



Family veto in organ donation: the experiences of Organ and Tissue Donation Coordinators in Ontario

Veto familial au don d'organes : expériences des coordonnateurs en don d'organes et de tissus en Ontario

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Abstract

Purpose In Ontario, an individual's registered wish for organ donation is legally valid consent following death. Family veto occurs when the deceased donor's substitute decision-maker (SDM) overrides this consent to donate, evoking a legal and ethical conflict. The objective of this study was to examine the experiences of Organ and Tissue Donation Coordinators (OTDCs) working with SDMs who vetoed a deceased donor's consent for organ donation.

Methods Qualitative focus groups were conducted with ten OTDCs in Ontario, Canada who reported experience with family veto. An interpretative phenomenological approach informed data analysis. Themes emerged through team consensus and were further refined through collaborative and reflexive engagement.

Results Four themes emerged regarding family veto: 1) the significance of the OTDC role, 2) emotional distress and the "understandable" family veto, 3) barriers contributing to family veto, and 4) strategies towards a culture of organ donation. Findings highlighted the importance of patient advocacy in the OTDC role, while revealing the emotional distress of experiencing family veto. OTDCs identified timing and healthcare providers' perceived ambivalence toward organ donation as critical barriers to family authorization. Value-positive language, role reframing, and increased education were offered as strategies to address these barriers and reduce family veto.

Conclusion This study highlights important considerations about organ donation authorization processes in Ontario. Findings support practice changes towards reducing family veto and further research nationally. Collaborations with key stakeholders are warranted to align healthcare practices, donation

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policies, and education initiatives towards a shared goal of increasing organ donation.

Résumé

Objectif *En Ontario, le souhait documenté et enregistré d'une personne de faire un don d'organes constitue un consentement valable d'un point de vue légal après sa mort. Le terme de veto familial est utilisé pour décrire une situation dans laquelle la personne habilitée à décider au nom du donneur décédé refuse ce consentement au don, provoquant un conflit juridique et éthique. L'objectif de cette étude était d'examiner les expériences des coordonnateurs en don d'organes et de tissus (CDOT) travaillant avec les personnes habilitées à décider au nom d'autrui ayant posé leur veto au consentement d'un donneur décédé pour le don d'organes.*

Méthode *Des groupes de discussion qualitatifs ont été menés auprès de dix CDOT de l'Ontario, Canada, qui ont fait état de leurs expériences de veto familial. Une approche phénoménologique interprétative a éclairé l'analyse des données. Des thèmes sont ressortis du consensus en équipe et ont été approfondis grâce à un engagement collaboratif et réflexif.*

Résultats *Quatre thèmes entourant le veto familial ont émergé : 1) l'importance du rôle du CDOT, 2) la détresse émotionnelle et le veto familial « compréhensible », 3) les obstacles contribuant au veto familial, et 4) les stratégies pour favoriser une culture de don d'organes. Les résultats ont souligné l'importance des stratégies de défense des droits des patients dans le rôle du CDOT tout en révélant la détresse émotionnelle liée à un veto familial. Les CDOT ont identifié le moment choisi et l'ambivalence perçue des fournisseurs de soins de santé envers le don d'organes comme des obstacles cruciaux à l'autorisation familiale. Un langage positif en matière de valeur, un recadrage des fonctions et une augmentation de la formation sont quelques-unes des stratégies proposées pour éliminer ces obstacles et réduire les cas de veto familial.*

Conclusion *Cette étude met en lumière d'importantes considérations concernant les processus d'autorisation du don d'organes en Ontario. Les résultats appuient les changements apportés aux pratiques visant à réduire les cas de veto familial et à encourager les recherches à l'échelle nationale. Des collaborations avec les principaux intervenants sont nécessaires afin d'harmoniser les pratiques de soins de santé, les politiques de dons et les initiatives d'éducation en vue d'atteindre l'objectif commun d'augmenter les dons d'organes.*

Keywords tissue and organ procurement · tissue donors · intensive care units · patient-care team · qualitative research · family veto

