

A Comparison of Request Process and Outcomes in Donation After Cardiac Death and Donation After Brain Death: Results From a National Study

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Available literature points to healthcare providers' discomfort with donation after cardiac death (DCD) and their perception of public reluctance toward the procedure. Using a national sample, we report on the communication content of actual DCD and donation after brain death (DBD) approaches by organ procurement organization (OPO) requesters and compare family decision makers' (FDMs') experiences of both modalities. We recruited 1601 FDMs using a validated protocol; 347 (21.7%) were of potential DCD donors. Semistructured telephone interviews yielded FDMs' sociodemographic data, donation attitudes, assessment of approach, final outcomes, and substantiating reasons. Initial analysis consisted of bivariate analyses. Multilevel mixture models compared groups representing authorization outcome and DCD/DBD status. No significant differences in family authorization were found between DCD and DBD cases. Statistically significant associations were found between sociodemographic characteristics and authorization, with white FDMs more likely to authorize DCD or DBD than black FDMs. FDMs of both modalities had similar evaluations of requester skills, topics discussed, satisfaction, and refusal reasons. The findings suggest that the DCD/DBD distinction may not be notable to families. We recommend the use of similar approach strategies and communication skills and the development of education campaigns about the public's acceptance of DCD.

Abbreviations: DBD, donation after brain death; DCD, donation after cardiac death; DSA, donation service area; FDM, family decision maker; HCP, health care provider; OPO, organ procurement organization

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Introduction

Donation after brain death (DBD) is currently the principal avenue for deceased organ donation, but before 1968, donation after cardiac death (DCD) was the standard mechanism for obtaining organs for transplantation (1,2). DCD was eclipsed after brain death criteria for organ donation expanded in the 1970s (3) but has incrementally returned as a source of solid organ donation in the United States since the 1990s. In 2015, DCD donors accounted for 16.5% of all donors, and seven of the 11 donation service areas (DSAs) saw at least a 10% rise in DCD during this same time period (4). The increase may be attributed to the promotion of DCD by government and nonprofit transplantation organizations in an attempt to alleviate the extreme shortage of transplantable organs (5–8). In contrast, DCD comprises an even larger proportion of deceased donations in other countries; it accounts for 40% of donations in the United Kingdom and for 60% in the Netherlands (9,10).

Nevertheless, the literature indicates a continued unease by healthcare providers (HCPs) regarding DCD, based largely on HCPs' *perceptions* of family decision makers' (FDMs') disposition toward DCD and ability to understand the patient's situation, as well as perceived conflict between patient care responsibilities and donor interest (11–13). In addition to fears over engendering public mistrust with organ procurement, HCPs cite other concerns, such as conflicts of interest between patient care and DCD and disagreement over the most appropriate time and manner of initiating donation discussions (14). Some HCPs view the process of stabilizing and procuring organs in DCD settings as interfering with patients' end-of-life wishes, particularly for designated donors with do-not-resuscitate orders, as these individuals may not have understood that donation requires such measures (15).

HCPs' discomfort with DCD may also stem from limited understandings of the determination and declaration of death needed to pursue this modality. One international study (13) found that 94% of HCPs who were shown DCD and DBD vignettes believed patients depicted in a

brain death scenario were dead as opposed to 85% and 57% in an uncontrolled and controlled DCD situation, respectively. Uncontrolled DCD donors arrive dead at the hospital (Maastricht Category I), are unable to be resuscitated (Category II), or experience unexpected cardiac arrest as an inpatient (Category V) (16). In the United States, DCD is primarily controlled, wherein potential donors either are anticipating cardiac arrest (Category III) or experience circulatory arrest after brain death (Category IV). HCPs' apprehensions regarding the finality of death have been mitigated when there is permanent cessation of cardiopulmonary function and when withdrawal of life-preserving interventions is consistent with the patient's or family's decision to refuse resuscitation (17).

