APPENDIX B: National Study Qualitative Codebook

National Study Qualitative Codebook

Coding Principles:

- Record key message(s) from each transcript (e.g., centrality of the health care team, centrality of family member support, etc.)
- Record key word(s) for subsequent searches (e.g., autopsy, horrified, etc.)
- Record transcript ID and line numbers for great quotes
- When coding always think content for publication
- When coding paragraphs, try to code in larger chunks (as opposed to really breaking things down at the sentence level). Any consecutive statement is coded together
- Include researcher comment if it is on the same topic as the participant

ATTRIBUTES	
ATTRIBUTE NAME	**RATIONALE (when required)**
Province	
Adult	
Pediatric	Up to 18
FM Wife	
FM Husband	
FM Mother	
FM Father	
FM Daughter	
FM Son	
FM Other relative	For example, uncle, niece, etc.
FM Friend	
Pt. NDD	
Pt. DCD	
Pt. Maid	

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Inter-hospital transfer	Refers to a patient that is transferred from a community hospital to a tertiary site
Donor Consent	
Donor Refused	
Donor Recovered	
Donor Not recoverable	
Pt wishes know – yes or no	
Confidence in decision to donate – yes or no	
FM Regret – yes or no	
FM contact with recipient - yes, no, **unknown**	
FM Wishes to make contact with recipient	
FM agreeable to follow up – yes or no	
Conversation decoupled by MD – yes, no, or unknown	This attribute will perhaps take some inference on the part of the analyst. We will continue to discuss this at our coding meetings.
Quality of the encounter – positive or poor	This way we can go back and analyze 'poor' and 'positive' transcripts together in order to be more-fine grained in a subsequent analysis

CODE	**ABBREVIATION**	**DEFINITION**	**NOTES**
Acts of kindness/care	Acts_kind_care	Reference to any gestures or acts of kindness that health care providers will do which are memorable to them	
Autopsy	Autop.	Clinical examination of deceased pt.	
Being with Pt. (body)	Being w/ Pt.	Refers to discussion about being able to spend time with the Pt. (body), being close, getting in bed with pt.	
Being with Pt. (Body) - NO	Being w/Pt. No	Refers to discussions about the FM not wanting to be present, this is particularly relevant during WLST	
Bereavement	Bereav.	Refers to discussions of grief typically following the question, "*how are you doing now*?" -guilt and regret -includes contextual factors (e.g., FM talks about experience with the death of another family member) -Use bereavement code to include any contextual factors (even if you are unsure if it 'impacts' FM's bereavement), we want to capture these factors.	

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Brain death	NDD	Any mention of brain death processes, and includes general discussion and talk of confusion over brain death (Note: it is most important to capture the confusion over brain death, i.e., does the FM/family understand what 'brain death" means?)	
Brain death declaration	NDD dec.	Any mention of process (discussion of medical testing leading up to declaration) to declare Pt. brain dead by MD.	
Body taken to OR	Body to OR	Refers to the time period when the FM/family is separated from the pt. as they are moved to the OR for the transplant surgery	
Cardiocirculatory death	DCD	Any mention of DCD processes	
Cardiocirculatory declaration	DCD dec.	Any mention of process to declare Pt. dead by DCD	
Confidence in decision (yes or no)	Confid in dec.	Refers to the specific question, "*looking back would you make the same decision [to donate*] *again?*" Note: Includes conversation about regret	
Correspondence with recipient	Corresp w/ recip.	Includes discussion if the FM had correspondence with recipient(s) or not. And, includes discussion of FM wanting (or not wanting) to have contact with recipients.	
Date of death/time	Date-Death_Time	Includes discussion on the actual time of death, and will often detail a confusion on the part of the FM surrounding the time of the exact death date. To be coded when the family specifically states the time or day given or when they specifically mention when the TOD was communicated to them.	
Understanding of medical condition	Understand. Med cond	Refers to the FM perception of what exactly is wrong with the Pt. Ensure this is flexible	
Who first brought up donation – FM/family	Who_first_don_FM	Refers to the person who first brought up donation (e.g., family, OTC, MD, RN, etc.)	
Who first brought up donation - MD	Who-first_don_MD	Ibid	
Who first brought up donation - ODC	Who_fisrt_don_ODC	Ibid	
Who first brought up donation - RN	Who_first_don_RN	Ibid	
Who first brought up donation – unclear/unknown	Who_first_don_un	Ibid	
Decoupling by MD (yes, no or unknown)	Decoup	Includes any mention if the MD held separate EOL & donation discussions with FM/family. Also includes conversations as related to palliation and harvesting.	Revision of question in interview guide due to wording clarity for participants ss
DCD preparedness	DCD prep	Refers to preparing the FM/family for withdrawal of life support (body functions), and timing of death/if pt. does not die in time/timeframes	

