysis units in southeast Michigan between June 2011 and September 2013. Patients who were on in-center hemodialysis, home hemodialysis, or peritoneal dialysis were included. Informed consent was obtained from all participants. The study was approved by the Henry Ford Health System Institutional Review Board as well as the University of Michigan Health Sciences Institutional Review Board.

Survey Development

The attitude scale used in this study was adapted from a similar instrument used by our research group in 3 prior organ donation studies in African American hair salons,¹³ African American churches,¹⁴ and alumni chapters of historically African American Greek Letter Organizations.¹⁶ The questionnaire used in our previous studies did not ask about beliefs specific to a person on dialysis donating organs after death and the ethical issues associated with the practice. Our research group generated potential questions for this domain based on input from the organ procurement organization and social work manager. The potential items were tested with the Continuous Quality Improvement committee of the dialysis provider and during a focus group of individuals

on dialysis. Ultimately, 5 items were added to address dialysis-specific barriers and benefits. The new items were numbered from 10, 11, 23 to 25 (see Table 2 in the Results section). Questions regarding dialysis-specific barriers include being too sick to donate or having organs that cannot be used. Questions regarding dialysis-specific benefits include serving as a role model to other dialysis patients and giving back.

The adapted survey comprised 35 items. All items were scaled 1 as “strongly disagree” to 7 as “strongly agree.” The survey assessed participants' barriers and benefits to organ donation. Questions to assess barriers to donation probe on family disapproval, cost, religious and spiritual beliefs, misconceptions about the donation process, and the “ick” and “jinx” factors. Ick factors are those related to a disgust response to the idea of the organ donation and transplantation process, and jinx factors are those related to unwarranted fears and superstitions about harm or premature death occurring as a result of signing a donor card.¹⁷ Questions to assess benefits to organ donation probe on altruism, providing comfort to family members after death and religious beliefs.

Baseline Measurements

Baseline measurements include attitudes toward organ donation, enrollment status on the Michigan Organ Donor Registry (DR), intention to donate, awareness of the DR, personal connections to organ donation, and demographics. Self-reported enrollment status on the DR was assessed through the question, “Have you ever signed up to donate your organs?” A response of “yes” indicated positive donation status. Subsequent questions asked which method was used to sign up and whether or not they have a red heart sticker on their license. Individuals with a red heart sticker were not included in the study because in Michigan, this indicates the individual is already signed up on the DR.

Intention to donate was assessed through the question, “How likely are you to sign up as an organ donor?” Response options were scaled 1 as “not at all likely” to 10 as “very likely.” Awareness of the DR was assessed through the question, “Have you ever heard of the Michigan Organ Donor Registry?” We used these items to describe the patient population.

Personal connection to organ donation was assessed through 5 “yes/no” questions. These questions asked the respondent if they know anyone who needs an organ transplant, has received on organ transplant, or has donated an organ. Questions also asked the respondent if they have talked to their family members about donating their organs and if they are currently pursuing an organ transplant. We used these items to describe the patient population.

Demographic data include date of birth, sex, race/ethnicity, education, and income. Educational status was determined by asking, “What is the highest grade or degree you have completed?” Response categories were “some high school or less,” “High school graduate or GED,” “some college or 2-year degree,” “4-year college graduate,” “masters degree,” and “doctoral or professional degree.”

To measure the household income, we queried “What is your current total yearly household income before taxes? (please include income from all sources in your home.)” Response categories were “under US \$10000,” “US \$10000 to US \$19999,” “US \$20000 to US \$39999,” “US \$40000 to US \$59999,” “US \$60000 to US \$79999,” “US \$80000 to US \$99999,” “US \$100000 to US \$149999,” “US \$150

000 to US \$199999,” and “US \$200000+.” Responses were collapsed into smaller categories as displayed in Table 1.

Survey Administration

The National Kidney Foundation of Michigan received funding from the US Department Health and Human Services, HRSA, Healthcare Systems Bureau, Division of Transplantation to implement an organ donation intervention among patients on dialysis. A research consortium consisting of the National Kidney Foundation of Michigan, the University of Michigan, Gift of Life/Minority Organ and Tissue Transplant Education Program, Greenfield Health Systems, and Henry Ford Health System designed the intervention.

