

OPEN

# Barriers and Enablers to Organ Donation After Circulatory Determination of Death: A Qualitative Study Exploring the Beliefs of Frontline Intensive Care Unit Professionals and Organ Donor Coordinators

Janet E. Squires, RN, PhD, 1,2 Nicole Graham, RN, BScN, 1 Mary Coughlin, RN, MNSc, 2 Michaël Chassé, MD, PhD, 3,4 Stefanie Linklater, MSc, 2 Megan Greenough, RN, MScN, 1 Jeremy M. Grimshaw, MD, PhD, 5,2 Sam D. Shemie, MD, 6,7,8 Sonny Dhanani, MD, 8,9 and Gregory A. Knoll, MD, PhD, 2,2

**Background.** A shortage of transplantable organs is a global problem. The purpose of this study was to explore frontline intensive care unit professionals' and organ donor coordinators' perceptions and beliefs around the process of, and the barriers and enablers to, donation after circulatory determination death (DCDD). **Methods.** This qualitative descriptive study used a semistructured interview guide informed by the Theoretical Domains Framework to interview 55 key informants (physicians, nurses, and organ donation coordinators) in intensive care units (hospitals) and organ donation organizations across Canada. **Results.** Interviews were analyzed using a 6-step systematic approach: coding, generation of specific beliefs, identification of themes, aggregation of themes into categories, assignment of barrier or enabler and analysis for shared and unique discipline barriers and enablers. Seven broad categories encompassing 29 themes of barriers (n = 21) and enablers (n = 4) to DCDD use were identified; n = 4 (14%) themes were conflicting, acting as barriers and enablers. Most themes (n = 26) were shared across the 3 key informant groups while n = 3 themes were unique to physicians. The top 3 shared barriers were: (1) DCDD education is needed for healthcare professionals, (2) a standardized and systematic screening process to identify potential DCDD donors is needed, and (3) practice variation across regions with respect to communication about DCDD with families. A limited number of differences were found by region. **Conclusions.** Multiple barriers and enablers to DCDD use were identified. These beliefs identify potential individual, team, organization, and system targets for behavior change interventions to increase DCDD rates which, in turn, should lead to more transplantation, reducing patient morbidity and mortality at a population level.

(Transplantation Direct 2018;4: e368; doi: 10.1097/TXD.000000000000805. Published online 26 June, 2018.)

Received 28 April 2018.

Accepted 15 May 2018.

This study is part of the Canadian National Transplant Research Program (CNTRP) and is supported by the Canadian Institutes of Health Research (CIHR) (grant TFU 127880).

The authors declare they have no competing interests. The data sets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

J.E.S., M.Ch., J.M.G., and G.A.K. conceptualized the study. J.E.S., M.Ch., J.M.G., S.D.S., S.D., and G.A.K. participated in securing funding for the study. J.E.S. oversaw all aspects of the study. S.L. conducted the interviews. N.G., S.L., M.G., M.Co., and J.E.S. participated in analysis of the data. All authors participated in final interpretation of the data. Article was drafted by J.E.S., N.G., M.Co. with critical input from all authors. All authors approved the final version submitted.

Correspondence: Janet E. Squires, RN, PhD, School of Nursing, Department of Health Sciences, University of Ottawa; Clinical Epidemiology Program, Ottawa Hospital Research Institute, Ottawa, ON, Canada, 501 Smyth Rd, PO Box 201-B, Ottawa, ON, Canada K1H 8L6. (janet.squires@uottawa.ca).

Copyright © 2018 The Author(s). Transplantation Direct. Published by Wolters Kluwer Health, Inc. This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

ISSN: 2373-8731

DOI: 10.1097/TXD.00000000000000805

<sup>&</sup>lt;sup>1</sup> School of Nursing, Department of Health Sciences, University of Ottawa, Ottawa, ON. Canada.

<sup>&</sup>lt;sup>2</sup> Clinical Epidemiology Program, Ottawa Hospital Research Institute, Ottawa, ON, Canada

<sup>&</sup>lt;sup>3</sup> Départment de Médecine, Université de Montréal, Montréal, QC, Canada.

<sup>&</sup>lt;sup>4</sup> Centre Hospitalier de l'Université de Montréal, Division of Critical Care, Montréal, QC, Canada.

<sup>&</sup>lt;sup>5</sup> Department of Medicine, University of Ottawa, Ottawa, ON, Canada.

<sup>&</sup>lt;sup>6</sup> Division of Critical Care, Montreal Children's Hospital, McGill University Health Centre, Montreal, QC, Canada.

<sup>&</sup>lt;sup>7</sup> Department of Pediatrics, McGill University, Montreal, QC, Canada.

<sup>&</sup>lt;sup>8</sup> Deceased Organ Donation, Canadian Blood Services, Ottawa, ON, Canada.

<sup>&</sup>lt;sup>9</sup> Critical Pediatric Critical Care Medicine, Children's Hospital of Eastern Ontario, Ontario, Canada.

<sup>&</sup>lt;sup>10</sup> Department of Pediatrics, University of Ottawa, Ottawa, Canada.

n this article, we explore frontline intensive care unit (ICU) professionals' and organ donor coordinators' perceptions and beliefs around the process of, and the barriers and enablers to, donation after circulatory determination death (DCDD). Organ donation is a life-saving or life-enhancing opportunity for people with end-organ failure. However, there continues to be a serious global shortage of organs in comparison to demand. In the United States, the organ shortage is estimated to be as high as 83000 each year, 29% of their need. In the United Kingdom, a shortage of 6389 organs is reported, 27% of their need<sup>1</sup> and in Canada, a shortage of 2100 organs each year is estimated, 50% of their need.<sup>2</sup> This global lack of available organs for donation results in lengthening of organ transplant wait lists which has serious population health consequences, most importantly being the increased likelihood of individuals dying while waiting for a life-saving donation.<sup>3</sup>

The majority of transplanted organs are received from deceased donors (approximately 85%). The rate of donation by donation after neurological determination of death has plateaued internationally in recent years, largely from the success of head injury prevention programs and strategies and also potentially in part by the growing support for DCDD. Tonation after circulatory determination death rates show the greatest potential for growth; for example, in the United States and Canada, DCDD cases account for only 16% and 21% of total donations made by deceased donors respectively, which is comparable to the global average of 16.9% reported in 2016. However, a potentially achievable benchmark is that of the United Kingdom where in 2016, DCDD accounted for greater than 34% of deceased donors.

