



Death determination by neurologic criteria—what do families understand?

Détermination du décès selon des critères neurologiques – que comprennent les familles?

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Abstract

Purpose Currently, there is little empirical data on family understanding about brain death and death determination. The purpose of this study was to describe family members' (FMs') understanding of brain death and the process of determining death in the context of organ donation in Canadian intensive care units (ICUs).

Methods We conducted a qualitative study using semistructured, in-depth interviews with FMs who were

asked to make an organ donation decision on behalf of adult or pediatric patients with death determination by neurologic criteria (DNC) in Canadian ICUs.

Results From interviews with 179 FMs, six main themes emerged: 1) state of mind, 2) communication, 3) DNC may be counterintuitive, 4) preparation for the DNC clinical assessment, 5) DNC clinical assessment, and 6) time of death. Recommendations on how clinicians can help FMs to understand and accept DNC through communication at key moments were described including preparing FMs for death determination, allowing FMs to be present, and explaining the legal time of death, combined with

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multimodal strategies. For many FMs, understanding of DNC unfolded over time, facilitated with repeated encounters and explanation, rather than during a single meeting.

Conclusion Family members' understanding of brain death and death determination represented a journey that they reported in sequential meeting with health care providers, most notably physicians. Modifiable factors to improve communication and bereavement outcomes during DNC include attention to the state of mind of the family, pacing and repeating discussions according to families' expressed understanding, and preparing and inviting families to be present for the clinical determination including apnea testing. We have provided family-generated recommendations that are pragmatic and can be easily implemented.

Résumé

Objectif À l'heure actuelle, il y a peu de données empiriques sur la compréhension des familles de la mort cérébrale et de la détermination du décès. Le but de cette étude était de décrire la compréhension des membres de la famille de la mort cérébrale et du processus de détermination du décès dans le contexte du don d'organes dans les unités de soins intensifs (USI) canadiennes.

Méthode Nous avons mené une étude qualitative à l'aide d'entrevues semi-structurées et approfondies avec des membres de la famille à qui on a demandé de prendre une décision de don d'organes au nom de patients adultes ou pédiatriques dont le décès avait été déterminé selon des

critères neurologiques (DCN) dans les unités de soins intensifs canadiennes.

Résultats Sur la base d'entrevues avec 179 membres de la famille, six thèmes principaux ont émergé : 1) l'état d'esprit, 2) la communication, 3) le DCN peut être contre-intuitif, 4) la préparation à l'évaluation clinique pour un DCN, 5) l'évaluation clinique pour un DCN et 6) le moment du décès. Des recommandations sur la façon dont les cliniciens peuvent aider les membres de la famille à comprendre et à accepter un DCN par la communication à des moments clés ont été décrites, y compris la préparation des membres de la famille à la détermination du décès, l'autorisation de la présence des membres de la famille et l'explication de l'heure légale du décès, combinées à des stratégies multimodales. Pour de nombreux membres de la famille, la compréhension du DCN s'est développée au fil du temps et a été facilitée par des rencontres et des explications répétées plutôt qu'au cours d'une seule rencontre.

Conclusion La compréhension qu'ont les membres de la famille de la mort cérébrale et de la détermination du décès représente un parcours qu'ils ont décrit lors de rencontres successives avec des acteurs de soins de santé, et particulièrement avec des médecins. Les facteurs modifiables pour améliorer la communication et les issues du deuil pendant un DCN comprennent l'attention portée à l'état d'esprit de la famille, le rythme et la répétition des discussions en fonction de la compréhension exprimée par les familles, ainsi que la préparation et l'invitation des familles à être présentes pour la détermination clinique, y compris pendant le test d'apnée. Nous avons fourni des recommandations

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familiales qui sont pragmatiques et peuvent être facilement mises en œuvre.

Keywords bereaved family members · brain death · brain death determination · death determination by neurologic criteria · qualitative

Death determination by neurologic criteria (DNC), or “brain death” as it is commonly known by the general public, is based on the cessation of brain function. Physicians make this determination following a series of medical tests to ensure specific criteria are met.¹ While members of the health care team are familiar with DNC, prior studies have confirmed that the general public often struggle to grasp the medical concept of death and death determination elements.^{2–13} Exacerbating this confusion is the media’s frequent misuse of language describing various aspects of death and dying.^{6,8} Notably, the media typically confuse the distinctions between brain death, coma, and persistent vegetative state.^{5,6,12–15} Little empirical evidence exists that examines the family perspectives on death and DNC, particularly in the context of confronting the imminent loss of a loved one.

Within the intensive care unit (ICU), family is defined by the patient, or in some cases, by the patient’s surrogate(s). As such, family members (FMs) may be related or unrelated to the patient but are generally individuals who provide emotional support and with whom the patient has a significant relationship.¹⁶ Understandably, when FMs must confront the reality of a loved one dying in an ICU with a DNC, the experience may be fraught with confusion. For some FMs, the determination of death is at odds with what they observe before them.^{4,17} After DNC, despite the permanent cessation of brain function, the body of their brain-dead relative remains warm, and their technologically supported body retains many essential biological functions, including a heartbeat, systemic circulation, digestion, and excretion.³ The uncertainty and tremendous stress experienced by FMs at this time can negatively impact their decision-making processes and limit their capacity for rational thinking.^{18–21} It is of utmost importance to understand FMs’ perspectives on DNC to support them not only during their time in the ICU but also in the weeks following discharge as they grieve the loss of their loved one and attempt to make sense of what has happened. When FMs have unanswered questions or difficulty accepting a death, it is linked with complicated bereavement outcomes.^{18,19,22,23}