Organ transplantation saves lives and improves quality of life for patients with end-stage organ failure.¹ However, substantial shortfalls exist in the number of organs available for transplantation.^{2,3} In 2018, over 4,300 Canadians were awaiting an organ, of whom 223 died waiting.⁴ In Canada, over 80% of transplanted organs are from deceased donors.^{4,5} Consent for organ donation depends on public support and a willingness to donate.⁶ A recent survey found that while 90% of Canadians supported organ donation, only 20% were registered organ donors.⁷

In Ontario, organ donation registration is a free and voluntary process available to individuals aged 16 years and older.^{8,9} A registered wish to donate is legally valid consent following death.^{9,10} Nevertheless, it is accepted practice for healthcare providers (HCPs) to seek authorization for organ donation from substitute decision-makers (SDMs), often members of the deceased donor's family but can be legal guardians and attorneys of care, to document this consent to donate. Reasons for this include the belief that initiating organ donation on a registered donor without explicit authorization may increase family distress.^{10–12} Seeking family authorization, however, permits SDMs to veto the deceased donor's registered wish to donate, a decision known as “family veto”.⁶ Family veto represents a legal and ethical conflict between respect for the deceased donor's wishes and those of the SDM.^{6,10,13,14} According to the Trillium Gift of Life Network (TGLN), family veto occurred in 15–20% of registered approaches for organ donation in Ontario over the past three years. In 2019/2020, there were 72 family vetoes, representing a loss of up to 250 potential transplant opportunities (TGLN, e-mail communication, July 2020).

Researchers seek a better understanding of family veto, which involves multiple stakeholders including Organ and Tissue Donation Coordinators (OTDCs) who facilitate the organ donation process.¹⁵ Organ and Tissue Donation Coordinators work at the nexus of family veto, with professional responsibilities including identifying potential donors, assisting physicians to declare brain death, introducing organ donation to SDMs, completing donor assessments for organ retrieval and following-up with SDMs after retrieval.¹⁶ Yet the perspectives of OTDCs are largely absent from the literature. The objective of this study was to examine the experiences of OTDCs who work with SDMs who vetoed a deceased donor's legal consent for organ donation. Findings will illuminate the underlying processes surrounding family veto and increase knowledge about family authorization in Ontario.

Methods

A qualitative study was conducted using semi-structured focus groups with TGLN OTDCs in Ontario, Canada. An interpretative phenomenology approach was employed to explore OTDCs' lived experiences with family veto through in-depth and rich accounts of their personal narratives.¹⁷ Focus groups are effective for collecting rich, insightful and synergistic data through interpersonal interactions,^{18,19} and can be used effectively within a phenomenology approach.²⁰ A small participant group is recommended in this context to illuminate individual experiences, with the ideal sample size ranging from five to eight participants.^{19–21} Institutional research ethics was approved by the University of Toronto Research Ethics Board (May, 2019).

Participants

Participants were recruited based on their knowledge of family veto. Inclusion criteria were i) working as an OTDC at TGLN for a minimum of six months, and ii) self-reported experience with family veto. All eligible OTDCs ($n = 48$) were informed of the study via a recruitment email from TGLN and were asked to contact the study team if interested. The study team telephoned interested OTDCs to confirm eligibility and obtain verbal consent. Written consent was collected in-person from all participants prior to commencing the focus groups.

Data collection and analysis

A semi-structured focus group script was developed by the study team based on existing literature, clinical and research experience, and feedback from TGLN

administrators. Two facilitators trained in qualitative methodology conducted the focus groups, each lasting approximately 60–90 minutes to elicit rich, insightful data from participants. Focus groups were audio-recorded, transcribed verbatim, and de-identified. Three study team members independently coded the transcripts using NVivo for qualitative data management.²² Study team meetings were held to facilitate interactions that represented a hermeneutic interpretative process of analysis.²³ For example, a textural description of participants' experiences was written to summarize the essence of the phenomenon; this was shared and compared within the study team and reflexive discussions deepened understanding and interpretation of the phenomenon.^{24,25} Themes emerged through team consensus and were further refined through collaborative and reflexive engagement.²⁴ This process was completed iteratively until thematic saturation was reached.^{26,27} Additional focus groups were not conducted as thematic saturation represented a rich understanding of participants' shared lived experiences.^{28,29}

Results

Two in-person focus groups were conducted with a total of ten TGLN OTDCs from across Ontario: one focus group each of OTDCs from hospitals within and outside the Greater Toronto Area. Participants were all female with at least four years of nursing experience and represented diversity across age, number of years employed at TGLN, number of years as an OTDC, and location of practice (Table 1). Four primary themes emerged from data analysis as described below (Table 2).