#### **Barriers and Enablers to DCDD**

Donation after circulatory determination death is a complex process with many interacting and parallel factors that can both inhibit (act as barriers) or promote (act as enablers) it. To develop interventions to increase DCDD that will have more pronounced and sustainable effects, knowledge of these barriers and enablers is critical. However, reasons for low DCDD rates are understudied and as a result, poorly understood. Perceived barriers, suggested in a limited number of studies, include varying clinician attitude, time and logistical constraints, ethical concerns related to withdrawal of life sustaining treatments and premortem interventions, inability to predict time of death to optimize DCDD, unknown incidence of autoresuscitation, and ethical/legal concerns about violation of the "dead donor rule" which states that organ retrieval itself cannot cause death. 11-15 Recently, a review of global barriers to organ donation, found DCDD largely depends on the existence of: (1) appropriate policies for the withdrawal of life-sustaining treatments and (2) specific protocols for the timing of interventions, such as the use of medications, the time between cardiac arrest and organ recovery, declaration of death, and organ retrieval, which are lacking in many institutions. 16 The ethical discomfort that many physicians feel with the management of comfort care was also mentioned as a barrier to effective DCDD processes. For example, some medications commonly used to ease pain (relief of discomfort) also have unintended adverse effects (eg, depressing the donor's respiratory drive and decreasing their blood pressure) which shortens their life. 16

Enablers of DCDD, also discussed in a small number of reports, include system level initiatives. For example, the United Kingdom's National Organ Retrieval Service, is credited with having played a vital role in contributing to their recent increases in deceased donors and organ transplants. The service, established by the National Health Service Blood and Transplant in April 2010, provides a 24-hour service for retrieving organs from deceased donors. The service has been highly successful; the number of deceased organ donors in the United Kingdom increased by 50% between 2007 and 2013. 17,18

No studies to date have investigated key factors which may impact the use of DCDD, such as considering perspectives of multiple healthcare professional groups and geographical differences. Further, no studies have specifically investigated DCDD from a behavioral theory approach which encompasses both barrier and enabler assessment of the broad range of the possible multifactorial determinants of DCDD. Therefore, the purpose of this study was to explore frontline ICU professionals' and organ donor coordinators' perceptions and beliefs around the process of, and the barriers and enablers to, DCDD. A behavioral theory perspective using the Theoretical Domains Framework (TDF) was taken. The TDF is a robust behavior change framework comprised of 14 theoretical domains derived from 33 different health, behavioral, and social psychology theories that explain health-related behavior change. 19,20 Although the TDF has been used previously to successfully identify the determinants of a wide range of healthcare professional behaviors, <sup>21-28</sup> this is its first application in the study of DCDD.

#### **MATERIALS AND METHODS**

#### **Study Design and Sampling**

A qualitative descriptive design was used. Semistructured interviews were conducted with intensivists, intensive care nurses, and organ donor coordinators from across Canada to determine their: (1) beliefs and attitudes about DCDD and (2) their perceptions of the multilevel factors that influence DCDD. A list of eligible participants in each key informant group from across the country (divided by region) was compiled by the national research team. A purposive and stratified (by key informant group and region) sampling strategy augmented with snowball sampling was then used to obtain information-rich cases and to ensure that each key informant group in all Canadian regions were represented in the final sample. The regions were: Atlantic Canada (New Brunswick, Nova Scotia, Newfoundland, Prince Edward Island); Ontario; Quebec; and Western Canada (British Columbia, Alberta, Saskatchewan, and Manitoba). The first key informant on each key informant by region list was chosen at random with subsequent key informants selected according to regular intervals. All potential key informants were contacted by email, we sent 2 follow-up emails to all nonresponders. Sample size was informed by the concept of data saturation, interviews were conducted until no new information was offered.<sup>29</sup>

# **Data Collection and Analysis**

The TDF informed the development of the semistructured interview guide and the subsequent analysis. A sample interview question for each of the 14 TDF domains is provided in Table 1. Interviews were conducted by telephone and digitally recorded. Interviewing, transcription, and analysis occurred concurrently, data were managed in NVivo software version 10.<sup>30</sup> Data were first analyzed separately for each

### TABLE 1.

#### The 14 theoretical domains of the theoretical domains framework

Domain	Definition <sup>19</sup>	Sample interview question
Knowledge	An awareness of the existence of something	Are you aware of any published practices or procedures regarding DCDD?
Skills	An ability or proficiency acquired through practice	What skills and experience are required to use DCDD properly?
Social/Professional Role and Identity	A coherent set of behaviors and displayed personal qualities of an individual in a social or work setting	Is considering DCDD a standard part of your practice?
Beliefs about Capabilities	Acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use	How easy or difficult is it to begin or follow the DCDD process?
Optimism	The confidence that things will happen for the best or that desired goals will be attained	What are your thoughts about the future of DCDD in your province and Canada?
Beliefs about Consequences	Acceptance of the truth, reality, or validity about outcomes of a behavior in a given situation	What are the negative aspects to DCDD?
Reinforcement	Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus	In the past, are there any personal or external incentives that you have experienced to be effective to help you use DCDD?
Intentions	A conscious decision to perform a behavior or a resolve to act in a certain way	Do you think about DCDD when a patient suitable for the process is dying?
Goals	Mental representations of outcomes or end states that an individual wants to achieve	On a scale of 1-10, with 10 being the most important, how important do you think it is for you to consider DCDD (when appropriate)?
Memory, Attention and Decision Processes	The ability to retain information, focus selectively on aspects of the environment and choose between 2 or more alternatives	Is considering DCDD an automatic part of your practice, or do you need to be reminded to do it?
Environmental Context and Resources	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behavior	What aspects of your work environment influence whether or not you consider DCDD?
Social Influences	Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviors	Do the expectations of your patients or their families influence you to consider DCDD?
Emotion	A complex reaction pattern, involving experiential, behavioral, and physiological elements, by which the individual attempts to deal with a personally significant matter or event	What feelings do you experience when you think about DCDD?
Behavioral Regulation	Anything aimed at managing or changing objectively observed or measured actions	If you wanted to implement changes in your own practice to increase the use of DCDD, what would be some ways to do this?