At present, little empirical data exist on how to address when family misunderstandings about brain death and death determination do not align with the medical

diagnosis.^{8,19} The objective of this study was to describe FMs’ understanding of brain death and the process of determining death in the context of organ donation within Canadian ICUs. Doing so can inform clinical practice as well as the development of bedside tools to improve FMs’ comprehension of DNC and aid them while making difficult decisions related to organ and tissue donation. Such tools are in line with the provision of patient and family-centred care, an approach to health care delivery that is respectful of and responsive to individual patients’ and families’ needs and values.¹⁶

Methods

Design and setting

This study was part of a larger Canadian-based qualitative study involving in-depth interviews with FMs asked to consider organ donation following DNC. The present study focused specifically on FMs ($n = 179$) of DNC patients. An earlier publication outlined the larger study protocol.²⁴ All study recruitment, data collection, and data analysis occurred after approval from multiple Canadian institutions’ Research Ethics Boards (see Electronic Supplementary Material [ESM] eAppendix 1) and are reported according to the consolidated criteria for reporting qualitative research guidelines (see ESM eAppendix 2).

Recruitment

All Canadian provinces with an organ donation organization (ODO) participated ($n = 9$). Family members were eligible for the study two months to three years after the death (DNC and death determination by circulatory criteria [DCC]) of their loved one, irrespective of whether or not they agreed to proceed with organ donation. Each ODO compiled a database of eligible FMs, including their names, telephone numbers, address, sex, relationships to the patient and donation decision, and the manner of death determination (neurologic or circulatory criteria) ($n = 1,500$). A total of 236 FM names were excluded because of language barriers and/or a lack of family contact information. Organ donation organization staff contacted FMs by mail to inform them of the study. Approximately two weeks later, ODO staff telephoned these individuals to explain the purpose of the study, and to request their permission to be contacted by research staff. A total of 338 FMs agreed to be contacted by the research team. Next, research staff contacted the FMs to explain the study, and to schedule a telephone interview with consenting individuals. Of the 338 FMs who agreed to be contacted, 265 agreed to proceed with an interview. Two

ODOs contacted FMs in a different manner. In Ontario, letters were not sent; instead, ODO staff contacted FMs by telephone within six months to one year after the death of a loved one. In Quebec, letters were sent to eligible FMs informing them of the study but also requesting a mail reply if they were interested in participating; only interested FMs (based on their mailed reply) were then contacted by the ODO staff.

Data collection

Informed by an earlier study of FM experiences in Ontario, we developed a semistructured interview guide to explore family interactions with health care teams within the ICU (see ESM eAppendix 3).²¹ An interdisciplinary team of investigators with experience in critical care, palliative care, organ donation, medical education, and sociological and qualitative research methods provided feedback to refine the interview guide. Next, we solicited feedback on the guide from a committee of FMs, members of the Canadian Critical Care Trials Group and organ donation leaders representing every ODO in Canada, and revised it based on their feedback (see ESM eAppendix 3 for guide). Members of the research team with prior interview training and experience conducted the telephone interviews using the semistructured interview guide. While the guide provided a predetermined line of inquiry, it was flexible enough to evolve as data collection unfolded, permitting the exploration of emerging themes. If requested by participants, multiple FMs were interviewed together, for example a mother and father. All interviews were audio-recorded and occurred between July 2018 and June 2020. The interviews lasted anywhere from 45 to 90 min.

Data analysis

All interviews were audio-recorded, transcribed verbatim, and uploaded into ATLAS.ti (Scientific Software Development GmbH, Berlin, Germany), a qualitative data analysis software, to facilitate data management and analysis.²⁵ The method of analysis was a modified grounded theory approach. The analysis was performed by five members of the research team (A. S., S. S., A. L., B. V. W., and S. V.) who participated in regular coding meetings to develop the codebook (see ESM eAppendix 4). The codebook included both inductive and deductive codes. All five analysis team members coded the same transcript separately, then met to discuss their codes, refine code definitions, and resolve any coding disagreements.²⁶ This process was repeated until the level of coder agreement, measured using Krippendorff alpha, reached a value of 0.858%;²⁷ thereafter, independent coding began. Later, codes were organized into themes relevant to the study objectives. Analysis procedures also included using the

Atlas.ti query tool to interrogate the data set using Boolean operators for the codes of interest, including brain death, family conflict/brain death, and death determination. The resulting reports were then coded to define subcodes, which permitted elaboration on the themes. The recommendations from FMs were developed by assessing the qualitative themes for quotes, whereby FMs explained how certain events helped or hindered their understanding of DNC. These quotes were aggregated and written into short, action-oriented prose.²⁸

Results

Overall, 265 telephone interviews were conducted; in six interviews, two FMs participated together. Of the 271 FMs interviewed, 179 were interviewed about a patient who underwent DNC. The other 92 FMs were interviewed about cases of DCC and were not included in this analysis.

Table 1 describes the 179 DNC study participants in terms of their province, sex, and relationship to the 174 DNC patients. Most patients in the study were male ($N = 103$) aged 19–30 yr followed closely by those in the 51–60 yr and 61–70 yr age ranges. Table 2 illustrates the six qualitative themes with a data display allowing for additional quotes to depict each theme.