Table 1 Demographic characteristics of participants

Variable	<i>n</i> (%)	Mean	Median	Range	Standard deviation
Female, <i>n</i> (%)	10 (100%)	–	–	–	–
Age, yrs	–	38.8	37.5	29.0–56.0	8.8
Number of years working as a Trillium Gift of Life Network Organ and Tissue Donation Coordinator	–	6.7	6.0	0.5–16.0	6.1
Number of years employed at Trillium Gift of Life Network	–	7.7	6.5	0.8–16.0	6.6
Hospital location, <i>n</i> (%)	10 (100%)	–	–	–	–
• Greater Toronto Area	6 (60%)				
• Non-Greater Toronto Area	4 (40%)				
Hospitals with Donation Physicians, <i>n</i> (%)	5 (50%)	–	–	–	–
• Greater Toronto Area	2 (20%)				
• Non-Greater Toronto Area	3 (30%)				

Table 2 Themes and quotes—participants' perspectives

Theme	Sub-theme	Supporting quotes
The significance of the OTDC role	Advocate	<ul style="list-style-type: none"> • “We’re honouring [the patient’s] decision. Yes, it’s hard for the families, and we’re here to support them through that process, and that’s our role. But, you’re advocating first and foremost for the patient always” (P6). • “Our focus is the patient, definitely...we’re the donor’s voice” (P3). • “I think that when the family sees that we’re advocating for the patient and their wishes, you develop that relationship with the family...It’s almost the same, because...I can probably honour [the patient’s] wish at the same time developing that therapeutic relationship with [the family]” (P8). • “The focus is always the patient and it should never veer from that. All the decisions made for the patients, or on behalf of the patient is...is for them” (P6). • “I think...disappointed in myself if I couldn’t say the right thing or get [the SDM] to see why [following the patient’s decision] is so important” (P2).
	Educator	<ul style="list-style-type: none"> • “There’s a common misconception, especially about skin donations. Even with families when we have consent, they say, ‘we don’t want to do skin donation.’ And then [I] explain, ‘it’s just a light graft, it doesn’t look like the entire skin’s removed’ and then they’re like ‘we’re okay with that’” (P9). • “Sometimes they ask about open-casket...we address it, that [organ donation] doesn’t affect open-casket viewing. I think donation is very accommodating, and that’s why we ask families what their concerns are” (P6). • “[SDMs will say] ‘well, they don’t want to be on a vent, we gotta take them off the vent,’ ‘well they wanted to be an organ donor.’ It’s navigating that and trying to explain to [SDMs] you have to be on a ventilator, [the donor is] not suffering. So, it’s educating too” (P1). • “You know when you stop to think about your job...It’s really amazing work that we’re able to do and be with families at a very bad time but turning it into...a good feeling in the end” (P2). • “Cases with families are great. And they get inside your head, and they stay with you, and it’s an honour to be with them” (P3). • “You’re with the best families at the moment of grief and whatever we can do to help them through it...That’s what brings us, I guess, job satisfaction” (P4).
Emotional distress and the ‘understandable’ family veto	Profound sense of fulfillment	<ul style="list-style-type: none"> • “[Family veto] brings a sense of distress because you feel like you want to protect the patient...You don’t want [their registered consent] to be taken away from them like you wouldn’t want your own, like you wouldn’t want something to be taken away from you...It causes distress” (P7). • “I leave kind of feeling gross and sick and devastated that there’s lives lost” (P2). • “How do I feel about the veto? It’s complicated...I feel mad, like I do feel mad when [SDMs] won’t...give any room for movement [to consider authorization]” (P6).
	Emotional distress	<ul style="list-style-type: none"> • “It’s harder because in our job with these—when we’re approaching families, we can’t necessarily talk to the patient. So, we can’t say ‘you really did want donation, can you just tell your family?’ So that’s the hardest. You can’t validate...it” (P3). • “You sort of feel like...Like one time when it happened, I just cried. I called my manager because I felt really sad about the situation. [The donor] was registered, and he had...lungs” (P7). • “I’m trying to really watch my tongue, but I get so pissed off [about family veto]...I think, how do you think you have the right? Like why do you get to come and play God and change their mind?” (P1). • “Every time I do get a family veto, it’s because of a traumatic experience where it’s—I understand why they are vetoing the decision” (P8). • “The family had been through a really traumatic...the patient had really been suffering...He had spoken with the family, they knew his wishes, they wanted to. So it was a really hard no because they were like, ‘we know he wanted to do this, but we can’t do anymore—we’re spent’” (P7). • “I gave it everything I had, and you know, I could say that’s a good no...because you didn’t just go ‘okay’ and walk away. You tried everything you could” (P4). • “I don’t mind a good no” (P3).
	‘Understandable’ family veto	