By contrast, the public's views toward DCD have been described as more favorable. One investigation presented participants with theoretical vignettes and found greater willingness to donate with the controlled DCD (69%) and uncontrolled DCD (70%) scenarios compared with the brain death scenario (66%) (18). Further, 80% of participants favored a rapid organ recovery program to make uncontrolled DCD possible, without concern that predesignating posthumous donation might lead to suboptimal medical care. Another study (N = 2693) determined that 45% of surveyed community members supported a time interval between death and organ recovery in DCD cases that aligned with a time period conducive for viable organs (ranging from "no time at all" to 10 min) (19).

The experience of families approached about the option to authorize DCD donation remains largely undocumented, as do the concomitant factors influencing family authorization among such cases. To date, no published work comparatively reports the experiences of family members of potential DCD and DBD patients. The current study used a large national sample to explore behavioral and communication factors related to the organ donation request process, understand the experiences of family members approached for donation, and compare authorization outcomes between organ donation requesters and family members of DCD and DBD patients. Based on families' perspectives, the findings have the potential to allay HCPs' angst regarding DCD and to inform future conversations about DCD among families, HCPs, and organ procurement organization (OPO) staff.

Methods

Overview

From January 2009 to March 2012, we collaborated with nine OPOs, representing five regions of the United States (i.e., Northeast, Midwest, South, Southwest, and Mid-Atlantic). To recruit FDMs, defined as adult family members and/or significant others who substantively made the donation decision, either alone or in conjunction with others family members (20), validated contact and interview protocols were used (21–24).

FDMs were mailed recruitment packets 2 months postdonation approach (3 months for pediatric cases). As published elsewhere (23), we received case information on a total of 4634 approaches, but 2402 (51.8%) were unable to be reached due to incomplete contact information. Of 2232 individuals contacted, 1601 (71.7%) FDMs agreed to be interviewed; 1254 (78.3%) were FDMs of DBD patients, and 347 (21.7%) were FDMs of potential DCD patients.

Methods and measures

On a monthly basis, we collected data on patients' mechanism of death and donation decision (authorized/refused) from participating OPOs' administrative databases.

Semistructured telephone interviews, which have been validated in previous studies with similar populations (21–24), were conducted with participating families of donor-eligible patients. The interviews collected FDMs' sociodemographic data, donation-related attitudes and knowledge, assessment of the quality and content of the discussions, final donation decisions (*authorized/refused*), and reasons for that decision.

To evaluate the quality of the communication during the request, two distinct sets of OPO staff requester skills were assessed, *relational communication skills* and *donation-request related skills*. For *relational communication skills*, 24 items assessed a range of interpersonal skills on a 5-point Likert scale (1 = *never* to 5 = *always*), including taking concerns seriously, ensuring the FDM's understanding of the patient's condition, and giving enough information about donation. Twenty-eight *donation request-related skills* were assessed by using a dichotomous response format (*yes/no*); the measure included skills such as allowing the family time to talk about the patient, inquiring after the patient's donation wishes, and providing information about the need for organs and the donation process. Past studies and health communication theory identified these communication skills as important components of effective communication about organ donation (25–29).

Discussion of *donation-related topics* during the request process was assessed by using a dichotomous response format (*yes/no*) that covered 17 donation-related topics identified from the authors' previous research as important to families considering donation (25,30). Composite scores for relational communication skills, donation request-related skills, and donation-related topics discussed were generated by summing individual items, with higher scores indicating greater relational communication skills (range: 18–84), use of more skills (range: 0–28), and more topics discussed (range: 0–17) by the requester.

FDMs' satisfaction with the request was assessed through a series of 7-point Likert-type items. Respondents rated the perceived level of hospital care administered to the potential donor (1 = *poor* to 7 = *excellent*), as well as the level of satisfaction with the amount of time spent speaking with the requester about donation (1 = *not at all* to 7 = *very*). Two items assessed comfort with the donation decision and overall satisfaction with the request process (1 = *not at all* to 7 = *very much*).

Analytic plan

Descriptive statistics summarize requester, FDM, and patient demographics for the overall sample, as well as by DCD/DBD status. Frequencies and percentages are presented for categorical-level variables and means and standard deviations for interval-level variables. Demographic characteristics of DCD/DBD participants were compared with use of the χ^2 test for categorical variables and analysis of variance for continuous variables.