State of mind

Family members described their state of mind impacting all their recollections of brain death and death determination. Many explained that this state rendered them unable to “hear” and/or retain the information that health care professionals (HCPs) provided. Family members explained being unable to comprehend information about their loved one and needed to have things repeated many times to absorb the details:

It was really hard to understand because two doctors came in and told whoever was in the room with us, “Unfortunately we weren’t able to save him and it didn’t look like there was any brain activity”... something along those lines. I was not able to comprehend what they were saying. All I remembered at that time was the word “unfortunately.” “Unfortunately,” just gave me what I needed to know. I couldn’t even hear them properly because I went into this state where I was thinking I wasn’t hearing things right.

Communication

Given FMs’ state of mind, and the complex nature of brain death, families recalled needing HCPs to take time and present information in a clear and concise manner. This

Table 1 Characteristics of 179 participating family members of DNC patients

Province	BC	AB	SK	MB	ON	QC	NB	NS	NL	Total
<i>n</i>	50	13	19	21	21	26	11	14	4	179
CONSENT (ORGAN DONATION)*										
Sex										
Male	15	3	7	1	4	9	3	6	-	48
Female	35	10	12	14	17	17	7	6	4	120
Relationship to patient										
Parent [†]	24	10	12	6	8	8	5	7	4	82
Spouse/partner	14	2	3	1	8	8	2	2	-	40
Child	2	-	1	5	3	8	2	1	-	22
Sibling	8	1	-	3	2	2	-	-	-	15
Other [‡]	1	-	3	-	-	-	2	3	-	9
DECLINE (ORGAN DONATION)*										
Sex										
Male	-	-	-	-	-	-	-	1	-	1
Female	-	-	-	6	-	-	1	1	-	8
Relationship to patient										
Parent [†]	-	-	-	1	-	-	1	2	-	4
Spouse/partner	-	-	-	2	-	-	-	-	-	2
Child	-	-	-	-	-	-	-	-	-	-
Sibling	-	-	-	-	-	-	-	-	-	-
Other [‡]	-	-	-	3	-	-	-	-	-	3

*Not all provincial ODOs retain data on FMs who decline organ donation

[†]In some interviews, both parents participated

[‡]Individuals in the other category included other family members (e.g., grandmother, nephew, niece) as well as friends and ex-wives.

DNC = death determination by neurologic criteria

entailed detailed descriptions and/or having information repeated:

The doctors were trying to explain it to me and I remember them saying that they had to go up and do testing that takes about one hour. A piece of me thought, maybe there's a chance that there's brain activity? But they were trying to explain to me that there was no brain activity but they had to do these tests to have 100% proof. They had to get very descriptive with me, which is unfortunate because it's a piece that's been the hardest for me to process about his death. They described the size of the bullet and how it went into his head and it didn't exit ... some people die immediately from a gunshot to the head but his bullet was so small that it bounced around it didn't have enough power to escape the skull. The bullet bounced inside and destroyed his brain. They had to get that detailed with me because I couldn't comprehend what they were saying.

Family members described not understanding the distinction between coma and brain death:

The neurologist briefly explained to me what happened because [Name 1] was in a coma at that point. I knew he was in a coma and he had been unconscious but I really didn't know what it meant. At one point I thought, "Oh he could wake up in five minutes or in an hour." I was fully expecting him to wake up and be fine. There was a point where I sort of went, "Okay I know he was without oxygen" ... I thought he was going to wake up or he might have some deficits because I understood he didn't have enough oxygen for a certain period of time, but I didn't appreciate the gravity of the situation at that point because I didn't have that information.

Many FMs recounted the importance of multimodal communication such as written notes and/or diagrams as well as having been shown radiographic images, when appropriate:

Table 2 Qualitative themes with illustrative quotations

Theme	Quotations
State of mind	<p>We had many conferences with the main doctor, I can't remember his name, the nurses always sit in as well as the social worker. We had probably four conferences in their meeting room just about where his brain function was, where he was going. And I think it was Thursday morning or Thursday afternoon, I can't remember, I went into his room and it was obvious that he was starting to deteriorate. So, the choice was made then to do another MRI and we had another conference and the doctor said, "You know, his condition has not changed." But we were still, you know, it's just the state of mind that you're in as well, but we were still very unclear whether he was brain dead, we didn't know that.</p> <p>I was in shock. It looked ... it was disbelief because all he had was a black eye. He had no other physical marks. You couldn't tell that he fell off a roof. There was just a black eye. Honestly, it pretty much took me until his funeral when it started to sinking in. I was just still in disbelief. I'm still in disbelief that I'll never be able to see him again. There were four people that came in to the room and I can't remember their names or anything like that, like I said, I was in such shock. Nothing was sinking in.</p> <p>It was really hard to understand because two doctors came in and told whoever was in the room with us to say, unfortunately they weren't able to save him and it didn't look like there was any brain activity ... something along those lines. I actually was not able to comprehend what they were saying. All I remembered at the time was the word "unfortunately." "Unfortunately," just gave me what I needed to know. I couldn't even hear them properly because I went into this state where I was thinking I wasn't hearing things right.</p>
HCP communication -Clear/consistent language -Multimodal	<p>... they took us to the room and explained to us what had happened, they even showed us the scan. And they told us it was an irreversible and they have to wait until there was absolutely no brain activity before they declare her dead and that took another 48 hours.</p> <p>And nothing was written down. Nothing was written down, so I have no written record of what was done. I was told, verbally but I don't remember. I remember them saying we had done the tests but I'm not sure what that included.</p> <p>Yes, I was at the airport and the doctor said in the same, short conversation, "Did your husband want to be an organ donor and I said, "Yes, it's on his driver's licence." We had had that talk many times; he did want to be an organ donor. So, he said "Well we will need to send him to a different hospital and you can meet him there." So, I went to [city name] and he had just arrived by plane, but then the doctor there told me, well it's not confirmed that he's brain dead, we cannot say that he's brain dead, he hasn't died as far as we're concerned.</p> <p>Your belief he's just in a coma. So, they did their tests, and this is the last part of the story. They did their tests, so they confirmed he was brain dead and then we proceeded from there.</p> <p>I hadn't ever heard it called a brain death, suffering a brain death. I'd only ever heard someone is brain dead. I'd never heard the term "suffering a brain death." But I think I might have asked at the time what it meant. Like does that mean he's brain dead or ... and then I don't remember him explaining it. I think he asked me if I had any more questions and then he asked me right away if I'd be willing to donate, like if he'd be an organ donor.</p> <p>It was a lot to take in within a day or two of finding that out. I often think what if he was left on life support for a month or two to see how he would have done and would have happened. There's always those questions. It does happen all the time where people are in comas and on life support and over time they're eventually able to recover. So, I always think about stuff like that.</p> <p>The neurologist briefly explained to me what happened because [Name 1] was in a coma at that point. But really I had no idea. I knew he was in a coma and he had been unconscious or they had to revive him. I really didn't know what all that meant. Today if I went through that again I would have went, "Oh my this looks much worse." Like at one point I thought, "Oh he could wake up in five minutes or in an hour." I was fully expecting him to wake up and be fine. There was a point where I sort of went, "Okay I know he was without oxygen" (pause) you know? Maybe there would be a little bit of a problem but I really didn't understand what was happening at that point. First of all I thought he was going to wake up or he might have some deficits because you understood he didn't have enough oxygen for a certain period of time, but in your mind you didn't appreciate the gravity of the situation at that point because you didn't have that information.</p> <p>The doctors were trying to explain it to me and I remember them saying that they had to go up and do testing that takes about one hour altogether. So, a piece of me was trying to say, "Oh, so maybe there's a chance? Maybe there's a chance that there's brain activity?" But they were trying to explain to me that there was no brain activity but they had to do these tests to have 100% proof, right? Actually, they had to get very descriptive with me, which is unfortunate because it's a piece that's been the hardest for me to process about his death. They described the size of the bullet and how it went into his head and it was small enough, it didn't exit ... like some people they die immediately from a gunshot to the head but his bullet was so small that it bounced around in his head and it couldn't escape, like it didn't have enough power to escape the skull. So, literally it bounced inside and destroyed his brain. They literally had to get that detailed with me because I couldn't comprehend what they were saying.</p>

Table 2 continued

Theme	Quotations
Brain death as counterintuitive	<p>That was the hard part, when you would go into to see him and he looked really good, because, you know, of course he was on life support so the machines were doing the work, but he looked really ... it was eerie that way, and you feel a little bit guilty leaving them there knowing they're still there. His hand is warm, his chest is rising, his heart is beating. And, they were keeping his eyes lubricated. So, every once in a while, you would see, saline come out of his eye. It would kind of like, oh my God, right, but it's like your heart and your mind plays tricks on you a little bit. It's really not an easy ... like I mean it's still not an easy thing to process, because your heart is breaking, right?</p> <p>I tried to reconcile between what I was seeing in front of me that [Name 3]'s whole body had come back and that he was strong and how could his body function this way if his brain is dead, like, I just ... it's all connected. So, how is that even possible? And then, you know, you wanted to ask a million questions, but you felt like you were always getting the same answer and I didn't want to hear that answer over and over again. So, it's kind of stopped me from asking a ton of questions and I was sitting on the floor crying ... (Crying)</p> <p>I think they had to do some due diligence and they had actually found that he had signed a card so then they get everything ready. I don't know, whatever goes on behind the scenes. And then they had to wait to see what the status of his body was because on Saturday I could see that there was a change when I came in. And then, they said he clinically died at 5:30 ... which was the weirdest experience, watching them pronounce him clinically dead when the blood's running through the tubes and his chest is rising and falling, you know?</p>
Preparing (or lack of) for the DNC clinical assessment	<p>I don't know if it's the neurosurgeon or the brain guy or the doctor that was just on that evening, but we met with quite a few people, and basically they said there was one more test where they were going to take her off the breathing apparatus and if she drew a breath, then she wasn't completely brain dead but if that test failed then we kind of knew that there was no going forward from where we were so then we could proceed on to the next steps, which was getting the organ donation stuff organized. I guess if she had failed that test, I would have to decide to pull the plug, I guess?</p> <p>The only thing that shocked me and was really upsetting about those few days, I mean of course everything, but the thing that kind of came from a side that I didn't see coming was when they did the test for brain death, they didn't tell me that he would be radioactive for 24 hours and that I wouldn't be able to touch him. And then, especially because I was actually present at the time, I had to be even further away. So, that was like really, really upsetting and I didn't know that until he came back from the test.</p> <p>The doctor explained everything. I really didn't have any questions because he explained it all so well and if I did have questions, he answered it, and I trusted his answers. I know I asked, "how you know exactly he's brain dead," you know those things? And so, we had a real in-depth conversation and he explained how the brain functions and in 24 hours you can tell if its healing or what have you, and these are the tests we do. He made sure that we knew there was no chance of recovery. So, that we laid the trust on the doctor. And we felt comfortable with that.</p> <p>We were in [city name] and they gave the family a room and neurosurgeon came in and spoke to us. I remember her telling us that our daughter had meningitis and her brain had swelled. I said, "Well, then, drain it." And they didn't do it because she said, "Well, it just doesn't work that way." And she told us that there was a trickle of blood left in her neck and when that went away, she would be declared brain dead. Now, they didn't offer any more explanation. I was presuming that when someone's brain dead they do not keep them alive any longer. From what she said that's what I was understanding because she said, "When that trickle of blood goes, and it will, she will be declared brain dead." I mean, probably back in the day they would keep people alive for while and see if they came around but I don't think they do that anymore. If they still did that, I'm sure they would have given us a choice, right?</p> <p>They kept saying to me that they had to let my mom ... I don't know... maybe it's because of what medical issue was going on with her but they had to let her die. They had to let her actually die? There was a lot of uncertainty for us because they needed to let her to die. They needed her to experience brain death and she wasn't there yet. I remember them telling us, "Okay, we're going to check to see if she's dead." I don't know what they do. It was like a weird situation because I knew they were trying to keep her alive for the donation but then also she had to experience brain death. I think that's what was going on. I remember them checking and then telling us, "She's actually still not dead yet so we're going to wait like a few more hours." And then having to do it again. Also, I think they had to fly in people for some of that stuff. I wasn't given any kind a clear time. It was like they had to wait until all these other things lined up and, like I said, she didn't die as fast as I think they thought she was going to. And, I can't remember when she actually like died per se, but it seemed to take a long time.</p> <p>It was always made to sound like it was on our schedule and the doctors needed to confirm the death. And at one point they said, "Oh, we think there was some movement in some baby toe or something, so we have to redo some tests." And I went, "Come on! Really?" I think they were stalling for time and I don't have a problem with that if they had been totally upfront. There was no way [Name 1] was going to be alive again, so let's get on with this.</p> <p>I mean there's procedures they have to follow and they keep you really well informed of what they're doing and the timelines and the only thing I would say on that and this is just hindsight for me is they could have told us and we just didn't pay attention, but it would be nice to have more of an understanding of how long it takes. For me, this was a first-time experience, and maybe I was just naive, but I kind of thought so he passed away on the 19th, they declared him legally gone on the 20th. I just thought you sign that off and then literally, like the next day everything happens, and then you get the remains back, but it was almost a week.</p> <p>The one doctor, he said that he would speak to the family, so it was myself, my husband, my son-in-law, and his parents who went into a room and they told us that they had declared her brain dead, and that there wasn't anything they could do for her and that was it. I guess that was their protocol and they made the decision so that the family didn't have to and then they were going to send somebody in if we up to it to talk about donating her organs. We didn't realize that they would have called her time of death without talking to us first. I don't know, I'd never been through anything like that before ... we had no idea what to expect. It was shocking.</p>