key informant group and then synthesized across groups. The data were analyzed using a thematic content analysis<sup>31</sup> and occurred in 6 systematic steps. First, 2 team members independently coded the transcripts into the 14 TDF domains. Second, specific beliefs were generated for each utterance (coded interview quote) in each TDF domain. A "specific belief" refers to a collection of participant responses with a similar premise that suggests a problem and/or influence on behavior, in this case on DCDD. 22-24 Following generation of specific belief statements, similar statements were merged. Third, themes were then generated from the merged belief statements, allowing for recognition of similarities and differences across the 3 key informant groups and regions. Fourth, the themes were grouped into broader categories. Fifth, each theme was classified as a barrier or an enabler to DCDD. For a small number of themes, key informants had opposing views (eg, DCDD process is difficult (a barrier)/DCDD process is easy (an enabler)); these themes were classified as "conflicting." Sixth, themes were examined in relation to whether they were shared (ie, said by 2 or more individuals): (1) across key informant groups—said by at least 1 key

informant in 2 or more groups, (2) within a key informant group but not across groups (discipline-specific beliefs), and (3) within a region but not across multiple regions (region-specific beliefs).

# **Ethics Approval**

Ethical approval was obtained from the Ottawa Hospital Research Ethics Board (protocol 20130635-01H).

### **RESULTS**

### **Sample Characteristics**

A total of 144 participants were approached to recruit 55 key informants for a response rate of 38%. Distribution across regions and key informant groups was intentionally similar through the use of purposive and stratified sampling. Within the sample, there were 22 male (40%) and 33 female (60%) participants. The majority of participants were 40+ years of age (n = 42, 76%) and had 10+ years of clinical experience (n = 34, 62%). Over half (n = 30, 55%) of the

participants had hands-on experience with DCDD. Additional demographic details of the sample are in Table 2.

### **Relevant Theoretical Domains**

All 14 TDF theoretical domains were identified as relevant to DCDD with the exception of 1 domain: optimism. More beliefs reflected barriers to DCDD (n = 21 themes across 13 TDF domains) compared with enablers to DCDD (n = 4 themes across 7 TDF domains) (Tables 3-5).

#### **Shared Themes Between Key Informant Groups**

#### **Barriers**

Eight categories of barriers were identified: (1) education, (2) DCDD guidance, (3) practice variation, (4) roles, (5) resources, (6) support, (7) communication, and (8) personal and public opinion. Twenty-one themes emerged across the 8 categories, 18 (86%) of these themes were shared across key informant groups. The individual barriers themes within each category along with their frequencies (overall and for each key informant group) and an illustrative quote is in Table 3.

The 5 highest frequency themes were mentioned by all 3 key informant groups with a frequency of greater than 60% overall: (1) DCDD education is needed for healthcare professionals (n = 46, 84%; category: education), (2) a standardized and systematic screening process to determine DCDD candidacy or identify a potential donor is needed (n = 45, 81%; category: DCDD guidance), (3) practice variation across regions with respect communication about DCDD with families (n = 45, 81%; category: practice variation), (4) role ambiguity—multiple

clinician groups have responsibility to identify/assess if a patient is a potential DCDD candidate (n = 36, 65%; category: roles), and (5) DCDD needs to be well resourced (n = 35, 64%; category: resources).

#### **Enablers**

Fewer themes (n = 4) were identified that represented enablers to DCDD. Enabler themes fell into 2 categories: (1) personal and public opinion (n = 3 themes) and (2) resources (n = 1 theme). The 4 themes along with their frequencies and an illustrative quote are in Table 4. Overall, the 4 enabler themes were mentioned less frequently compared to the highest frequency barriers themes, with only 1 enabler being mentioned by greater than 50% of key informants compared with 10 barriers themes. The highest frequency enabler was DCDD/organ donation is a priority for me and I believe it should be an option (n = 35, 64%; category: personal and public opinion). Although this particular enabler was mentioned by all 3 key informant groups, it was mentioned substantially more by nurses (n = 16, 100%) and organ donor coordinators (n = 14, 93%) compared with intensivists (n = 4, 17%). Other enablers included: DCDD/donation is positive and beneficial for recipients (n = 22, 40%; category: personal and public opinion), DCDD is important for families and fulfills patient wishes which act as personal incentives to use DCDD (n = 11, 20%; category: personal and public opinion), and availability of an external dedicated physician for DCDD (n = 10, 18%; category: resources).

**TABLE 2.**Sample characteristics (N = 55)

Characteristics	Intensivist N = 24 (%)	Nurse N = 16 (%)	Coordinator N = 15 (%)	Total N = 55 (%)
Regions				
Western	10 (42)	7 (44)	7 (47)	24 (44)
Ontario	6 (25)	4 (25)	2 (13)	12 (22)
Quebec	5 (21)	3 (19)	2 (13)	10 (18)
Atlantic	3 (13)	2 (13)	4 (27)	9 (16)
Gender				
Male	21 (88)	0 (0)	1 (7)	22 (40)
Female	3 (13)	16 (100)	14 (93)	33 (60)
Age, years				
20-29	0 (0)	5 (31)	0 (0)	5 (9)
30-39	2 (8)	3 (19)	3 (20)	8 (15)
40-49	11 (46)	4 (25)	6 (40	21 (38)
50-59	6 (25)	2 (13)	5 (33)	13 (24)
60+	4 (17)	2 (13)	0 (0)	6 (11)
Missing data	1 (4)	0 (0)	1 (7)	2 (4)
Years of experience				
< 1	0 (0)	0 (0)	3 (20)	3 (5)
1-5	1 (4)	4 (25)	5 (33)	10 (18)
6-10	0 (4)	2 (13)	4 (27)	6 (11)
11-15	5 (21)	2 (13)	1 (7)	8 (15)
16+	18 (75)	8 (50)	0 (0)	26 (47)
Missing data	1 (4)	0 (0)	1 (7)	2 (4)
DCDD Experience				
Hands on	14 (58)	6 (38)	10 (67)	30 (55)
Around cases	4 (17)	3 (19)	1 (7)	8 (15)
No experience	6 (25)	7 (44)	4 (27)	17 (31)

