

Organ donation focus group guide

Study overview:

Problem: Many imminently dying patients who desire donation cannot successfully donate organs because not all patients with devastating injuries or life-limiting neurological diseases will meet the criteria for “brain death.” For imminently dying patients who are *not* brain-dead, the only currently available option for organ donation is donation after circulatory death (DCD). However, donation after circulatory death is not guaranteed, e.g. some patients do not die fast enough to donate organs that are suitable for transplant.

Proposal: To remove organs from imminently dying patients before circulatory death.

Aim: To characterize professional (role based) attitudes of stakeholders about donation before circulatory death for imminently dying patients.

Approach: Focus groups of transplant surgeons, anesthesiologists, palliative care docs, ICU docs, OPO personnel, policy makers (1 FG each, sample attendees at national or regional meeting, no more than 10 participants/group, purposefully selected to achieve variability in gender, years in practice and geography of practice setting)

Inclusion criteria– first hand exposure with either successful or unsuccessful DCD donation, for example: cared for a patient who was a candidate for DCD donation either before or after attempted donation, supported/interacted with family members during the decision process or after failed DCD, cared for a patient with a terminal neurologic disease who considered DCD donation, participated in any way with DCD organ recovery, evaluated policy regarding DCD donation.

Exclusion criteria – no previous exposure/familiarity with DCD, not at meeting

INTRODUCTION AND OPENING QUESTION

Hello and welcome. Thanks for joining our discussion. My name is [NAME] and I am a [TITLE AND ROLE AT UW]. I will be moderating our discussion. This focus group is being held on behalf of researchers at the UW School of Medicine and Public Health and is supported by the Greenwall Foundation, a private foundation that funds ethics-related research. The Principal Investigator in this study is Gretchen Schwarze, a vascular surgeon who studies ethical issues in surgery.

The purpose of today's discussion is to get your professional response and insight about organ recovery strategies for non-brain dead donors. Specifically, the controversial topic of imminent death donation.

We are meeting with different groups of physicians and stakeholders who have familiarity with organ donation including transplant surgeons, intensivists, anesthesiologists, OPO staff and policy makers. Our goal is to better understand key stakeholder perspectives in order to inform discussion about organ donation and imminent death donation.

We will present several hypothetical scenarios. Mainly, we are interested in your response based on your role as [XXX/e.g. MD, policy maker], your professional insights and how you might imagine your role within the hypothetical situations we describe. I'm interested in your candid thoughts and opinions, particularly your opinions as they relate to your professional work.

The session will be audio-recorded so that I don't miss any of your comments. But I want to emphasize that your comments here today are strictly confidential. No names will be used in any reports or publications. The researchers will not even hear your recorded voices. Rather, they will have access only to the written transcripts. And all names and identifying information such as the name of the hospital where you practice will be redacted from the transcripts before the researchers begin working with them. Please keep our discussion confidential and do not disclose anything that was discussed outside of this group.

I put name tents around the table. You shouldn't feel as if you have to direct your comments to me. If you want to follow up on something someone has said, if you want to agree, disagree, provide an example, please feel free. I ask that only one person talks at a time. My role is to introduce questions and make sure everyone has a chance to talk.

If you have a cell phone, please put it on quiet mode. If you need to take an urgent call, please step out in the hall and rejoin us as soon as you're able. Feel free to get up for more refreshments if you'd like.

With that in mind, let's get started by going around the table one at a time. Please tell us your name and what area of the country you practice in. Feel free to give only your first or last name, depending on what you're most comfortable with or prefer to be called. Names or other identifying information will not be included the transcript of this discussion.

Hand out debrief cards

To start, I'd like to hand out cards that describe current strategies for organ donation for deceased donors. Please take one and pass the rest around.

Donation after Brain Death (DBD)

- Brain is determined to be dead based on official brain-death criteria, and the heart is still beating up until just before the organs are removed
- Donation after brain death is more common than donation after circulatory death
- Donors can typically give all organs including heart, lungs, liver, and kidneys

Donation after Circulatory Death (DCD)

- Brain is very damaged but the donor has not met all the official brain-death criteria
- Doctors stop life supporting treatments and wait until the heart stops beating before they start removing the organs
- Organ donation not always possible because the heart keeps beating for a long time after life support is stopped
- Donors can typically only give liver and kidneys. Other organs (lungs, pancreas, small bowel) are possible, but this is unusual
- The liver and kidneys are often of lesser quality than those provided from officially brain-dead donors

Debrief for ICU, anesthesia, palliative care:

We're assuming that the information on the card is very familiar to everyone here, but we want to make sure we're on the same page, so I'd like to go over the card point by point for us. We also recognize that these descriptions are simplified and that we have left out some precise, technical details. This is meant to represent a general understanding that a lay-person could appreciate.