Table 2 continued

Theme	Quotations
DNC clinical assessment	<p>... and then the doctor said, well we'll do a third test, I told him that I need to know, because you always hear about these miracles, you know that people can just come out of this. Do you know what I mean? I told him I can't make a decision until I know for sure, so they said would do a third test. I was there and they took him off the respirator and if he breathed on his own, then there would be brain function, that's what it was. Yeah, and he didn't so then I knew for sure. It was so helpful.</p> <p>They just said, "Here comes the machine, do you want to watch, go ahead and watch. If you don't want to watch, don't watch." It wasn't like, oh you can't see this, it might make you upset. It's like well you're here, we're going to explain what we're doing. Like Dr. [Name 6] and Dr. [Name 9], they would explain what they were looking at and what they were looking for. You could leave it or watch, as long as you didn't get in the way of the machine obviously. It was good. I don't think anything was held back.</p> <p>I: Can you tell me more about being present for that final test? And, if that was helpful or not?</p> <p>R1: I think it was very helpful. It was hard for me, but I really didn't want to leave her and I don't think anyone else did either. We wanted to be with her right through the testing.</p> <p>They just kind of came in, shoed me out, did some tests and then let me go back in. And then I waited and waited and waited and then they came and said "Okay, we're done." It was really hard on me.</p> <p>I wasn't there for that test. Well, they didn't invite us into that because that's their thing. You know, two doctors have to sign off that she didn't breathe for eight minutes. I think is what it is. So, we met for eight o'clock on the Friday morning and everybody said goodbye and then they declared her. Oh no, I'm sorry we were there for the declaration of death but the next morning, at eight o'clock, Saturday morning, that's when we all met, said our goodbyes, and then about twenty after ten they took her body to the right and we went to the left. On the Friday, I was there but I wasn't in the room when they did the test because I chose not to be, plus I don't think they wanted me to be there.</p> <p>I: Did the doctors sit down with you when they were talking about the brain swelling or did they talk about a diagnosis of brain death with you?</p> <p>R: Yes, they talked to me about a huge risk and they were going to do an MRI to see how the brain was behaving. My son was on the respirator all the time. I think two days before he died, he started to breathe on his own. When they told me that I was so excited but they said it was not good news so don't get your hopes up because that doesn't mean anything because the brain is still swelling and they had to consult with the doctor and told me when that would be. They said that they would disconnect him from the life support and his body didn't respond. At that time, they had pronounced him brain dead.</p> <p>I: Did you have any questions about that? Was it explained well?</p> <p>R: You know, I didn't have any questions about it. I am not an expert in the medical field and I didn't know what to expect. I do know when somebody is brain dead there is nothing there, it is the end of life.</p> <p>They did the test where they blew the CO₂ into his vent to see if he triggered a breath, a response. When he failed that he basically ... and then he was nice enough, he did another EEG to confirm it, but he basically said that he had to pronounce him then at that point. Because it was kind of conclusive that he had failed that test and that was the end of the road and he said basically I have to pronounce which was shocking to us that he used those words. So, that's when I said, "Oh, I got it." Again, I allude to the fact that I am a black and white finance guy, but in that kind of stuff there is no chance you can be that way, so they spent a significant amount of time, I'm not talking two minutes here or two minutes there, I had more than a couple of hour full discussions, and this as I understand is the neurosurgeon and obviously, he is a busy guy.</p> <p>R: I was there for the neurologic testing and when they took him off the respirator and just had oxygen going through a tube. So, when they shut it down there was no involuntary response or anything. His heart was beating, but he didn't take a breath</p> <p>I: So, you were there when they withdrew the ventilator?</p> <p>R: Yes, it was part of the testing, I think the final test. They shut it down for ten minutes just so that the machine is not breathing for him and his lungs were not aren't filling. Yes, his dad and I were both there and my aunt. We all elected to be there. They were there to support me, but I just felt that I needed to be there. I felt it was important that I was there.</p> <p>We were all sitting in his room and I said, "Yeah, okay, we will donate." I didn't want him to walk to the other side by himself. I sat in the room while they were observing for his last cough or breath. So, the lady doctor is talking to me, right. And, and I kind of looked at her and I said, "So what you're what you're telling me is that Elvis has left the building." She couldn't grasp what I was saying. The other ones that were sitting around said, "Oh yes. Yeah, there is no more life."</p>