# TABLE 3.

# **Barriers to DCDD**

			Frequency	of belief, n		
Catagony	Theme illustrative quote	Total, N = 55	Intensivist, n = 24	Nurse, n = 16	Coordinator, n = 15	TDF domains
Category	•					
Education	DCDD education is needed for healthcare professionals "More education, more frontline basic education of the entire process to raise the awareness and the knowledge level of the frontline staff that are the ones that are really gonna be the first person to consider it and then therefore contact [OPO] or answer questions directly from family." Nurse, Ontario DCDD education is needed for the public	46 (84) 28 (51)	18 (75) 8 (33)	16 (100) 14 (88)	12 80) 6 (40)	Knowledge Social/professional role and identity Beliefs about consequences Reinforcement Goals Environmental context and resources Emotion Behavioral regulation  Knowledge
	"Most people because of social marketing messages support organ donation but they support the concept they don't necessarily support it in understanding the details, the practical issues behind it. So even to say that we have consent from people for DCDD is you know fundamentally, you know fundamentally wrong because we don't go into issues like we will recover your organs after 5 minutes that we determine death has occurred oh by the way there might be electrical impulses in the heart but we still consider your family member to be dead. Those types of very detailed discussions with the general public have		5 (4-7)		- ()	Social/professional role and identity Beliefs about consequences Reinforcement Goals Environmental context and resources Emotion Behavioral regulation
DCDD Guidance	never occurred." Intensivist, West  A standardized and systematic screening process to determine DCDD candidacy or identify a potential donor is needed "If I wanted to augment the DCDD use at this center I think a systematic process of you know screening and identifying patients for DCDD would be helpful." Intensivist, Ontario  "On the other hand, it could be done more appropriately in my opinion if there were clear you know guidelines about all these issues I've already discussed;	45 (81)	23 (96)	10 (63)	10 (67)	Skills Reinforcement Goals Memory, attention and decision processes Environmental context and resources Behavioral regulation
	eligibility, process, etc." Intensivist, West We need or are working to develop new DCDD policy as these are important for effective DCDD use "organ donation policies and procedures were allowed in the dying patients rather than the dead patient then there would be a whole new set of opportunities." Intensivist, Ontario "Written policies are very helpful because people have questions about the process a very good written policyis broken down into provider rolea package for the bedside nursea package for the charge nurse a package for the attending physician outline the process and the specified roles for each actor" Nurse, West	38 (69)	14 (58)	15 (94)	9 (60)	Knowledge Skills Beliefs about capabilities Beliefs about consequences Intentions Goals Memory, attention and decision processes Environmental context and resources Behavioral regulation
	More guidance and better tools for predicting time of death and prognostication would increase the use of DCDD " the first concerns that comes to mind repeatedly when DCDD is discussed is the issue of variability, imperfections in our ability to prognosticate critically ill patients." Intensivist, West	33 (60)	16 (67)	9 (56)	8 (53)	Knowledge Social/professional role and identity Beliefs about capabilities Beliefs about consequences Goals Memory, attention and decision processes Environmental context and resources Emotion Behavioral regulation

5

# TABLE 3. (Continued)

	Theme illustrative quote		Frequency (	of belief, ı		
Category		Total, N = 55	Intensivist, n = 24	Nurse, n = 16	Coordinator, n = 15	TDF domains
DCDD guidance	Mandatory or automatic notification of Organ Procurement Offices is needed to increase DCDD use "they should be referring for any patient that we have because they matchthe Gift criteria." Organ Donor Coordinator, West	26 (47)	7 (29)	12 (75)	7 (47)	Social/professional role and identity Goals Memory, attention and decision processes Environmental context and resources Behavioral regulation
	Heparin administration guidance is unclear which influences DCDD use  "there's very little science around thisno trialswhy is heparin given well it's mostly just from the belief of transplant surgeons that it's necessary you know without really a lot of good data to prove that." Intensivist, West	9 (16)	6 (25)	-	3 (20)	Knowledge Beliefs about capabilities Beliefs about consequences Reinforcement Memory, attention and decision processes Environmental context and resources Social influences Emotion
Practice variation	Regions have different policies and/or accepted practices for communication about DCDD with families "There are some that will hide behind the policy that the family has to bring it up and so they could, the patient be a perfect candidate for DCDD and if the family	45 (81)	21 (88)	12 (75)	12 (80)	Beliefs about consequences Reinforcement Intentions Goals Environmental context and resources Behavioral regulation
	brings it up then the physician will support it." Organ Donor Coordinator, West There are varying practices for the DCDD withdrawal process "best reference in the Canadian context is a paper by [deidentified] and colleagues in the [deidentified]wide variability even when you adjust for patient characteristics across centers in Canada in their tendency to withdraw life sustaining interventions."	10 (18)	4 (17)	1 (6)	5 (33)	Knowledge Memory, attention and decision processes Environmental context and resources Emotion Behavioral regulation
Roles	Intensivist, West  Role ambiguity - multiple clinician groups (ie, physician, nurse, organ donor coordinator) have responsibility to identify/assess if a patient is a potential DCDD candidate "l identify potential candidates and then you know the [0PO] you know staff will help finalize the decision and usually they are consulting with their own physicians	36 (65)	19 (79)	7 (44)	10 (66)	Skills Social/professional role and identity Intentions Environmental context and resources Social influences
	as well" Intensivist, Ontario Keeping roles between patient care and donation separate would help DCDD use "I knowing the patient is dead but separating when you change care patterns so doing things for organ preservation versus letting the person die when does that occurdepending on different institutional DCDD practices that can be a problem." Intensivist, West "We need to define the roles clearly, the role of the intensivist is exclusively, before everything else, taking care of a patient, defining a diagnosis, prognosis and once the prognosis is understood by the family and we decide to move on to comfort measures, making that decision to go on to comfort measures and not involving organ donation before that step." Intensivist, Quebec	23 (42)	16 (67)	3 (19)	4 (27)	Social/professional role and identity Beliefs about capabilities Beliefs about consequences Intentions Goals Memory, attention and decision processes Social influences Emotion Behavioral regulation