Contingency tables determined whether the DCD/DBD cases differed significantly on rates of authorization. Authorization outcomes for DCD and

DBD cases were examined separately for associations with demographic characteristics. Reasons given by the FDMs for authorizing (e.g. to give meaning to the death) and for declining (e.g. the family had already been through enough) were compared for DCD and DBD. Multilevel mixture models were used to compare four groups representing authorization outcome and DCD/DBD status for FDM ratings of requester communication skills and satisfaction with the request experience. The four groups are as follows: (1) authorized DCD, (2) authorized DBD, (3) refused DCD, and (4) refused DBD. Previous analyses have indicated significant differences between authorizing and refusing FDMs on the indicators under consideration (21,22,31–36). Thus, while the omnibus test of significance is reported for the main effect, planned contrasts compared the four groups with an adjustment applied to control the overall α level. A generalized linear mixture model (MIXED) was used to assess these associations. These mixed models are appropriate for continuous outcomes and accommodate the longitudinal study design. Models correct for the correlation between repeated request exchanges within requester and for the nesting of requesters within OPOs. Due to the association between race and authorization status, all models control for race. However, due to small cell sizes of blacks in the sample (DCD cases, $n = 26$), we did not statistically evaluate the interaction. All statistical analyses were performed by using SAS 9.3 (SAS Institute, Cary, NC).

Results

Sample characteristics

Participating FDMs (Table 1) had a mean age of 47.4 years. The majority of FDMs were female (69%), white (69.5%), married (72.4%), and of Christian faith (94.9%). FDMs of potential DCD patients were more likely to be white [85.6% vs. 65.0%; $\chi^2(2) = 54.6$,

$p < 0.0001$], have graduated college [51.6% vs. 43.9%; $\chi^2(3) = 25.36$, $p < 0.05$], and have been raised in the United States [96.0% vs. 87.7%; $\chi^2(1) = 19.7$, $p < 0.0001$] compared with FDMs of potential DBD patients. FDMs of potential DCD patients were also more likely to report higher annual household income [$> \$70\,000$; 40.9% vs. 30.5%; $\chi^2(2) = 28.6$, $p < 0.002$]. The mean ages of FDMs of potential DCD and DBD patients were similar (49.5 vs. 47.0 years). Comparison of DCD- and DBD-eligible patients revealed significant between-group differences (data not tabled), with the former being younger (42.1 vs. 44.5; $t = 2.5$, $p < 0.02$) and more likely to be white [84.1% vs. 59.4%; $\chi^2(2) = 72.9$, $p < 0.0001$] and female [65.4% vs. 58.4%; $\chi^2(1) = 5.6$, $p < 0.02$].

Authorization for donation

Overall, 84.1% of participants authorized donation. Statistically significant differences were not found in FDM authorization of donation for potential DCD and DBD patients (82.4% vs. 84.6%; $\chi^2 = 0.97$, $p = 0.32$).

Exploration of the DCD and DBD subsamples revealed statistically significant associations between FDMs' race/ethnicity, marital status, age, and authorization for donation. Compared with white FDMs, black FDMs were less likely to authorize donation for potential DBD [88.6% vs. 69.6%; $\chi^2(2) = 54.21$, $p = 0.0001$] and DCD patients [84.5% vs. 46.15%; $\chi^2(2) = 27.48$, $p = 0.0001$] alike. Thus, while authorization rates for whites were similar for DCD and DBD patients, blacks' rates of authorization

Table 1: Sociodemographic characteristics of FDMs of potential DCD and DBD patients