Table 2 continued

Theme	Quotations
Time of death	<p>I wasn't in the room at the time they issued the death certificate, so I struggled with that. When had they declared the time of death? It would have been very late and the donation operation wasn't until, like, 11:00 or something on the 6th? It was a night time surgery, so I wasn't there and this idea of him passing without me by his side is really hard.</p> <p>Monday he self declared. Tuesday two neurologists came in and declared him to have passed. And Wednesday was when the transplant was done. So, I don't know when did he die?</p> <p>I: So, you said goodbye to your dad at the community hospital and then they transferred him?</p> <p>R: No. Because he wasn't declared dead yet, he was taken to the [hospital name] and at that point he was still alive. My understanding is that they kept him alive and they monitored him constantly until they got to the other hospital and that's where they declared him legally dead and then they had a whole bunch of tests that they had to do, I guess to make sure that he was dead. I guess that they do a bunch of tests that your body should respond to. If it does not respond, you are legally dead.</p> <p>R: We told our family on the 14th [Name] had died and then calling them back and saying he's not really gone but don't like ... and then telling them on the 15th at two o'clock that he really is gone this time. And it was just unneeded stress at the time. It was hard enough as it was.</p> <p>I: Did anyone on the medical team tell you they thought he was brain dead at that time or was that just your feeling?</p> <p>R: I guess I knew all along. I don't think they ever used that word, "brain dead." They just said "We've done everything we can." I don't think I heard that word once even after. I don't recall them ever saying ... using that word "brain dead," "brain death." I don't think they used that.</p> <p>R1: She wasn't brain dead 'til 5:00 o'clock. Like her body, I guess you'd say was dead, but her brain wasn't dead so for them to pronounce her dead was at 5:00 o'clock on the 5th.</p> <p>R2: When the doctor called us at 11:00 o'clock, they said that she was already unconscious, that she was nonrespondent but she wasn't dead or brain dead.</p>

DNC = death determination by neurologic criteria; FM = family members; HCP = health care professionals; MRI = magnetic resonance imaging

Nothing was written down, so I have no written record of what was done. I was told, verbally, but I don't remember. I remember them saying we had done the tests but I'm not sure what that included.

Brain death as counterintuitive

Family members explained that the diagnosis of brain death seemed implausible or contradictory to how their loved one looked. In particular, FMs experienced difficulties understanding that their loved one could be brain dead given the fact they appeared as though they were sleeping:

That was the hard part, when you would go in to see him and he looked really good, because, of course he was on life support so the machines were doing the work, but he looked really good. It was eerie that way. You feel a little bit guilty leaving them there knowing they're still there. His hand is warm, his chest is rising, his heart is beating. And, they were keeping his eyes lubricated. So, every once in a while, you would see, saline come out of his eye. It was like, oh my God, but it's your heart and your mind playing tricks on you a little bit. It's still not an easy thing to process, because your heart is breaking.

Preparing for the death determination by neurologic criteria clinical assessment

Family members explained their preparedness, or lack of preparedness, on a continuum. At one end, FMs recounted not being told the DNC testing was going to happen. While some FMs felt they were not adequately prepared, others did feel ready for the assessment. Many FMs expressed frustration, and even suspicion, when the DNC clinical assessment was delayed, or needed to be repeated, without explanations from HCPs. The first quote is a description of a FMs reaction when they are not adequately (or not at all) prepared for the DNC clinical assessment:

The one doctor said that he would speak to the family, so it was myself, my husband, my son-in-law and his parents who went into a room and they told us that they had declared her brain dead, and that there wasn't anything they could do for her and that was it. I guess that was their protocol and they made the decision so that the family didn't have to, and then they were going to send somebody in to talk about donating her organs. We didn't realize that they would have called her time of death without talking to us first. I'd never been through anything like that before ... we had no idea what to expect. It was shocking.