Table 2 continued

Theme	Sub-theme	Supporting quotes
Barriers contributing to family veto	Timing	<ul style="list-style-type: none"> • “In my experience, any overturn has always been about timing... You hear from families ‘if you would’ve talked to me about this three days ago and started things, absolutely, but not now. Now I’m withdrawing care and now we’re done’” (P1). • “I’ve had families say, ‘well, if you asked me two days ago, then I would move forward. Why couldn’t you have had this conversation two days ago?’ And I have to explain ‘I can only have that conversation once you’ve made that withdrawal decision’” (P5). • “I think it’s the timing. [SDMs] are in support of it, but as soon as you start exploring how long this is going to take, on top of what they’ve already been through...they just want to get from where they are to the endpoint very, very quickly” (P4). • “This family, they’re overwhelmed, they had a lot of external factors. They just weren’t able to give that time for us to assess for donation” (P7).
	Delayed referral	<ul style="list-style-type: none"> • “In my experience, it’s usually, [SDMs] understand...they understand why you need the time. They’re not arguing that... ‘Yeah, we get it, we’re just done.’ Or whatever their reason is” (Unidentified). • “It’s a very frustrating situation to be caught in...This golden thing is slipping away from you, and you don’t quite know how to... get it back delicately” (P2). • “It was a late referral...[the SDMs] just wanted it over. So, for us to even approach, it’s all the timing. Just asking for 24 more hours or 48 hours, it’s just too much for them” (P10). • “I don’t think [HCPs] realize the impact [late referrals] could have on the timing of the call...so sometimes they just wait. And we can only speak to families after they’ve made the decision to withdraw...But sometimes [HCPs] just call us at that moment and then the families are like ‘well we want to withdraw now’...And then it’s like you’re in that situation when [the family is] ready and they want to withdraw and you’re asking <i>them</i> for time...I think that’s the tough part verses [HCPs] calling us early. Then we can...find out what donation potential we have and take our time and then we’re ready to say ‘this is a good potential or this is not’” (P6). • “I think sometimes the nurses are just too busy that it doesn’t even enter their mind to call [TGLN] yet. When you have a really sick patient and it’s fresh admission, then you’re really, really busy so you’re running off your feet pretty much all day. And then you’re leaving for your shift and it might just slip your mind to say, ‘hey actually, we should’ve called [TGLN] as well’” (P9). • “The journey is different for everyone and that’s why it’s hard too. We can’t really standardize the practice necessarily other than getting [HCPs] to call us early and getting these answers” (P6).
HCP’s perceived ambivalence towards organ donation		<ul style="list-style-type: none"> • “These nurses too have gone through the process with families and then for whatever reason [the transplant] didn’t work out. And it’s viewed as a negative thing. So, when you’ve had a few of those happen as a bedside nurse, I can imagine that also impacts how positive you’re going to be in your next interaction with a case” (P2). • “It’s really tough...a lot of the nurses who care for the transplant patients that don’t do well—they’re really jaded...A lot of them, they only see the bad stuff and when it’s bad, it’s really ugly” (P6). • “Being around that population...only seeing the bad...[HCPs are] not seeing the ones who are home back at work and there can be such wonderful things” (P7). • “The other day I had to do a phone approach and the healthcare team was saying ‘I don’t think you should speak to the [SDM] because she hasn’t, she’s grieving, she’s not in the right mind space’” (P8). • “I’ve had one of the doctors say, ‘well what’s the consequence if we don’t call?’ And I said, ‘well to you personally, probably not much’” (P9). • “Even if [HCPs] feel like they’re doing a good thing by being this protector and dividing you away from [SDMs], it’s actually hurting the family more to see people on two different sides and not coming together to support them in what their loved one wanted” (P2). • “You might have some [HCPs] that are really proactive and are like, ‘yup that’s great, I’ll keep you in the loop.’ And then you’ll hit the one day where you’re going to have the withdrawal conversation and then you’ve got the nurse that doesn’t support you as much as the other ones do... You’ve got extremes” (P4). • “When that consent gets signed, [HCPs] work...They get busy” (unidentified). • “Yeah, we are work. We are the face of work [for HCPs]” (P3).