The 12 dialysis units that participated in the study were randomized into the intervention or control group and pair-matched by size (\geq or $<$ 150 patients) and racial composition (\geq or $<$ 50% of patient population categorized as African-American). All data collection for these analyses occurred before any intervention activity was initiated.

One of 3 study coordinators approached patients in the dialysis units to invite them to participate in the study. All participant recruiters for this project were members of the consortium and had social work backgrounds. The recruiter was unknown to the patient except at one unit where the recruiter was the unit social worker. A complete list of eligible patients was provided by the clinical social worker(s) on staff

at the dialysis unit. Patients who were on in-center hemodialysis, home hemodialysis, or peritoneal dialysis were eligible. Patients were excluded from the study if they were younger than 18 years, non-English-speaking, less than 90 days on dialysis, unable to provide consent due to dementia or cognitive impairment, or had a red heart sticker on their license, indicating enrollment on the DR. Patients who met the study criteria and agreed to participate were asked to complete a consent form and a baseline questionnaire. Program recruiters carefully reviewed the consent form with interested patients. If possible, the paper questionnaire and consent form were completed individually by the patient. However, the questionnaire was most often administered orally by a program coordinator or social worker because many patients reported difficulty writing during dialysis treatment or had low literacy. A color-coded, large print copy of the scale used in the survey was provided to patients when the survey was administered aloud. Patients received a US \$10 gift card incentive upon completion of the survey.

Each questionnaire contained a unique participant code that indicated the unit from which the participant was recruited. The participants' name and address were associated with the unique participant code on the cover sheet and in a separate database of cover sheet information. Survey responses were stored separately from the participant contact information to protect confidentiality.

TABLE 1.

Patient demographics and baseline information

	Intervention ^a , % (n = 314)	Control ^a , % (n = 239)	Total, % (n = 554)
Age group, y			
45 or less	17.83	16.74	17.5
45-60	31.53	32.22	31.8
> 60	50.64	51.05	50.7
Sex (female)	45.86	44.35	45.21
Race			
Black	77.71	70.29	74.37
Hispanic/Latino	1.27	5.86	3.25
White	18.15	20.92	19.31
Other	2.87	2.93	3.07
Education			
Some high school or less	18.91	13.81	16.7
High school or GED	29.81	34.31	31.8
Some college or 2-y degree	35.26	35.56	35.4
4-y college or above	16.03	16.03	16.2
Income			
< US \$20000	51.83	50.00	51.01
US \$20000-59999	38.53	36.67	37.69
US \$60000 or more	9.63	13.33	11.31
Mean scale 1: general benefits (SD)	5.83 (1.06)	5.78 (1.12)	5.81 (1.08)
Mean scale 2: general barriers ^b (SD)	5.69 (1.01)	5.70 (0.95)	5.69 (0.99)
Rate of positive donor registry enrollment	16.61	13.30	15.19
Intended donor registry enrollment among nonenrolled			
Low (1-3)	10.27	15.87	12.71
Medium (4-7)	38.02	33.65	36.23
High (8-10)	51.71	50.48	51.06
No. patients per unit (mean, range)	52.33 (21-98)	39.33 (24-71)	44 (21-98)

^a Items were reverse coded so that higher scores indicate more positive feelings toward donation.

^b Dialysis facilities were randomized to intervention or control condition. Patients at the given site were then considered intervention or control based on the facility with which they were associated.

Participants in both the intervention and control conditions were asked to complete a baseline survey about organ donation attitudes. Participant data were collected from the baseline survey instrument, which was completed by 554 dialysis patients from 12 dialysis centers between June 2011 and September 2013.

Statistical Analysis

Factor analysis, with varimax rotation, was used to identify potential subscales. Fourteen of the items were reverse coded so that higher values for all items are considered more positive, prodonation attitudes. After identifying a 2-factor solution, we computed internal consistency of each scale (Cronbach α) and then examined the relationship between scale scores, demographics, and intended donor status. Two subscales were identified, and the associations between scale scores, demographics, and intended donor status were examined. Multivariate analyses included age, sex, race, education, and income as covariates. Because we used a cluster randomized design, we accounted for the effect of sampling individuals from clusters (dialysis units) rather than randomly sampling individuals from the population. All *P* values adjust for the intraclass correlation due to the design effect of sampling individuals within chapters. The intraclass correlations of the 2 scales identified ranged from 0 to 0.002. The data analysis for this article was generated using Proc Mixed in SAS software, version 9.3 (SAS Institute Inc., Cary, NC).