Table 3 Family generated recommendations and changes in HCP practice

Recommendation	Translation to HCP in practice
State of mind	Recognize that FMs' understanding of what is happening to their loved one may be impacted by the emotional distress, grief, and/or exhaustion Early in the process, ask FMs what they understand about their loved one's condition to gain insight as to where they are at
Communication	Use clear and consistent language Avoid medical jargon Differentiate between coma and brain death Do not state someone is brain dead until the determination has been completed and they have been declared Avoid using only verbal communication: Show images, when possible, with FMs (e.g., a catastrophic permanent brain injury has occurred or scans illustrating no blood flow to the brain) Provide written information on brain death and/or a diagram on how death is determined so as to be used for ongoing reference
DNC may be counterintuitive	Recognize that sensory information, i.e., visual (see breathing), and touch (feel warm) can be challenging for FMs to process, contrasting to brain death
Preparing for the DNC clinical assessment	Inform FMs that a DNC clinical assessment will be performed and explain the possible outcomes Offer the opportunity for FMs to watch the DNC clinical assessment Ensure the FMs know why they are waiting. That is if the DNC clinical assessment needs to be delayed because of confounders (e.g., drugs), explain why and provided expected time frames
DNC clinical assessment	Explain, in advance, the components of the DNC clinical assessment for FMs who chose to witness the apnea test Provide a support person to the FM who attend the DNC clinical assessment
Time of death	Communicate the time of death and be clear on the meaning of this as the legal time of death, not of actual death

DNC = death determination by neurologic criteria; FM = family members; HCP = health care professionals

Family members who were not provided sufficient details of DNC (e.g., various processes including timing of death) reported feeling additional confusion and anxiety:

They kept saying to me that they had to let my mom, and I don't know maybe it's because of what medical issue was going on with her, but they said they had to let her die. There was a lot of uncertainty for us. I remember them telling us that they needed her to experience brain death and she wasn't there yet. The doctor would say, "Okay, we're going to check to see if she's dead" It was a weird situation because I knew they were trying to keep her alive for the donation but then also she had to experience brain death. I think that's what was going on. I remember them checking and then telling us, "She's actually still not dead yet so we're going to wait like a few more hours." And then having to do it again. I wasn't given any kind of a clear time.

Clinicians who provided clear and straightforward explanations that met the FM's needs resulted in gratitude and acceptance:

The doctor explained everything. I really didn't have any questions because he explained it all so well and if I did have questions, he answered them, and I trusted his answers. I know I asked, "How do you know exactly he's brain dead," you know those things? And so, we had a real in-depth conversation and he explained how the brain functions and in 24 hours you can tell if its healing or what have you, and these are the tests we do. He made sure that we knew there was no chance of recovery. We laid our trust on the doctor, and we felt comfortable with that.

When delays and/or the need for additional testing was not clearly explained, some FMs became suspicious of the medical team's motives:

It was always made to sound like it was on our schedule and the doctors needed to confirm the death. At one point they said, "Oh, we think there was some movement in some baby toe or something, so we have to redo some tests." And I went, "Come on! Really?" I think they were stalling for time and I don't have a problem with that if they had been

totally upfront. There was no way [Name 1] was going to be alive again, so let's get on with this.

The death determination by neurologic criteria clinical assessment

Family members articulated the importance of being invited to be present and witness the DNC clinical assessment, specifically the apnea test. The first two quotes are illustrative of how beneficial it was to be present for the apnea test:

... and then the doctor said, well we'll do a third test, I told him that I need to know, because you always hear about these miracles, you know, that people can just come out of this. Do you know what I mean? I told him I can't make a decision until I know for sure, so they said would do a third test. I was there and they took him off the respirator and if he breathed on his own, then there would be brain function, that's what it was. Yeah, and he didn't, so then I knew for sure. It was so helpful.

They did the test where they blew the CO₂ into his vent to see if he triggered a breath. When he failed that the doctor was nice enough to do another EEG to confirm it, but he basically said that he had to pronounce him dead at that point. It was kind of conclusive that he had failed that test and that was the end of the road. When he said, "I have to pronounce," it was shocking to us that he used those words. So, that's when I said, "oh, I got it." They spent a significant amount of time explaining things to us and I'm not talking two minutes here or two minutes there, I had more than a couple of hours of full discussions, and this as I understand is the neurosurgeon and obviously, he is a busy guy.

Family members wanted the option to be invited to attend the DNC clinical assessment and when they felt as though they were not welcome to be present, they reported more negative bereavement outcomes:

They just kind of came in, shooed me out, did some tests and then let me go back in. And then I waited and waited and waited, and then they came and said "Okay, we're done." It was really hard on me.

Time of death

The legal time of death appeared to be confusing for many families. Family members experienced guilt if they felt their loved one was declared dead in their absence:

I wasn't in the room at the time they issued the death certificate, and I struggled with that. When had they declared the time of death? It would have been very late and the donation operation wasn't until, 11:00 or something on the 6th? It was a night time surgery, so I wasn't there and this idea of him passing without me by his side is really difficult.

Families struggled with the distinction between when the person died and when the body died:

Mother: She wasn't brain dead 'til 5:00 o'clock. Like her body, I guess you'd say was dead, but her brain wasn't dead so for them to pronounce her dead was at 5:00 o'clock on the 5th.

Father: When the doctor called us at 11:00 o'clock, they said that she was already unconscious, that she was nonrespondent but she wasn't dead or brain dead.

Table 3 illustrates the six broad and overlapping themes that emerged from the FM data, phrased in terms of practice-based recommendations to improve FM understanding of brain death and death determination in the context of organ donation.