Characteristic	Potential DCD (n = 347)	Potential DBD (n = 1254)	Total (N = 1601)
Age, mean \pm SD years	49.5 \pm 14.7	47.0 \pm 14.3	47.4 \pm 14.5
	n (%)	n (%)	n (%)
Female	243 (70.0)	861 (68.7)	1104 (69.0)
Donation outcome (consented)	285 (82.4)	984 (85.4)	1269 (84.7)
Race			
White/Caucasian	297 (85.6)	815 (65.0)	1112 (69.5)
Black	26 (7.5)	250 (19.9)	276 (17.2)
Other	24 (6.9)	189 (15.1)	213 (13.3)
Marital status			
Never married/single	35 (10.1)	185 (14.8)	220 (13.7)
Married/cohabit	258 (74.4)	901 (71.9)	1159 (72.4)
Divorced/separated	54 (15.6)	168 (13.4)	222 (13.9)
Household income			
<\$30 000	85 (24.5)	417 (33.3)	502 (31.4)
\$30 000–\$70 000	120 (34.6)	454 (36.2)	574 (35.9)
>\$70 000	142 (40.9)	383 (30.5)	525 (32.8)
Education, mean \pm SD			
Did not complete high school	29 (8.4)	145 (11.6)	174 (10.9)
Completed high school	78 (22.5)	332 (26.5)	410 (25.6)
Some college	61 (17.6)	227 (18.1)	288 (18.0)
College graduate	179 (51.6)	550 (43.9)	729 (45.5)
Religious affiliation			
Non-Christian	23 (6.6)	59 (4.7)	82 (5.1)
Mostly raised in the United States	333 (96.0)	1100 (87.7)	1433 (89.5)

DBD, donation after brain death; DCD, donation after cardiac death; FDM, family decision maker.

were lower than those for whites for DBD and lower still for DCD patients. While marital status was unrelated to FDM authorization for DCD-eligible patients, unmarried/single FDMs of DBD-eligible patients had the lowest donation rate (74.6%) compared with those who were married (85.5%) or divorced [91.1%, $\chi^2(2) = 20.13$, $p < 0.0001$]. FDM age was significantly related to authorization for DCD-eligible patients only, with FDMs who refused DCD being significantly younger (44.9 years) than those agreeing to donation (49.5 years) [$F(1,1599) = 4.67$, $p < 0.03$].

Reasons for the donation decision

The most frequently endorsed reasons for authorizing donation were the same for FDMs of potential DCD and DBD donors, but in some instances, rates of endorsement differed. The most frequent reasons given for authorizing donation for DCD and DBD, respectively, include the following: to help others [66.1% vs. 72.1%; $\chi^2(1) = 3.95$, $p < 0.05$], knowledge of the patient's desire to donate [49.0% vs. 39.0%; $\chi^2(1) = 9.2$, $p < 0.01$], favorable feelings toward organ donation [37.2% vs. 42.7%; $\chi^2(1) = 2.8$, $p < 0.09$], and because the patient would no longer need the organs [24.1% vs. 20.0%; $\chi^2(1) = 2.58$, $p < 0.10$]. The most frequently endorsed reasons for *not* authorizing donation were largely similar for FDMs of potential DCD- and DBD-eligible patients respectively including: felt patient had already been through enough [14.7% vs. 11.9%; $\chi^2(1) = 0.34$, $p < 0.50$], felt patient would not want to donate [8.2% vs. 18.1%; $\chi^2(1) = 3.5$, $p < 0.06$], knew patient would not want to donate [22.3% vs. 18.0%; $\chi^2(1) = 0.50$, $p < 0.40$], unsure of patient's wishes [11.5% vs. 14.0%; $\chi^2(1) = 0.25$, $p < 0.60$], timing of the request was wrong [13.1% vs. 16.1%; $\chi^2(1) = 0.31$, $p < 0.58$], family was too emotional to make a decision [11.5% vs. 9.8%; $\chi^2(1) = 0.13$, $p < 0.71$], did not want patient disfigured [11.5% vs. 10.4%; $\chi^2(1) = 0.06$, $p < 0.80$], and made own determination of eligibility of patient's organs [9.8% vs. 11.9%; $\chi^2(1) = 0.20$, $p < 0.60$]. There were two notable exceptions to these similarities: FDMs of DCD patients more frequently reported that the family had already been through enough [23.0% vs. 11.4%; $\chi^2(1) = 5.1$, $p < 0.03$] and that procurement took too long [23.0% vs. 9.8%; $\chi^2(1) = 7.0$, $p < 0.01$]. Refusing DCD and DBD FDMs provided the following reasons for refusal at similarly low rates: mistrust of the healthcare system [3.3% vs. 4.7%; $\chi^2(1) = 0.21$, $p < 0.60$], feeling pressured or harassed by HCPs/requesters [1.6% vs. 1.6%; $\chi^2(1) = 0.002$, $p < 0.90$], and feeling dissatisfied with treatment at the hospital [0.0% vs. 0.05%; $\chi^2(1) = 0.32$, $p < 0.50$].