RESULTS

In total 554 patients (314 intervention, 239 control) completed the baseline survey instrument. Of the 1294 patients

approached, about 45% consented to participate in the study. The average number of participants per dialysis unit was 44 with a range of 21 to 98. Given the strong psychometric properties of the scale, we retained all the items in the final scale. This was also due to the fact that we have previously used most of the items, except for the dialysis-specific questions, in several prior studies. All of the dialysis-specific items were loaded on the scale so none were removed for the purposes of reporting results.

Patient Demographics

Half of the sample was older than 60 years, and about one third was aged 45 to 60 years as shown in Table 1. More than half of participants were male (55%). The majority (74%) was black/African American and 19% were white. About half reported an annual income below US \$20,000, whereas 38% reported an income of US \$20,000 to \$59,000 and 11% reported an income greater than US \$60,000. The majority (84%) received some college or less education, whereas 16% received a 4-year college education or above. About half indicated “high” intention to sign up to donate their organs. There were no significant differences between participants in intervention and control groups.

Regarding personal connection to organ donation, 45% of the respondents indicated they were pursuing an organ transplant. Thirty percent had a friend or family member who has received an organ transplant, and few (9%) had a friend or family member who has donated an organ. Regarding awareness, 63% had heard of the DR. Finally, 30% responded “yes” to the question, “Have you ever talked to any of your

TABLE 2.
Survey questions, subscale grouping, and factor loading

		Rotated factor loading
Scale 1	(1) Organ donation is an act of charity.	0.39
General Benefits	(2) Organ donation allows something positive to come out of a person's death.	0.54
$\alpha = 0.86$	(3) Signing up to donate my organs is a way I can do something good for others.	0.66
	(4) Signing up to donate my organs will allow my family to carry out my wishes.	0.75
	(5) Signing up now to donate my organs can help my family by removing the stress of making that decision.	0.77
	(6) Donating my organs allows me to help others to live.	0.69
	(7) Donating my organs may provide my family with some comfort.	0.74
	(8) Donating my organs can help my family cope with their grief.	0.71
	(9) Donating my organs is consistent with my religious tradition.	0.62
	(10) By donating my organs, I am serving as a role model for other dialysis patients.	0.58
	(11) If I donate my organs, it shows that dialysis patients can still give something back.	0.57
Scale 2	(12) If I signed up to donate my organs, my family members would not approve. ^a	0.37
General Barriers	(13) If a person has donated his or her organs, it is impossible for that person to have a regular funeral service. ^a	0.41
$\alpha = 0.80$	(14) It costs a donor family money to donate organs. ^a	0.56
	(15) Organ donation is against the rules of my religion. ^a	0.39
	(16) It is possible for a brain dead person to recover from their injuries. ^a	0.37
	(17) A person needs to have all of their parts in order to go to heaven. ^a	0.54
	(18) It would be weird to have my organs inside someone else. ^a	0.57
	(19) Even thinking about death could bring about bad things. ^a	0.52
	(20) I cannot decide whether I want to donate my organs until I know more about brain death. ^a	0.62
	(21) If a person has signed the organ donor registry, doctors will not try as hard to save that person's life. ^a	0.58
	(22) Organs can be bought and sold in the United States. ^a	0.40
	(23) Dialysis patient cannot donate any organs at all. ^a	0.65
	(24) Dialysis patients are too sick to donate their organs. ^a	0.68
	(25) I would donate my organs, but they would not accept my organs. ^a	0.56

^a Items were reverse coded so that higher scores indicate more positive feelings toward donation.