# **TABLE 3. (Continued)**

	Theme illustrative quote		Frequency o	of belief, ı		
Category		Total, N = 55	Intensivist, n = 24	Nurse, n = 16	Coordinator, n = 15	TDF domains
Roles	Physicians have competing role priorities with DCDD cases "my goal is to get people betteryou	17 (31)	14 (58)	2 (13)	1 (7)	Social/professional role and identity Beliefs about consequences Goals
	have to be very careful about conflict and so we don't sort of introduce the idea to them you know it seems to sometimes come in a more indirect way."					Memory, attention and decision processes
Resources	DCDD needs to be well resourced "Yeah resource intensive and so when a case doesn't move forward you have held up that OR for 3 hours potentially as well as all of the supplies that have been opened and not utilized but open and now have to be disposed of. So absolutely that's a can be viewed as a deterrentyou're bumping	35 (64)	16 (67)	9 (56)	10 (66)	Beliefs about consequences Reinforcemer Environmental context and resources Emotion Behavioral regulation
	cases." Organ Donor Coordinator, Atlantic Extra staff is needed for DCDD to proceed " it still requires extra time for the nurses on call for DCDD and for the nurses in the OR. Obviously, there's costs affiliated to this, it usually gets people's teeth grinding because it usually means that they do more overtime, to organize everything that CDC [DCDD?] entails." Organ Donor Coordinator, Quebec	31 (56)	9 (38)	12 (75)	10 (67)	Knowledge Goals Environmental context and resources Memory, attention and decision processes Behavioral regulation
Support	Institution, healthcare provider and public support is needed to increase use of DCDD  " it's a supportive environment, a collegial environment and everybody's onboard with the concept. Were that not to be the case; ie, that there's a lot of conflict involved then that would make it more difficult you know for use to pursue it. But in general, all staff are supportive of the need for organ donation" Intensivist, Atlantic	30 (55)	15 (63)	11 (69)	4 (27)	Beliefs about capabilities Goals Environmental context and resources Social influences Behavioral regulation
Communication	Effective communication skills are required for DCDD use "I think you need to have exceptionally good communication skills, you need to have compassion and you need to have information about the process." Nurse, West	18 (33)	6 (25)	9 (36)	3 (20)	Skills Reinforcement Environmental context and resources
	Communication with family about DCDD is difficult  "The communication piece for approaching you know the family and it's difficult DCDD because you're approaching the issue of organ donation before the patient has died which is a different scenario than brain death where that is our definition of death." Intensivist, Ontario	15 (27)	5 (21)	8 (50)	2 (13)	Beliefs about capabilities Beliefs about consequences Goals Emotion Behavioral regulation
Personal and public opinion	People believe that we just want organs  "it could be bad if they just think that we're taking organs from living people you know so that could be a deterrent you know." Organ Donor Coordinator, Atlantic	12 (22)	5 (21)	3 (19)	4 (27)	Social/professional role and identity Beliefs about consequences Beliefs about capabilities Social influences

# **Conflicting Themes**

In some cases, beliefs shared between key informants could be a barrier or an enabler, depending on the key informant interview. Four themes fell into this situation (Table 5). Under the category of DCDD guidance, 41 (75%) of key informants felt the DCDD process was challenging and complex (a barrier),

whereas 25 (45%) felt the DCDD process was easy (an enabler); some key informants felt it could be both a barrier and an enabler depending on the situation. Also, within the category of DCDD guidance, there were conflicting views with respect to how difficult (a barrier) (n = 23, 42%) or easy (an enabler) (n = 20, 36%), it is to assess which patients are viable

# TABLE 4.

# **Enablers to DCDD**

	Theme <i>illustrative quote</i>		Frequency	of belief, n		
Category		Total, N = 55	Intensivist, n = 24	Nurse, n = 16	Coordinator, n = 15	TDF domains
Personal & Public Opinion	DCDD/organ donation is a priority for me and I believe it should be an option  "I struggle with the whole concept but I think it's up to if people are well-informed I think that option should be left up to them." Nurse, West	35 (64)	4 (17)	16 (100)	14 (93)	Social/professional role and identity Intentions Goals Environmental context and resources
	DCDD/donation is positive and beneficial for recipients  "it's hopeful and it's wonderful to see them get their life back and so the benefits are you know unlimited to those people who are able to receive organs and continue their lives and go back to work and enjoy life with their families.  And you know not have to worry or carry a pager around day-to-day wondering if they're going to die or if they're going to be able to plan the next 10 years of their life so yeah." Nurse, Ontario	22 (40)	11 (46)	11 (69)	_	Beliefs about consequences
	DCDD is important for families and fulfills patient wishes which act as personal incentives to use DCDD  "I think hearing stories about what happens after the fact are really helpful they're very uplifting and positive and I think that's really important on just like a personal level for closurethose messages after the fact really confirming of what we're doing that we're impacting other people's lives." <i>Nurse, Ontario</i>	11 (20)	2 (8)	4 (25)	5 (33)	Social/professional role and identity Reinforcement Social influences
Resources	Availability of an external dedicated physician for DCDD "if there is a DCDD and if you have an external call system where say it's another Intensivist who happens to be on call for DCDD then they can organize and be the DCDD process more like a coordinator." Intensivist, Atlantic "And in some smaller hospitals it's hard to find 2 physicians on-site for that timeframe." Organ Donor Coordinator, West	10 (18)	7 (29)	_	3 (20)	Environmental context and resources Behavioral regulation

for DCDD. Other conflicting themes centered on: institutional support and funding.