Table 2 continued

Theme	Sub-theme	Supporting quotes
Strategies towards a culture of organ donation	Value-positive language	<ul style="list-style-type: none"> • “A lot of times, we’ll use the wording, ‘we can honour their wish, we know this is their wish... They’re registered, and they’ve obviously put a lot of thought into this and it’s something they really wanted’” (P8). • “It helps families with making their decision knowing that this is what their loved one wanted. I usually use language like, ‘it’s their registered consent decision’ trying a little bit more—stronger language” (P5). • “You really feel like you’re trying to build [SDMs] up... to a place of strength. And encouraging them that they can do it. How can we help you do it, and... bringing the healthcare team into that too” (P2). • “If [the patient is] registered, [we say to SDMs] ‘we know they wanted to, because they had that thought process.’ So, we change our language a little bit differently” (P8). • “When I have a registered decision, I say like, ‘listen, this patient registered to help other people, I’m here to help them too. I’m not here to cause this family any pain’” (P1). • “Sometimes [HCPs will] say, ‘well it’s just so exhausting, and they’re just so upset’. And I’m like ‘what about if we think about this, how we’ve seen families transition. It’s so helpful for them and just the hope that they have of helping others. Can you... build them up too?’ Turning it back around” (P2). • “You know this could be so good. Like, if something good could happen, this could be so good for the family” (P7). • “Speaking with the team ahead of time. Having [HCPs] on board with you and the way that the information is being shared with [SDMs] are really important” (P2). • “I think one thing that we all will probably agree on, what we all say is that ‘we are here to support you in honouring this person’s wishes’” (P6).
	Increased public education	<ul style="list-style-type: none"> • “It’s trying to explain to [SDMs]... [the patient is] not suffering... Because I think it’s the perceived suffering... nobody wants their family to suffer, right?” (P2). • “Like in Grey’s Anatomy... the episode’s done in an hour... It makes it hard to kind of argue because... that’s probably the public’s perception of it” (P3). • “A lot of families don’t realize that you have to stay on a ventilator to be an organ donor” (P5). • “There’s no information about what organ donation is, what tissue donation is” (P6). • “I want the public to be educated. Like if we’re talking pie in the sky things, I want... I want the public educated. I want them to know” (P1). • “I think education... We need so much more education in this province... To the public a hundred percent... and the healthcare team” (P4). • “I honestly think everybody, not just a will, but how do you want to see things? Do you want to die at home? Do you want to be in the hospital? Too many people are scared to talk... Family doctors need to talk to their patients about death, about DNRs (do not resuscitate)” (P1). • “Talk to your family... [It’s] so important” (P3). • “What’s the reason that you registered yourself? I mean we assume that it’s always to help others because you know, why else? But somebody would want to give organs to someone else in need... it needs to be explicit so that we can share that with families, or families know that was the specific intention” (P6). • “I see it in my families, it’s not dinner time conversations for most of you. For me it is. So, lots of them are shocked. Some of them are like... ‘okay yeah, that’s what they would’ve wanted, that’s the person they are’... Have a conversation at your family doctor. Have... a talk in schools when they’re all in grade 12... They need to know you got to be on a ventilator. They need to know these things” (P1).
	Open conversations about end-of-life wishes	

HCP = healthcare providers; OTDC = Organ and Tissue Donation Coordinators; P = participant; SDM = substitute decision-maker