Requesters' communication and skills

Relational communication skills: The omnibus test revealed significant differences between the four groups (DCD donors, DBD donors, DCD nondonors, and DBD

nondonors) for OPO requester use of positive relational communication skills [$F(3,1458) = 115.44$, $p < 0.0001$]. Contrasts indicate that FDMs who authorize either DCD or DBD had similar scores, and the scores for these two groups were significantly higher than FDMs refusing either modality (Table 2). Refusing FDMs' ratings of requesters' relational communication were statistically similar for the DCD and DBD groups.

Donation-related communication skills: Significant between-group differences were also found in the mean number of donation-related communication skills used by requesters [$F(3,1458) = 177.78$, $p < 0.0001$]. (Table 2) Contrasts indicate that FDMs authorizing either type of donation had similar scores, and the scores for the DCD donors and DBD donors were significantly higher than those reported by FDMs who refused either donation type. However, refusing FDMs of potential DCD patients reported significantly greater use of donation-related communication skills compared with FDMs refusing DBD.

Donation-related topics discussed: The omnibus test comparing the mean number of donation-related topics discussed by requesters was also statistically significant [$F(3,1458) = 176.79$, $p < 0.0001$]. Although FDMs authorizing either DCD or DBD had similar scores about donation-related topics, these scores were significantly higher than those reported by families refusing both donation mechanisms. FDMs who refused DCD donation reported discussing significantly more topics with the requester than did FDMs who refused DBD.

Satisfaction ratings: Omnibus tests comparing FDM ratings of the care received at the hospital [$F(3,1458) = 7.97$, $p < 0.001$], satisfaction with the amount of time spent discussing donation with the requester [$F(3,1458) = 39.06$, $p < 0.0001$], satisfaction with the donation decision [$F(3,1458) = 27.37$, $p < 0.0001$], and satisfaction with the request process [$F(3,1458) = 93.28$, $p < 0.0001$] were significant, as well (Table 2). Specifically, both groups of authorizing FDMs of DCD and DBD, as well as families refusing DCD donation, reported significantly higher ratings of the care received at the hospital compared with the DBD refusal group. The pattern of results for satisfaction with time spent talking to the requester and comfort with the donation decision were parallel. Families authorizing for either type of donation reported similar levels of satisfaction with the time talking about donation and comfort with the donation decision, both of which were higher than all those declining authorization for time spent and decision comfort. FDMs who declined DCD had greater satisfaction ratings for the amount of time spent and greater comfort with the donation decision than did FDMs who declined DBD. Finally, FDMs