As the card notes, there are 2 ways for deceased donors to donate organs. In the first way, called Donation after Brain Death, or DBD, the brain is determined to be dead based on official brain-death criteria, and the heart is still beating up until the time the organs are removed. Donation after brain death is more common than donation after circulatory death and donors can typically give all organs including heart, lungs, liver, and kidneys.

In the second way, called Donation after Circulatory Death, or DCD, the brain is very damaged but the donor has not met all the criteria for "official brain death" so doctors stop the life support and wait until the heart stops beating before they remove the organs. Organ donation is not always possible because the heart keeps beating for a long time after life support is stopped. Donors can typically only give liver and kidneys. It's possible to donate other organs --

lungs, pancreas, small bowel -- but this is unusual. The liver and kidneys are often of lesser quality than those provided from officially brain-dead donors.

Does anyone have any questions or clarifications about these procedures?

Debrief for transplant surgeons, OPO and UNOS

The study team is assuming that the information on the card is very familiar to everyone here, but we want to be sure there is no confusion. We recognize that these descriptions are simplified and that we have left out some precise, technical details. This is meant to represent a general understanding that a lay-person could appreciate.

Does anyone have any questions or clarifications about these procedures?

Next I'd like to ask for your reaction to several hypothetical scenarios surrounding organ donation. I am interested in your professional opinion as someone who could be involved with the care of the patient we describe in each situation....

DOMAIN #1: Impressions of unsuccessful DCD donation

I'll start by telling you about a 25-year old woman named Jamie. She has been in a serious accident and suffered a devastating head injury without other injuries to her body. It is clear her brain will never recover, but she does not meet all official criteria for brain death. Her family has made the decision to stop all life supporting treatments. Her family feels it is very important to donate her organs as doing so would be a way to honor Jamie's wishes, which are both documented on her driver's license and clearly recalled by her family members. Because Jamie is not officially brain dead, the doctors need to wait until Jamie's heart stops beating before they can begin to recover her organs. Although Jamie's family is deeply saddened by her impending death, they are hopeful about the possibility of a DCD donation for Jamie.

In this first scenario, Jamie's family consents to DCD donation. They are disappointed when the recovery team returns from the operating room with Jamie's heart still beating, albeit slowly, 2 and a half hours after withdrawal of life supporting treatment. Jamie was unable to donate her organs because she did not die from circulatory death in time.

QUESTION

1. How have you seen families respond in this type of scenario?

PROBE: if you don't have first-hand experience with unsuccessful DCD, how do you think families might respond?

DOMAIN #2: Attitudes about imminent death donation (kidney only)

Now I'd like to describe a second, slightly different scenario. Again, we are considering a 25-year old woman, Jamie, with a devastating head injury who does not meet all official criteria for brain death. Her family has made the decision to stop all life supporting treatments and would like to honor Jaime's previously stated wishes to donate organs.

In this second scenario, Jamie's doctors are concerned that her heart will not stop in time for her organs to be recovered successfully. Given their desire to honor her wishes, Jamie's family is very interested in having Jamie donate a kidney before her doctors withdraw life supporting treatments.

1. As a [XXX: transplant surgeon, anesthesiologist...etc.], what would you think about [removing a kidney/anesthetizing Jamie/caring for Jamie in the ICU/ supporting Jamie] in order to recover her kidney before circulatory death?

PROBE: Assuming there were no legal or professional consequences how would you think about participating [in the removal of Jamie's kidney, in the care of Jamie]?

2. Now I'd like you to step back a bit and consider this from the view of people in your field. As a member of your profession, what do you think of the role of [XX use profession of respondents XX: e.g. surgeons, anesthesiologists etc.] who would participate in the recovery of Jamie's kidney before circulatory death?

PROBE: As someone outside the field of surgery, what do you think about the role of surgeons who would recover Jamie's kidney before circulatory death? [NOT ASKED AT FOCUS GROUP FOR TRANSPLANT SURGEONS]

PROBE: As someone outside the field of anesthesiology, what do you think about the role of anesthesiologists who would assist in recovery of Jamie's kidney before circulatory death? [NOT ASKED AT FOCUS GROUP FOR ANESTHESIOLOGISTS]

3. How do you think the public would view [XX profession of respondents XX (surgeons/anesthesiologists/physicians)] who participate in the recovery of Jamie's kidney before circulatory death?