TABLE 3.
Predictors/correlates of attitudes toward donation (n = 554)

	Mean attitude (1: General benefits)	Mean attitude (2: General barriers) ^a
Age, y		
45 or younger	5.47 ¹	5.77
45-60	5.82 ²	5.73
> 60	5.92 ^{1,2}	5.64
Sex		
Male	5.77	5.67
Female	5.86	5.72
Race		
Black	5.76 ¹	5.64 ¹
Hispanic/Latino	5.21 ¹	5.74
White	6.08 ¹	5.88 ¹
Other	5.75	5.85
Education		
Some high school or less	5.76	5.37 ^{1,2,3}
High school or GED	5.82	5.70 ¹
Some college or 2-y degree	5.76	5.73 ²
4-y college or above	5.97	5.93 ³
Income		
< US \$20000	5.89	5.64
US \$20000 to \$59999	5.77	5.73
US \$60000 or more	5.94	5.95
Intended donation status		
Low (1-3)	4.91 ¹	5.34 ¹
Medium (4-7)	5.59 ¹	5.48 ²
High (8-10)	6.05 ¹	5.80 ^{1,2}

^a Items were reverse coded so that higher scores indicate more positive feelings toward donation. Common superscript indicates groups significantly different in pairwise comparison with *P* value < 0.05 based on mixed effect modeling on the mean scales accounting for correlation of subjects in the same center.

family members about whether or not you want to donate your organs?”

Dialysis Beliefs

Regarding dialysis-specific items, 29% responded neutral to “strongly agree” (response options 4, 5, 6, or 7) to the statement, “Dialysis patients cannot donate any organs at all.” Similarly, 27% responded neutral to “strongly agree” to the statement, “Dialysis patients are too sick to donate their organs,” and 39% responded neutral to “strongly agree” to the statement, “I would donate my organs, but they would not accept my organs.”

Internal Consistency and Scale Validity

Two subscales were identified: scale 1—general benefits ($\alpha = 0.86$) and scale 2—general barriers ($\alpha = 0.80$) as shown in Table 2. The general benefits scale contains 11 items, and the general barriers scale contains 14 items. In general, there were no items whose removal would have increased the internal consistency on either scale.

Association of Scale Scores

On both scales, increasing levels of intended donation status were associated with higher scores as shown in Table 3. For scale 1, all pairwise comparisons were statistically significant. For scale 2, higher scores were observed for “high” intention to donate compared with the 2 lower intention groups.

For all other measures, on scale 1, higher mean scores were observed among those older than 60 years compared with the 2 younger age groups. Also, on scale 1, highest scores were observed among whites, followed by blacks and then Hispanic/Latinos. For scale 2, whites had higher scores compared with blacks. Those who reported an education level of “some high school or less” had lower scores compared with each of the other 3 education groups. No significant differences were observed between sexes or income levels on either scale.

Both scales were positively associated with current enrollment on the DR at baseline as shown in Table 4. For each 1 point of increase in the mean score on scale 1, the odds of indicating enrollment increased by 64%. Similarly, on scale 2, the odds of indicating enrollment increased by 78%.

DISCUSSION

This study aimed to: (a) examine psychometric properties of an organ donation attitude scale adapted for patients at dialysis units and (b) assess the associations of scale scores with demographics and donation status. The attitude scale had not previously been used among a chronically ill population. Moreover, prior research has not investigated the attitudes of adults with chronic conditions, specifically individuals on dialysis, toward deceased donation and signing up on a DR.

Psychometric analyses identified 2 subscales with good psychometric properties—general benefits and general barriers. Alpha coefficients for both subscales were at least 0.80. Higher scores on each of the scale items indicate more positive organ donation attitudes. For both scales, more positive donation attitudes were associated with higher intent to sign up as an organ donor. These associations are in the expected direction, suggesting validity of the measure. Furthermore, this finding is in alignment with the results of our research group's previous studies among African American church members¹⁴ and members of alumni chapters of historically African American sororities and fraternities.¹⁶ The results illustrate that contrary to the belief that it is inappropriate to discuss deceased donation with individuals on dialysis, study participants were open to discussing the topic. This suggests the feasibility for adding deceased organ donation to advance care planning discussions in persons with CKD of any stage. Furthermore, the topic of organ donation could be addressed with other chronically ill populations. Survey results can be shared with renal healthcare professionals and administrators at dialysis providers, thus dispelling the myth that the topic of organ donation is too sensitive to be discussed with those on dialysis. The survey can be administered to individuals with any stage of CKD to understand their beliefs about the ability of a person with CKD to donate organs after death. These items can also be used to design individually tailored educational interventions that address specific person-level beliefs and barriers, thus