Table 2: Association of authorization and DCD and DBD with outcome variables

	(1) Authorized DCD n = 286	(2) Authorized DBD n = 1061	(3) Refused DCD n = 61	(4) Refused DBD n = 193	1 vs. 2	1 vs. 3	1 vs. 4	2 vs. 3	2 vs. 4	3 vs. 4
	M (SE)	M (SE)	M (SE)	M (SE)	t value (p)	t value (p)	t value (p)	t value (p)	t value (p)	t value (p)
Relational communication skills	77.64 (0.56)	76.51 (0.34)	65.10 (1.1)	65.02 (0.69)	1.83 (0.08)	9.71 (0.0001)	14.63 (0.0001)	9.35 (0.0001)	15.91 (0.0001)	0.06 (0.95)
Donation-related communication skills	26.03 (0.25)	26.15(0.14)	20.65 (0.55)	19.05 (0.31)	0.41 (0.61)	9.03 (0.0001)	17.7 (0.0001)	9.78 (0.0001)	21.3 (0.0001)	2.57 (0.01)
Donation-related topics discussed	11.61 (0.22)	11.67 (0.12)	7.21 (0.46)	5.64 (0.26)	0.26 (0.79)	8.71 (0.0001)	17.79 (0.0001)	9.36 (0.0001)	21.37 (0.0001)	2.97 (0.003)
FDM satisfaction ratings										
Rating of care received	6.40 (0.08)	6.40 (0.05)	6.34 (0.18)	5.8 (0.10)	0.08 (0.93)	0.30 (0.76)	3.98 (0.0001)	0.35 (0.72)	4.83 (0.0001)	2.26 (0.02)
Satisfaction with time spent with requester	6.56 (0.07)	6.53 (0.04)	5.93 (0.16)	5.55 (0.09)	0.39 (0.69)	3.67 (0.0002)	8.78 (0.0001)	3.69 (0.0002)	10.17 (0.0001)	2.1 (0.03)
Comfort with donation decision	6.62 (0.07)	6.57 (0.04)	6.21 (0.15)	5.78 (0.09)	0.62 (0.53)	2.26 (0.02)	7.7 (0.0001)	2.07 (0.03)	8.67 (0.0001)	2.73 (0.006)
Satisfaction with request process	6.49 (0.08)	6.50 (0.05)	5.00 (0.17)	4.9 (0.10)	0.08 (0.93)	8.08 (0.0001)	12.26 (0.0001)	8.58 (0.0001)	14.72 (0.0001)	0.06 (0.95)

DBD, donation after brain death; DCD, donation after cardiac death; FDM, family decision maker.

authorizing DCD and DBD reported similarly high levels of satisfaction with the request process, which was significantly higher than for FDMs who declined with no difference between DCD and DBD.

Discussion

DCD has recently been heralded as one answer to the shortage of transplantable organs (18,19,39). HCPs, however, continue to express reticence to pursue this modality. This is the first study to compare families' experiences of the request process and authorization outcomes for potential DCD- and DBD-eligible patients. These findings indicate that overall FDMs are *equally* as likely to authorize donation for potential DCD and DBD donors. It is important to note that while white FDMs authorized at similar rates for DBD and DCD patients, black FDM rates of authorization were lower than those of white FDMs for DBD and lower still for DCD patients. However, given the small sample size for black FDMs approached about DCD donation (n = 26), this finding is inconclusive. Studies recruiting larger samples of black and other ethnic minorities are needed to assess whether and how their experiences differ from those reported herein. Future research should focus on developing and adopting data-driven and culturally sensitive techniques for use during donation discussions with black and minority FDMs.

Consistent with past research (20,21,23–25,36,40), authorizing FDMs of both DCD and DBD, compared with their refusing counterparts, reported the highest scores for requesters' communication skills (relational and donation related), number of donation-related topics discussed, and satisfaction with the amount of time spent discussing donation. Satisfaction with the request process and comfort with the donation decision were also highest for authorizing FDMs. Notably, the results obtained for FDMs authorizing either DCD or DBD were strikingly similar. Comparatively, refusing FDMs of DCD or DBD donation also had similar levels in their ratings of requesters' relational communication skills and satisfaction with the request, albeit these scores were lower than those of their authorizing counterparts. Moreover, declining FDMs of DCD rated patient care at the hospital similarly as FDMs authorizing DCD or DBD. They also assessed requester communication skills, reports for number of topics discussed, time spent talking with the requester, and comfort with the donation decision more highly than declining DBD FDMs.

These findings indicate that for FDMs who authorize donation, there is no evidence of distinction between the DCD and DBD approach, and FDMs who decline DCD have a more favorable impression of the request experience than did those who decline DBD. The pattern of results suggests a gradient such that those who

authorize report the best process; those who decline DCD are next in terms of favorability ratings; and FDMs who decline DBD have the least favorable reported experience. That more families declining DCD indicated that they had “been through enough” compared with those refusing DBD suggests that fatigue and emotional weariness may be a meaningful factor in DCD cases. However, the absence of reasons, such as mistrust of the healthcare system, feeling pressured or harassed by HCPs/OPO, and FDMs’ dissatisfaction with treatment at the hospital, suggests the request process is experienced with a high degree of integrity in both conditions. A post-hoc exploratory analysis of authorization by race and donation modality (DCD vs. DBD) revealed no statistically significant race differences in satisfaction with the amount of time spent, satisfaction with the request process, comfort with donation decision, reported number of topics discussed, or ratings of requesters’ communicative behavior, and suggests that authorizing Black FDMs had a similarly positive request experience compared to other FDMs authorizing either DCD and DBD.