Discussion

We conducted a large, high-quality qualitative cohort study of FMs experiences of understanding brain death. We described FMs' understanding of brain death and death determination in the context of organ donation within Canadian ICUs and have provided family-generated recommendations to improve understanding and acceptance. Family members' understanding of brain death and death determination represented a journey that was reported as sequential meetings with HCPs, most notably physicians. Family members in our study indicated that the process of death determination, specifically bedside clinical assessment including observing the apnea test, was critical for providing concrete understanding and often closure. Nevertheless, some families felt they were not welcome to attend clinical assessments, including the apnea test, and these FMs were more distrusting of the medical team and reported more negative bereavement outcomes.

Family members described a state of intense grief and exhaustion, which impaired their capacity to think rationally or objectively, consistent with previous studies.^{17,20–23} In their state of mind, FMs must endure an additional psychological burden as they struggle to comprehend brain death, a construct that research has shown to not be well understood by members of the general public.^{3–14} Many FMs explained their state of mind often

rendered them unable to “hear” and/or retain the information that HCPs provided. FMs explained being unable to comprehend information about their loved one and needed to have things repeated many times to absorb the details.

Our data, as others’,^{8,9,11–15,19} reveal that many FMs struggle with the difference between brain death and coma, and some continue to struggle with this differentiation years after the death of their loved one. Despite several decades of research on this topic, many FMs, and the public continue to be confused about the differences between brain death and other neurologic disorders such as comas or persistent vegetative state.^{8,11,19,29–32} We have found that the timing and frequency of conversations with families are important for their comprehension. Families need to be informed early in the death determination process, and need to have information repeated several times to understand. Moreover, multimodal communication strategies (e.g., notes, diagrams, images) are critical for FM reference thereby helping to ensure they do not have unanswered questions about the process. A growing body of research finds that bereaved FMs who lack understanding of brain death are at a higher risk of developing symptoms of post ICU syndrome, such as anxiety, depression, and post-traumatic stress.^{18,19,23,33}

The counterintuitive nature of brain death served to contribute to FMs’ confusion. Indeed, appearances can be deceiving as FMs try to reconcile the ambiguity of the dead body’s appearance. We, as others have shown,^{4,34} found that conflicting sensory information including touch (feels warm) and visuals (see them breathing), challenges the acceptance of DNC. Accepting DNC for someone who appears to be still breathing and whose heart is still beating, albeit with support of ventilators or other devices, seems to violate a basic understanding of what constitutes life.³⁵ Similar to Tawil and colleagues study findings,³⁴ FMs confirmed that when they were able to witness the DNC clinical assessment, they were able to overcome any lingering conflict and move towards acceptance and closure.

Less reported in the literature are depictions of FMs who witnessed death determination testing, specifically the apnea test. FMs were clear that being present for the apnea test was beneficial on three important levels: 1) they clearly understood that their loved one was indeed dead, 2) it was beneficial for their bereavement process in that they had obtained closure in that moment, and 3) they were able to begin grieving without any unanswered questions. Post-traumatic stress symptoms are prevalent in FMs of ICU patients and may be exacerbated by their participation in end-of-life decisions without truly understanding if life has actually ended.^{17–20,23,31,33,36} Ongoing monitoring and

research are needed on the impacts on FMs of routinely offering and witnessing of the DNC clinical assessment.

Our findings highlight the negative impacts of not making families aware of the DNC clinical assessment. Family members who were told their loved one had already been declared brain dead experienced additional confusion, stress, and grief. Nevertheless, FMs whose medical team took the time to explain the DNC clinical assessment in advance reported feeling more prepared for the determination and accepting of the result. More research is needed to explore why clinicians would not inform FMs that the clinical assessment is going to take place. While this practice may simply have been overlooked and require education on the importance to FMs, undoubtedly, there could be anxiety on the part of physicians that families may refuse the assessment or discomfort that FMs may request to be present to observe the assessment. Nevertheless, patient- and family-centred care advocates that clinicians provide family support and open lines of communication.¹⁶

Another important aspect for clinician–family communication, though not well documented in the literature, concerns the dual nature regarding time of death. Many FMs reported that the legal time of death was confusing. The time of death appears to take on a double meaning, for example, death as a moment or a state. Some FMs expressed feeling guilt in thinking their loved one died without them being present. Others noted that the confusion over the time of death was an unnecessary additional stressor during an extremely traumatic time. Some families questioned why the time of death on the death certificate was different from the time of death they had been told while in the ICU. Clinicians need to help families reconcile the legal aspect of the time of death, so families are not left with unanswered questions.

Our study has several limitations. There may be selection bias in terms of who agreed to an interview, which could be impacted by FMs who had relatively good experiences and trust in research or those who had very bad experiences and wished to express it. As such, family-generated recommendations might not apply to all and should be adapted to the individual needs of FMs. It is important to note that only a small number of families declined organ donation; hence further research is required to better understand their unique experiences. Finally, interviews were conducted with English- and French-speaking Canadian FMs only and, as a result, other ethnicity-based views have not been included.

Conclusion

In this study, we have identified important themes related to FMs’ understanding and acceptance of brain death and

have identified practice-based family recommendations to address the barriers, support the facilitators, and promote more positive outcomes. These recommendations are pragmatic and can be easily implemented. Notably, we have compiled evidence on the benefits of FMs witnessing death determination, especially the apnea test. Overall, our study has provided recommendations with regard to modifiable factors such as cognitive readiness of families given their state of mind, pacing and repeating discussions according to families need to absorb, having the confidence to prepare and invite families to be present for determination to inform clinical practice, and the development of tools that can be used at the bedside. Knowledge translation tools must be developed and used selectively at the bedside depending on FMs' needs. Ongoing qualitative research will permit better insight into minority and culturally specific experiences.

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