TABLE 4.
Association of attitudes and donor status

	Odds ratio	95% CI	<i>P</i>
General benefit (scale 1)	1.64	(1.23-2.18)	0.0008
General barriers (scale 2) ^a	1.78	(1.31-2.41)	0.0002

^a Items were reverse coded so that higher scores indicate more positive feelings toward donation.

increasing the likelihood of individuals registering on the DR. The belief that illness, even stage 5 CKD, can preclude donation after death should be combatted in all organ donation awareness campaigns among people of all ages. Finally, the questions could be used for surveillance if looking at population attitudes over time to help identify if attitudes toward organ donation are shifting.

Of the 5 demographic variables explored in this study, differences were observed across age, race, and education. Interestingly, those over age 60 years had higher scores, or more positive attitudes, on scale 1—general benefits. This finding is similar to our previous study among sorority and fraternity members, which showed that younger adults (under 30 years) had lower scores on all scales.¹⁶ This finding is opposite to previous research that determined that younger adults typically have higher organ donor registration rates than adults older than 50 years.² Our finding may be related to the older sample reached in the current study, with over 80% of respondents older than 45 years.

There were some significant differences by race on scales 1 and 2, with more positive attitudes observed among white respondents compared with minorities. This finding aligns with that of numerous studies highlighting unique barriers to donation experienced by African Americans and other ethnic minorities.¹⁸⁻²⁰ These barriers include medical mistrust, religious beliefs, and misconceptions and fear regarding the donation process. Additionally, African Americans are less likely to grant permission to donate their organs after death.²¹ Because this research group's previous studies were focused on African Americans, we cannot compare this finding.

In regard to education, respondents with “some high school or less” had lower scores, or less positive attitudes, on scale 2. This finding indicates that individuals at lower education may have more misconceptions regarding donation and may perceive greater barriers to signing up.

Limitations

During the recruitment process, anyone with a red heart sticker on their license was not eligible to participate in the study. In Michigan, a red heart on the license indicates enrollment in the DR. However, 15% of survey participants indicated that they had signed up to be a donor but did not have a red heart on their license. Using self-reported enrollment DR status is a limitation but validating positive enrollment status during study recruitment was not logistically possible. Often the survey was administered orally, which may have influenced patients' responses. One of the program coordinators was a social worker at one of the units which could introduce bias. Occasionally, patient beliefs about their ability to donate organs directly contradicted survey responses given when surveys were completed aloud. Some patients chose not to answer the income question. In addition, we did not use a random sample of individuals or dialysis units. Selection bias may be present on the individual level, especially because more than half of the patients approached chose not to participate in the study. Although we kept the recruitment message brief and noninformative, we do not know if or how much it influenced baseline survey responses. There is a lack of generalizability of our findings to patients on in-home dialysis or peritoneal dialysis; the majority of participants were on in-center hemodialysis. It would be

interesting to survey individuals with stage 5 CKD, not yet on dialysis, or earlier stages of CKD.

Furthermore, the sample was largely African American (74%) and of low income (51%), so results may not be generalizable to populations with a different racial and economic make-up. Furthermore, this study was cross-sectional, so we cannot infer causal relationships between attitudes and demographic variables or intention to donate. A longitudinal study would be required to verify the relationships suggested here.

This study identified 2 valid organ donation scales among the population—general benefits and general barriers. Attitude differences were observed across age, race, and education. Patients who were identified as older than 60 years, white, and having above high school education reported more positive attitudes toward donation. When looking at response options to individual, dialysis-specific questions, it is apparent that misconceptions exist among dialysis patients regarding their ability to be a deceased organ donor.

Almost 30% of patients surveyed believed that dialysis patients are unable to be donors, and 39% believed their organs would not be accepted. Although persons on dialysis are not able to donate their kidneys, other organs and tissues may be viable for donation. This observed misconception shows a need for education about deceased donation among persons with any stage of CKD, regardless of whether they are on dialysis or not. In addition, similar misconceptions may exist among individuals with other chronic health conditions; further research into their attitudes is warranted.

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