The significance of the OTDC role

The significance of the OTDC role was prominent as participants reflected upon their role as advocates for the deceased donor as well as educators to the SDM. Many participants emphasized their responsibility to advocate for the donor's wishes when first introducing organ donation to SDMs: "We're honouring [the patient's] decision. Yes, it's hard for the families, and we're here to support them through that process, and that's our role. But you're advocating first and foremost for the patient always." Another participant described their role as giving a voice to the donor after death: "Our focus is the patient, definitely...we're the donor's voice." This advocacy remained in instances of family veto, and participants revealed feelings of personal responsibility when they were unable to honour the deceased donor's wishes: "I think...disappointed in myself if I couldn't say the right thing or get [the SDM] to see why this is so important."

Also, participants frequently became educators to SDMs. Education is critical to dispel myths and quell distress around organ donation. Many OTDCs spoke about funeral arrangements as an example of misinformation: "Sometimes they ask about open-casket...we address it...[organ donation] doesn't affect open-casket viewing. I think donation is very accommodating, and that's why we ask families what their concerns are." Overall, participants expressed a profound sense of fulfillment in engaging with SDMs, highlighting job satisfaction: "It's really amazing work that we're able to do and be with families at a very bad time but turning it into...a good feeling in the end." One participant commented: "[Families] get inside your head, and they stay with you, and it's an honour to be with them."

Emotional distress and the "understandable" family veto

While participants described family veto as "not that common" and "less than it used to be," experiencing family veto produced lingering feelings of emotional distress. One participant reflected: "[Family veto] brings a sense of distress because you feel like you want to protect the patient." Another participant said: "I leave kind of feeling gross and sick and devastated that there's lives lost." Emotional distress often increased when SDMs were unwavering in their decision to veto: "How do I feel about the veto? It's complicated...I feel mad, like I do feel mad when [SDMs] won't...give any room for movement [to consider authorization]."

Participants also acknowledged the trauma experienced by SDMs after a sudden death and this introduced the idea of an "understandable" family veto. One participant

described: "Every time I do get a family veto, it's because of a traumatic experience where it's—I understand why they are vetoing the decision," suggesting that there are situational factors influencing family authorization. Another participant recognized the additional suffering that SDMs might experience when asked to consider organ donation: "The family had been through a really traumatic...the patient had really been suffering...So it was a really hard no because they were like, 'we know he wanted to do this, but we can't do anymore—we're spent.'" In these instances, participants understood the veto because they felt they had done everything possible for the patient given the grief experienced by SDMs: "I gave it everything I had...I could say that's a good no."

Barriers contributing to family veto

Participants revealed several barriers that challenged the OTDC role, contributing to family veto. Timing was a significant barrier that impacted authorization as participants navigated when to approach SDMs to discuss organ donation: "I've had families say, 'well, if you asked me two days ago, then I would move forward. Why couldn't you have had this conversation two days ago?' And I have to explain 'I can only have that conversation once you've made that withdrawal decision.'" Delayed referrals from HCPs of potential donors were especially frustrating as SDMs were often less receptive to the donation conversation: "It was a late referral...[the family] just wanted it over. So, for us to even approach, it's all the timing. Just asking for 24 more hours or 48 hours, it's just too much for them." Participants recognized how the extensive donation process often overwhelmed SDMs, impacting their authorization decision-making: "I think it's the timing. [SDMs] are in support of it, but as soon as you start exploring how long this is going to take, on top of what they've already been through...they just want to get from where they are to the endpoint very, very quickly." Ultimately, organ donation was described as a missed opportunity due to timing: "It's a very frustrating situation to be caught in...This golden thing is slipping away from you, and you don't quite know how to...get it back delicately."

Healthcare providers' perceived ambivalence towards organ donation was another barrier for OTDCs. Participants acknowledged that HCPs sometimes seemed reluctant to support organ donation because of rare but influential past experiences caring for transplant recipients, and this impacted their interactions with SDMs. Participants noted: "Being around that population...only seeing the bad...[HCPs are] not seeing the ones who are home back at work and there can be such wonderful

things”; “These nurses have gone through the process with families and then for whatever reason [the transplant] didn’t work out...I can imagine that also impacts how positive you’re going to be in your next interaction with a case.” Another participant reflected: “It’s really tough...a lot of the nurses who care for the transplant patients that don’t do well—they’re really jaded.”