# **Intensivist-specific Themes**

The intensivists were the only key informant group to report discipline-specific beliefs. These beliefs grouped into 3 themes, each of which was a barrier to DCDD. Almost a third (n = 7, 29%) of intensivists commented that it would be a substantial challenge to increase DCDD rates due to reservations from the public that DCDD is unethical. Intensivists were also the only key informant group to report that clinician religious views could act as a barrier to DCDD (n = 4, 17%). Finally, a small number (n = 2, 8%) of intensivists felt that the lack of legislation mandating DCDD was a barrier as it increased concerns about the ethical and legal concerns of DCDD.

# **Regional Differences**

Although the frequency of barriers and enablers themes was largely similar between regions, 2 distinct differences were noted. First, Ontario and Quebec key informants more frequently reported that the process of assessing which patients are viable candidates for DCDD is a difficult process. Second, Quebec and Western Canadian key informants reported that the administration of heparin is unclear, acting as a barrier to DCDD use; this belief was not shared by key informants in any other region.

# **DISCUSSION**

### **Summary of Findings**

To our knowledge, this is the first study to use a comprehensive behavioral theory approach to explore healthcare

9

# TABLE 5.

# Conflicting themes (acting as barriers and/or enablers) to DCDD

	Theme <i>illustrative quote</i>		Frequency o	f belief, ı		
Category		Total, N = 55	Intensivist, n = 24	Nurse, n = 16	Coordinator, n = 15	TDF domains
DCDD guidance	The DCDD process is challenging and complex to follow (barrier) "it can be rather challenging to not let	41 (75) 25 (45)	19 (79) 11 (46)	11 (69) 7 (44)	11 (73) 7 (47)	Beliefs about capabilities Beliefs about consequences Reinforcement
	that process get taken over by somebody else meaning the coordinating the time because there are some physicians that want to just get everybody to agree themselves and they forget that there might be 2-3 other parties that have to be consulted before they can agree on something." Organ Donor Coordinator, West The DCDD process is easy to follow (enabler) "Actual making the phone calls filling out the forms that's not difficult at all that's easy,					Environmental context and resources Emotion
	that's a well-defined protocol." Nurse, Ontario					
	It is difficult to properly decide/assess which patients are viable/a candidate for DCDD (barrier)  " we're not and then I would say that nobody is because we don't have good prognostication for the brain yet and there's been numerous documented cases in the evidence that suggests that sometimes we don't prognosticate the brain well enough and that is the conflict	23 (42) 20 (36)	12 (50) 13 (54)	7 (44) 2 (13)	4 (27) 5 (33)	Beliefs about capabilities  Memory, attention and decision processes
	of DCDD." Intensivist, West  It is easy to properly decide/assess which patients are viable/a candidate for DCDD (enabler)  "I think we're pretty confident that we are fairly good at being able to decide which patient should be taken through the process and which one is probably not a good idea." Intensivist, Quebec					
Support	My institution/team/ICU does not support DCDD (barrier)  "our group isn't comfortable with it so that's you know for spiritual, religious, for a whole bunch of things the group isn't comfortable with it." Intensivist, West My institution/team/ICU does support DCDD (enabler)  "it's supported by our institution and supported by our ICU culture." Intensivist, Ontario	23 (42) 40 (73)	6 (25) 13 (54)	8 (50) 8 (50)	9 (60) 14 (93)	Social/professional role and identity Goals Environmental context and resources Social Influences Emotion
Resources	Funding or payment does not affect DCDD use (barrier) "I think it reflects whether or not we get referrals. So, I think cost to physicians working up and I know there's been an issue with anesthesia here when we're retrieving lungs in the OR of them not being, them wanting to be compensated for thatit also affects how friendly people are and how willing people are to participate with us."  Organ Donor Coordinator, West  Funding or payment does affect DCDD use (enabler) "we actually do have you know a fee schedule in place to support organ donors so I mean I don't think that will be a barrier and you know	17 (31) 3 (6)	15 (63) 1 (4)	2 (13) 1 (6)	0 (0) 1 (7)	Knowledge Reinforcement Goals Environmental context and resources Behavioral regulation
	the whole system is funded publicly so again I don't think it's an issue for the hospital." Intensivist, West					

professionals' perceptions of the barriers and enablers to DCDD. By taking this approach, a comprehensive and systematic understanding of the determinants (barriers and enablers) to DCDD was possible. These determinants, which ranged from individual beliefs to team, organizational and system factors, hold potential as targets for future behavior change interventions to improve DCDD rates.

From this national study, enablers to DCDD were seldom reported, and when they were, they were typically associated with beneficence, such as the positivity felt by organ donors and their families, and by the recipients of the donation. Barriers to DCDD were more commonly reported, with the most frequent barriers relating to: need for healthcare professional and public education on DCDD, need for additional DCDD guidance, the current practice variation in DCDD processes, DCDD role—who is responsible at which stages of the DCDD process, and the significant resources needed to do DCDD. Most barriers and enablers were shared between the 3 key informant groups interviewed, indicating there is much common ground for developing efficient implementation interventions that target multiple players, to improve DCDD rates.