Further, this study revealed that DCD approaches entail the provision of more donation-related information to families. Perhaps requesters believe that DCD is more complex and thus necessitates a more-detailed approach. Hospitals may also require more-detailed family discussions about the DCD process (17,41–45). Some commentators have argued that FDMs must comprehensively understand the different forms of donation and processes before consent to ensure the donor’s autonomy. Empirical evidence highlights the key issue for families is a belief that the patient is no longer “there” and relying on lay interpretations of death rather than using medicolegal definitions (37,38). We recommend requesters that deploy similar high-quality communication strategies and skills regardless of the patient’s circumstance. Future research should examine whether psychosocial needs of FDMs of DCD- and DBD-potential patients differ—particularly among refusing FDMs—and how these needs can be supported through requesters’ use of effective communication skills.

FDM age was also associated with donation decision for DCD patients but not for DBD patients. FDMs who authorized DCD were significantly older than were those who declined. The reason for the lower donation rates among FDMs of DCD-eligible patients is unclear; however, it is possible that younger FDMs may not have discussed their donation wishes and/or advanced care directives with the patient and based their decision on their own feelings toward donation or interpretation of the patient’s wishes. Knowledge of a patient’s desire to donate—in the form of either first person authorization or prior discussions about donation—has been strongly associated with the decision to donate (46). This reason was cited by 41.1% of donors in this study. Together, the results support the importance of donor designation,

advanced directives, and prior discussions with family to ensure an individual’s donation preference is actualized. Future studies should examine reasons for refusal between younger and older FDMs to identify how donation requests can be tailored accordingly and to understand how community-based campaigns assisted by mobile communication devices and social media can raise donor awareness among younger and technologically savvy populations.

Although this study is the first to compare the donation request experiences of FDMs of DCD- and DBD-eligible patients, our findings must be interpreted in light of several limitations. Although the sample was representative of the U.S. donor population, the findings with regard to sociodemographic differences must be interpreted with caution, especially with regard to Asian and Hispanic populations. In addition, most participants authorized donation, and all self-selected into the study. Although the consent rate to the study was high (71.7%), the sample skewed towards those who had consented to donation, typical of studies of this type. A post-hoc examination of the larger sample from which the interviewed FDMs were solicited reveals a consent rate of 69%, suggesting that those who agreed to be interviewed had more favorable impressions of donation overall. Analyses did not adjust for demographic differences between FDMs of DCD and DBD samples; FDMs of DCD patients were of high socioeconomic status (e.g. education, income) and more likely to be white, compared with FDMs of DBD. Future research conducted with larger numbers of representative racial and donation condition combinations (e.g. greater numbers of black DCD and DBD cases) would better inform the influence of these factors.

Despite these limitations, this study entails one of the largest samples of individuals who experienced the in-hospital donation request process and the most detailed examination of their experiences. Insights from the current study may inform policymakers, HCPs, educators, and researchers about effective request procedures and authorization outcomes regarding DCD. Specifically, the findings show that effective requester communication skills that foster supportive, trusting relationships with families, address relevant donation-related topics in a timely manner, and provide comfort to FDMs, increase the likelihood of authorization in both potential DCD and DBD contexts. Importantly, FDMs’ support for DCD appears greater than is commonly believed by HCPs and is reflected in the similarly high authorization rates for potential DCD and DBD patients in the current study. Educational efforts that dispel misconceptions about families’ views of DCD requests and its impact on the quality of care received may cultivate more supportive HCP attitudes toward DCD and ultimately lead to increased rates of authorization. In sum, the current findings lend additional support to the public’s already favorable views toward DCD; they also highlight the need for HCPs to

realize that families will not likely view DCD requests as an overall poorer or more compromised experience.

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