Experienced OTDCs described confronting these perceived sentiments from HCPs: “I say like, ‘listen, this patient registered to help other people, I’m here to help them too. I’m not here to cause this family any pain.’” Less experienced OTDCs expressed frustration around the conflicting priorities and lack of shared professional goals within the patient-care team: “Even if [HCPs] feel like they’re doing a good thing by being this protector and dividing you away from [SDMs], it’s actually hurting the family more to see people on two different sides.” Participants suggested that some degree of this perceived ambivalence stemmed from the increased work required when SDMs authorize donation: “When that consent gets signed, [HCPs] work...They get busy.” Many participants agreed that the OTDC role represented increased work for HCPs preparing the deceased donor and potential recipient for transplantation: “Yeah, we are work. We are the face of work [for HCPs].”

Strategies towards a culture of organ donation

Participants frequently discussed strategies to mitigate family veto in organ donation. Value-positive language that emphasizes the deceased donor’s desire to donate³⁰ was cited as helpful in communicating with SDMs: “A lot of times, we’ll use the wording, ‘we can honour their wish, we know this is their wish...and it’s something they really wanted.’” Within patient-care teams, many participants described reframing their role to establish stronger relationships with HCPs: “Sometimes [HCPs will] say, ‘well it’s just so exhausting, and they’re just so upset’. And I’m like ‘what about if we think about this, how we’ve seen families transition. It’s so helpful for them and just the hope that they have of helping others.’” This reframing allowed OTDCs and HCPs to approach SDMs as a united patient-care team: “Speaking with the team ahead of time. Having those people on board with you...[is] really important.”

Many participants also called for increased public education and open conversations about end-of-life wishes with families and friends. Participants revealed how SDMs were often surprised about the organ donation process and this lack of knowledge made authorization more difficult: “It’s trying to explain to [SDMs]...they’re not suffering...Because I think it’s the perceived suffering...nobody wants their family to suffer, right?”

Several participants discussed how popular medical shows can impact expectations around organ donation: “Like in *Grey’s Anatomy*...the episode’s done in an hour...It makes it hard to kind of argue because...that’s probably the public’s perception of it.” Many participants agreed that open conversations about end-of-life wishes is critical to creating a culture of organ donation: “Too many people are scared to talk...Family doctors need to talk to their patients about death, about DNRs (do not resuscitate).” Open conversations could help SDMs anticipate the donation conversation and alleviate the pressure they feel when asked about authorization: “I see it in my families, it’s not dinner time conversations...So, lots of them are shocked. Some of them are like...‘okay yeah, that’s what they would’ve wanted, that’s the person they are.’”

Discussion

To our knowledge, this is the first qualitative study to explore family veto from the perspective of OTDCs. Our findings highlight the importance of patient advocacy in the OTDC role, while revealing the emotional distress of experiencing family veto. Participants identified timing and HCP’s perceived ambivalence towards organ donation as two key barriers to fulfilling their role. Participants offered value-positive language, role reframing and increased education as strategies to reduce family veto and increase organ donation.

Legal and ethical conflict

Emerging evidence questions the legal and ethical legitimacy of family veto by presenting the conflict between respect for the previously expressed wishes of the deceased donor and the current wishes of the SDM. Under Canadian law, SDMs have no legal authority to withhold organ donation authorization if the deceased donor had previously consented.^{9,10} Nevertheless, many provincial/territorial donation organizations still indicate, implicitly or explicitly, that family wishes should be followed.¹⁰ Family veto, counter to the legal requirements for organ donation, places OTDCs in a difficult position.

In this study, OTDCs emphasized their role as advocates for the deceased donor. Experiencing a family veto evoked emotional distress and many OTDCs reflected upon feelings of personal responsibility for failing to support the deceased donor. This distress can be likened to the concept of moral distress in healthcare, defined as the “painful feeling and/or psychological disequilibrium that occurs when [HCPs] are conscious of the morally appropriate action...but cannot carry out that action because of institutional obstacles” (p382).³¹ With family

veto, OTDCs identified several barriers preventing them from fulfilling their “morally appropriate action” of upholding the donor’s legal wish.³¹ Nevertheless, OTDCs also recognized “understandable” family vetoes, highlighting the nuanced nature of situational versus dispositional factors in organ donation.^{32,33} More research is needed to explore this novel finding.