# **Comparison to Previous Research**

Several findings from this study reinforce the limited knowledge we have on barriers and enablers to DCDD practice and its acceptance from previous studies. For example, key themes from this study around the need for more education on DCDD, for training on communication between healthcare professionals and family, and the need for continued development of policy and procedures were also noted in previous studies in the United States. 32,33 Also, similar to past studies, all key informant groups in this study desired additional guidance regarding how to care for the dying patient who is a candidate for DCDD. There is also evidence to support the integration of palliative care into critical care units as a means to maintain a high standard of care for patients while optimizing the potential for organ donation by making the process routine. 34,35 Improving end-of-life care in critical care by means, such as involving palliative care consultants or specific palliative care beds within critical care units, has been shown to be effective in recent studies in terms of improving quality of care and potential for organ donation.<sup>36,3</sup>

Despite longstanding evidence that clearer roles and responsibilities lead to better communication, <sup>38,39</sup> this continues to be a challenge for healthcare professionals as evidenced by the beliefs of participants in this study who eluded to overlapping and unclear roles in the DCDD process. In recommendations specific to DCDD, Steinbrook<sup>40</sup> suggested a "surgical timeout," or "team huddle," before the withdrawal of life sustaining therapy as a measure that can be taken to verify roles and responsibilities of the staff compliment when beginning the donation process. Development and implementation of appropriate policy and procedures are also a way to address role clarification along with a systematic protocol for all aspects of the DCDD process from initiation, prognostication to completion which is consistent across regions. Likely holding most potential however to reduce role ambiguity in DCDD is early referral to organ donation procurement programs. These programs remove the burden of assessing an individual's viability for DCDD from busy clinicians and place it with trained organ donor coordinators/specialists following a referral. Early referral programs improves communication

with family, helps mitigate ethical concerns of the clinical care team, and ensures that best practices are in place if and when any organ donation, including DCDD, becomes appropriate. The core advantage of this type of program is that it prevents withdrawal of care prior to determination of patient's wishes and potential opportunity for organ donation. <sup>41</sup> Other advantages include provision of: a consultation resource of specialized knowledge and information on organ donation, assistance in clarifying donor eligibility, on-site donor coordinator support when required, early engagement with staff and families, and normalizes the integration of donation into end-of-life care. <sup>42</sup>

#### Limitations

Although we provide much needed valuable insight into the factors that may influence DCDD, there are some limitations to our study. First, although the specific beliefs identified represent intensivists', nurses', and organ donor coordinators' views about what might influence DCDD, they do not provide evidence of actual influences on DCDD. Second, we limited key informant interviews to groups that most frequently encounter DCDD but other healthcare professionals (eg, emergency and pediatric ICU clinicians) and families of DCDD donors may also have valuable insight into the barriers and enablers to DCDD. Third, it is possible that the 55 key informants participating in the study (who agreed to be interviewed) may differ from the 89 individuals approached who did not agree to participate and may have different perceptions of the barriers and enablers to DCDD. Finally, because the purpose of this study was to identify frontline ICU professionals' and organ donor coordinators' perceptions and beliefs of the barriers and enablers to DCDD, we used a behavior change theory that facilitates the identification broadly of all possible barriers and enablers. This framework does not drill down on any specific barriers or enablers. Thus, we are not able to comment on reasons for incorrect beliefs about DCDD where they existed by interviewees.

# **CONCLUSIONS**

In summary, limited consideration of DCDD continues to be a major challenge globally. This study demonstrated the utility in using psychological theories commonly used in behavior change research to explore the barriers to and enablers of DCDD. Our results provide a much-needed and better understanding of intensivists', ICU nurses', and organ door coordinators' behavior change processes in relation to DCDD and can be used to inform the design of future implementation strategies to improve DCDD rates. These implementation strategies will need to be multifaceted and address the individual clinician, team, organizational, and system-level barriers identified in this study.

Based on our findings, we recommend the following behavior change techniques be part of future multifaceted implementation strategies aimed to improve DCDD: (1) provision of DCDD education to ICU professionals and organ donor coordinators, (2) communication skills training for ICU professionals and organ donor coordinators specific to DCDD situations, and (3) development and implementation of a standardized screening process to identify potential DCDD donors and determine DCDD candidacy. Professional education initiatives could include a national education toolkit for DCDD donor identification and referral. The toolkit can provide resources to ICU professionals and organ donor

coordinators (eg, clinical trigger cards, posters, simplified messaging) in areas, such as how and when to identify and refer potential donors, how to effectively and compassionately discuss donation with family members, and how to provide optimal end of life care in DCDD cases. Mandatory skills training in donor identification and referral and importantly, in how to communicate with the multidisciplinary team and families around DCDD, should be offered on an ongoing basis to ICU professionals. Finally, establishment of organizational standardized screening processes to determine DCDD potential donors and candidacy will be critical to improving DCDD rates. These processes should be documented in easy-to-follow checklists and policies and make clear distinctions between referral and notification to organ donor organizations.

#### REFERENCES

- National Health Service. Organ donation and transplantation—activity figures for the UK as at 7 April 2017. https://nhsbtdbe.blob.core.windows.net/ umbraco-assets/1343/annual\_stats.pdf. Accessed August 2017.
- Government of Canada. Blood, organ and tissue Donation. Government of Canada website. https://www.canada.ca/en/public-health/services/ diseases/blood-organ-tissue-donation.html. Accessed August 2017.
- Abouna GM. Organ shortage crisis: problems and possible solutions. Transplant Proc. 2008;40:34–38.
- 4. U.S. Department of Health & Human Services. Organ Donation Statistics. U.S. Government Information on Organ Donation and Transplantation website. https://www.organdonor.gov/statistics-stories/statistics.html. Accessed August 2017.
- Canada's Organ Donation and Transplantation Community CBS. Call to Action: A strategic plan to improve organ and tissue donation and transplantation performance for Canadians. Canadian Blood Services website. www.organsandtissues.ca/s/wp-content/.../OTDT-INDX-final-C2A.pdf? 2011. Accessed August 2017.
- Shemie SD, Doig C, Dickens B, et al. Severe brain injury to neurological determination of death: Canadian forum recommendations. CMAJ. 2006;174:S1–S12.
- Bendorf A, Kelly PJ, Kerridge IH, et al. An international comparison of the effect of policy shifts to organ donation following cardiocirculatory death (DCD) on donation rates after brain death (DBD) and transplantation rates. *PloS One*. 2013;8:e62010.
- Canadian Blood Services. Organ Donation and Transplantation in Canada—System Progress Report 2006–2015. Canadian Blood Services website. https://blood.ca/sites/default/files/ODT\_Report.pdf. 2016. Accessed August 2017.
- Israni AK, Zaun D, Bolch C, et al. OPTN/SRTR 2015 annual data report: deceased organ donation. Am J Transplant. 2017;17(Suppl 1):503–542.
- NHS Blood and Transplant. Organ Donation and Transplantation Activity Report 2016/2017. ODT Clinical website. https://www.odt.nhs.uk/ statistics-and-reports/annual-activity-report/. Accessed August 2017.
- Hernadez-Alejandro R, Wall W, Jevnikar A, et al. Organ donation after cardiac death: donor and recipient outcomes after the first three years of the Ontario experience. Can J Anaesth. 2011;58:599–605.
- 12. Robertson JA. The dead donor rule. Hastings CentRep. 1999;29:6-14.
- Dhanani S, Ward R, Hornby L, et al. Survey of determination of death after cardiac arrest by intensive care physicians. *Crit Care Med*. 2012;40:1449–1455.
- Dhanani S, Hornby L, Ward R, et al. Variability in the determination of death after cardiac arrest: a review of guidelines and statements. *J Intensive* Care Med. 2012;27:238–252.
- Manara AR, Murphy PG, O'Callaghan G. Donation after circulatory death. Br J Anaesth. 2012;108(Suppl 1):i108–i121.
- Da Silva IR, Frontera JA. Worldwide barriers to organ donation. JAMA Neurol. 2015;72:112–118.
- National Health Service Blood and Transplant. National Organ Retrieval Services. ODT Clinical website. http://www.odt.nhs.uk/retrieval/nationalorgan-retrieval-services/. Accessed April 2018.
- National Health Service Blood and Transplant. National Organ Retrieval Service (NORS) Review. https://nhsbtdbe.blob.core.windows.net/ umbraco-assets-corp/1411/nors\_review\_report\_2015.pdf. Published May 2015. Accessed April 2018.