PROBE: What support would the public have for physicians who participate in the recovery of Jamie's kidney?

PROBE: What opposition would the public have against physicians who participate in the recovery of Jamie's kidney?

DOMAIN #3: Attitudes about imminent death donation (all organs)

Now I'd like to describe a third scenario. Again, we are discussing Jamie, a young woman with a devastating head injury who had expressed clear preferences for organ donation, and her family has decided to stop all life supporting treatments. Jaime is unlikely to die in time to donate after circulatory death.

In this third scenario, Jamie's family is very interested in having Jamie donate all organs, including heart and lungs before her doctors withdraw life supporting treatments.

1. As a [XXX: transplant surgeon, anesthesiologist...etc.], what would you think about [operating /anesthetizing Jamie/caring for Jamie in the ICU/ supporting Jamie] in order to recover all of her organs before circulatory death?

PROBE: Assuming there were no legal or professional consequences, how would you think about participating [in the removal of all of Jamie's organs, in the care of Jamie]?

2. Again, I'd like you to step back a bit and consider this as a member of your field. As a member of your profession, what do you think of the role of [XX use profession on respondents XX: e.g. surgeons, anesthesiologists etc.] who would participate in the recovery of all of Jamie's organs before circulatory death?

PROBE: As someone outside the field of surgery, what do you think about the role of surgeons who would recover Jamie's organs before circulatory death? [NOT ASKED AT FOCUS GROUP FOR TRANSPLANT SURGEONS]

PROBE: As someone outside the field of anesthesiology, what do you think about the role of anesthesiologists who would assist in the recovery of Jamie's organs before circulatory death? [NOT ASKED AT FOCUS GROUP FOR ANESTHESIOLOGISTS]

3. How do you think the public would view [XX profession of respondents XX (surgeons/anesthesiologists/physicians)] who participate in the recovery of all of Jamie's organs before circulatory death?

PROBE: What support would the public have for physicians who participate in the recovery of Jamie's organs?

PROBE: What opposition would the public have against physicians who participate in the recovery of Jamie's organs?

DOMAIN #4: Attitudes about policy support and not being the pioneer

For our next question, I'd like you to recall the scenario about Jamie where we considered donating just a kidney. As a reminder, she has a devastating head injury and her family is very interested in honoring her wishes to donate.

In this hypothetical scenario, UNOS supports a policy for imminent death donation just for kidneys and several transplant centers have recovered kidneys from donors before their death. I would like to reinforce here that this is a hypothetical scenario.

1. As a [XXX: transplant surgeon, anesthesiologist...etc.] What would you think about [removing a kidney/anesthetizing Jamie/caring for Jamie in the ICU/ supporting Jamie] in order to recover her kidney before circulatory death?

DOMAIN #5: Reactions to donor family testimonials

Next, we'd like to share 2 quotes from interviews our study team did with family members whose loved ones attempted but were unable to donate organs after circulatory death. These interviews were performed months to years after their experience with unsuccessful DCD donation. We chose these 2 quotes as they represent a range of the findings from our interviews with donor families.

Pass out quotes, give everyone 2 minutes to read and think

- 1) *"I think it just added despair to a...situation that I didn't think could get worse. But then, all of sudden, when despair changes to a small hope that it's going to help somebody else, that's what you focus on...I don't know, it was very hard to accept. So, even at that time, it was just hard to believe that there wasn't a better process."*
- 2) *"You mean I can sign these papers to pull the plug, end his [their son's] life, but I can't sign a paper to donate one kidney, which won't even hurt him? I can kill him, in other words, but I can't take one kidney that's not even going to hurt him?... That— it was wrong. Very wrong."*

Questions:

1. What do you think about these quotes?

PROBE: What resonates with you about these quotes?

PROBE: Does anything surprise you about these quotes?

2. How might this shift your thinking about the role of your profession in the recovery of Jamie's kidney, if at all?
3. How might this shift your thinking about the role of your profession in the recovery of all of Jamie's organs, if at all?

Ending question:

You have helped us a great deal this evening by sharing your thoughts and opinions about imminent death donation. Is there anything else that you would like to add to what you said already about your professional role in organ donation?

CLOSING

Thank you very much for sharing your ideas and perspectives with us this evening. Before you leave, we'd like to invite you to fill out a very brief questionnaire. Your responses to the questionnaire are confidential and voluntary. Please take a moment to fill them out and return them to [MODERATOR] when you're done.