Timing and support for organ donation

Consistent with previous findings, timing in organ donation was a significant barrier that increased the potential of family veto. Organ donation is a time-sensitive process demanding that patient-care teams work collectively towards a common goal.³⁴ This includes timely identification and referral of potential donors and timely initiation of the donation conversation.^{34–36} In this study, OTDCs discussed how limited time and the prolonged donation process impacted SDMs’ decision around authorization. Siminoff *et al.*³⁷ reported similar findings, identifying both timing and duration of the donation conversation as significant factors influencing the number of donation-related topics discussed with OTDCs and family authorization. Further, Sque *et al.*³⁸ identified the concept of “waiting” during the donation process to be especially distressful for bereaving families.

Another barrier to family authorization was a perceived ambivalence from some HCPs towards organ donation, suggesting conflicting personal and professional priorities.^{12,15,39} In a study by Oczkowski *et al.*,³⁹ intensive care unit (ICU) staff acknowledged differing viewpoints and personal willingness to participate in donor-related activities. Weiss *et al.*¹² found the most common reasons for physician non-referrals in organ donation were due to assuming the donation process would be dysfunctional, not wanting to impact the family’s trust in the donation system, believing the family was under too much distress, and a misunderstanding of the law regarding authorization. In our study, OTDCs reported concerted efforts to motivate and engage HCPs by reframing their role and organ donation to ways that could support SDMs through their grieving. Research indicates collaborative efforts between hospitals and donation organizations and positive relationships between HCPs and OTDCs to be critical drivers for creating a culture of donation in healthcare settings.^{15,39–42} These findings suggest a real need for inter-organizational and inter-professional goal sharing and priority setting.

Education and a culture of donating

While Kentish-Barnes *et al.*⁴³ found that SDMs expressed a need for additional information about organ donation to aid

their decision-making, OTDCs in this study recommended that this education should occur at the societal level. Many SDMs have incomplete knowledge of the organ donation process.⁴⁴ In a study with SDMs, Sarti *et al.*⁴⁵ revealed that informational gaps and “lingering unanswered questions” remained long after the donation experience. Recommendations to encourage discussions around organ donation have been forwarded by other authors. Shaw *et al.*¹⁴ argued that explaining one’s registered wish to family and friends would indicate the strength of the wish. Traino *et al.*⁴⁶ and Kentish-Barnes *et al.*⁴³ found the strongest and most consistent predictor of family authorization was knowledge of the deceased donor’s wish to donate. In our study, OTDCs highlighted the importance of integrating open conversations about end-of-life wishes into everyday conversations to create a culture of donating. This knowledge would aid SDMs to anticipate the donation conversation and could support their grieving and healing process, enabling a more meaningful parting from the deceased.^{15,47}

Limitations

Limitations of this study include the small sample size and a focus on Ontario OTDCs only, impacting the transferability of findings to ICUs elsewhere in Canada. While efforts to recruit all eligible TGLN OTDCs were made, about 20% joined this study. Non-participating OTDCs may have different experiences than those who participated. Nonetheless, the sample was heterogeneous across multiple demographic characteristics (e.g., age, number of years as an OTDC, etc.). Our qualitative methodology allowed participants to provide nuanced reflections on their experiences with family veto, addressing calls in the literature for more qualitative research in this area.^{43,48,49}

Conclusion

This study explored the experiences of OTDCs who work with SDMs who vetoed a deceased donor’s legal consent for organ donation. Our findings highlight important considerations about organ donation authorization processes in Ontario, specifically around waiting times for families of potential donors and the need for enhanced public education on organ donation. The identified barriers and facilitators could support practice changes towards reducing family veto and inform future research to understand and address this phenomenon nationally. Further research is needed to investigate alternative stakeholder perspectives surrounding family veto and the organ donation process, including SDMs, critical care staff,

and OTDCs across provincial and territorial legislation. Collaborations with these stakeholders are warranted to align healthcare practices, donation policies, and educational initiatives to increase organ donation.

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