 Cane J, O'Connor D, Michie S. Validation of the theoretical domains framework for use in behaviour change and implementation research. *Implement Sci.* 2012;7:37.

- Michie S, Johnston M, Abraham C, et al. Making psychological theory useful for implementing evidence based practice: a consensus approach. Qual Saf Health Care. 2005;14:26–33.
- Presseau J, Mutsaers B, Al-Jaishi AA, et al. Barriers and facilitators to healthcare professional behaviour change in clinical trials using the Theoretical Domains Framework: a case study of a trial of individualized temperature-reduced haemodialysis. *Trials*. 2017;18:227.
- Islam R, Tinmouth AT, Francis JJ, et al. A cross-country comparison of intensive care physicians' beliefs about their transfusion behaviour: a qualitative study using the theoretical domains framework. *Implement Sci.* 2012;7:93.
- Patey AM, Islam R, Francis JJ, et al. Anesthesiologists' and surgeons' perceptions about routine pre-operative testing in low-risk patients: application of the Theoretical Domains Framework (TDF) to identify factors that influence physicians' decisions to order pre-operative tests. *Implement Sci.* 2012;7:52.
- Amemori M, Michie S, Korhonen T, et al. Assessing implementation difficulties in tobacco use prevention and cessation counselling among dental providers. *Implement Sci.* 2011;6:50.
- Duncan EM, Francis JJ, Johnston M, et al. Learning curves, taking instructions, and patient safety: using a theoretical domains framework in an interview study to investigate prescribing errors among trainee doctors. *Implement Sci.* 2012;7:86.
- 26. McSherry LA, Dombrowski SU, Francis JJ, et al. 'It's a can of worms': understanding primary care practitioners' behaviours in relation to HPV using the Theoretical Domains Framework. *Implement Sci.* 2012;7:73.
- Curran JA, Brehaut J, Patey AM, et al. Understanding the Canadian adult CT head rule trial: use of the theoretical domains framework for process evaluation. *Implement Sci.* 2013;8:25.
- Mazza D, Chapman A, Michie S. Barriers to the implementation of preconception care guidelines as perceived by general practitioners: a qualitative study. BMC Health Serv Res. 2013;13:36.
- Francis JJ, Johnston M, Robertson C, et al. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. Psychol Health. 2010;25:1229–1245.
- NVivo qualitative data analysis software, Version 10. Victoria, Australia: QSR International; 2012. QSR International wesbite. http://www.gsrinternational.com/products\_nvivo.aspx. Accessed August 2017.
- 31. Morse JM, Field PA. *Qualitative research methods for health professionals*. 2nd ed. Thousand Oaks, CA: Sage; 1995.
- D'Alessandro AM, Peltier JW, Phelps JE. Understanding the antecedents of the acceptance of donation after cardiac death by healthcare professionals. Crit Care Med. 2008;36:1075–1081.
- Mandell MS, Zamudio S, Seem D, et al. National evaluation of healthcare provider attitudes toward organ donation after cardiac death. *Crit Care Med*. 2006;34:2952–2958.
- Serri K, Marsolais P. End-of-life issues in cardiac critical care: the option of organ donation. Can J Cardiol. 2017;33:128–134.
- Citerio G, Cypel M, Dobb GJ, et al. Organ donation in adults: a critical care perspective. *Intensive Care Med.* 2016;42:305–315.
- Nunnink L, Cook DA. Palliative ICU beds for potential organ donors: an effective use of resources based on quality-adjusted life-years gained. Crit Care Resusc. 2016;18:37–42.
- Melville A, Kolt G, Anderson D, et al. Admission to intensive care for palliative care or potential organ donation: demographics, circumstances, outcomes, and resource use. *Crit Care Med*. 2017;45: e1050–e1059.
- 38. DuBois JM, DeVita M. Donation after cardiac death in the United States: how to move forward. *Crit Care Med*. 2006;34:3045–3047.
- 39. Linyear AS, Tartaglia A. Family communication coordination: a program to increase organ donation. *J Transpl Coord*. 1999;9:165–174.
- Steinbrook R. Organ donation after cardiac death. N Engl J Med. 2007; 357:209–213
- Pacific Northwest Transplant Bank. Making the Referral. PNTB website. http://pntb.org/hospital-partners/donation-resources/real-time-resources/making-the-early-referral. Accessed August 2017.
- Canadian Blood Services. Potential Organ Donor Identification and System Accountability Workshop: Canadian National Transplant Research Program. 2017.