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DCD Heart	DCD heart	Refers to all conversation about the possibility of DCD heart donation	Hypothetical – if it had been an option ss
Donation decision	Don dec	Includes details surrounding the decision to donate (or not), and includes processes around consent. Includes conversation about FM signing (or not signing) their donor card. ss	
Donation decision – conflict (yes or no)	Don dec conf	Includes any mention of family conflict over the FM's decision to donate Pt.'s organs as well as descriptions of consensus for decision	
Donation process	Don process	Refers to the events that occur up to the actual harvesting. Includes the scheduling of the harvesting, additional measures taken on Pt. to preserve organs. Typically, the medical/procedural activities that lead up to donor harvesting.	
Donor event/ceremony	Don cerm	Any discussion of FM (and family) attending an event/ceremony sponsored by the ODO, and/or receiving a commemorative artifact (e.g., medal, plaque, ribbon, etc.)	
Donor care / End of Life Care	DC/EOLC	Typically refers to adjectives describing how the Pt was cared for by HCP. Direct patient care. Includes positive and negative perceptions of care (e.g., positive – "they had brushed his hair", negative "the way they were cleaning his breathing tube, it was like he was working on someone's car")	
EOLC discussion/decision making	EOL discss_dm	Refers to any conversation(s) regarding the decision and plan for EOLC	
Failed donation transition back to EOL care	Failed don transp	When the body is taken from the OR back to end of life care	
First encounter with hospital	First encount	Refers to descriptions about FM arriving at hospital, and often includes the fist time they see the Pt. and initial communication from HCPs (note: can be a call from the hospital)	
Family meeting	Fam meet	Refers to any meeting/discussions led by an MD, includes family decisions re: removal of breathing tube, end-of-life discussions	
Family relations stress	Fam rel stress	Refers to stress on family relationships of having their loved one in the ICU, causing family relationships to change in a negative way	
Follow up	FU	Any news post donor surgery after FM left the hospital (outside of ODO)	
Great Quote	Great quote	For any great quote based on the coder's judgement	
Impact – positive or negative	Impact	What the FM was left feeling, how it made an impression on them. Outcome, lasting impression.	
Initial event	Init event	Includes finding out what happened to Pt. (and from other people). INCLUDES PT. BEING TRANSPORTED TO HOSPITAL	
In-hospital donor rituals	In hos don rit	Includes any particular rituals the hospital (NOT ODO) does typical prior to harvesting. E.g., include all staff standing around holding hands and saying a prayer for the pt.	

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Inter-hospital transfer	Inter-hosp trans	Refers to text describing patient being transferred from one hospital to another.	
Legal FM	Legal FM	Reference to who is making decisions or who should make decisions	
Location of conversation(s)	Loc of conv	Refers to descriptions of conversations between HCP and FM/family in specific locations (e.g., hallways, nursing station, etc.). A movement of the FM/family to another location for a conversation can trigger the use of this code.	
MD presence post donation	MD post don	Refers to any reference of MD being present (and interactive) or absent post donation decision (still within the hospital)	
ODO communication/satisfaction	ODO comm/sat	Communication with the provincial organ donation organization Includes any comments regarding their communication with the ODO or any comments on the satisfaction or if unsatisfied with the ODO. Follow up after FM has left the hospital post donor surgery	
Prognosis	Progn	Medical condition of the Pt (from HCP)	
Quality of encounter (pos or neg) – General	QofE - gen	For when not sure who referring to or general comment on quality.	
Quality of encounter (positive or negative) - MD	QofE - MD	Capturing code per HCP role. Descriptors include: flippant, technical, dehumanizing and amazing, caring. Note: We are also capturing this code as an attribute	
Quality of encounter (pos or neg) - RN	QofE - RN	Note this encounter is typically while in hospital - important to contrast to ODO communication	
Quality of encounter (pos or neg) - ODC	QofE - ODC	Ibid	
Quality of encounter (pos or neg) - Resident	QofE -Res	Ibid	
Quality of encounter (pos or neg) – soc worker	QofE – soc work	Ibid	
Quality of encounter (pos or neg) – pastor/clergy	QofE - pastor	Ibid	
Questionnaire	Quest	Refers to FMs talking about the questionnaire's questions bothering them or causing them more grief. Alternatively, was the questionnaire process ok for FM?	
Recommendations from families	Recomm - fm	Includes suggestions from FM/families to make the donation process better (e.g., provide time/space for me to be with my loved one). Note: this will come out throughout the interview	
Saying good-bye	Say GB	Refers to process of FM (family/friends) saying good-bye to Pt (typically just before harvesting)	
FM participation/reflection on interview	FM reflect of iv	For example, was it cathartic for the FM? Includes any discussion about the letter we sent ahead of the interview (all provinces except ON)	
FM perceived pressure in making decision (yes or no)	FM perc pressure DM	Did the FM feel any pressure by HCP in making their decision for donation	
Space for families	Space FM	Private space for families to gather in the hospital (ICU area)	

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State of mind	State of mind	Includes memory and cognitive burden during ICU stay	
Support (positive or negative)	Supp	Includes emotional support	
Time	Time	Text would contain descriptions of the 'quality' of the time. For example, "That's what I believe when it was happening, I was aware of that of how the critical time was and yet somehow this hospital staff and organ donor staff managed to make it that we could still have the best time with our child, so that was something that really did strike me at the time too, like wow, this is really amazing that we can do this, help everybody right?" Also includes references to the 'extra time' required to be a donor, and 'time' spend waiting to hear information about Pt.	
Time after death for FM recruitment	Time ad fm recruit	Refers to the time FM perceives that is "best" to participate in research studies (interview)	
Trust (yes or no)	Trust	References to trust in "the system" or "HCPs" or lack of trust	
Unanswered questions (yes or no)	Unanswered ques	Includes overall unanswered questions that can be answered (i.e., by hospital staff) and questions that can never be answered (i.e., why did Pt. do what they did), lingering questions	
Wishes known (yes or no)	Wish known	Refers to if the FM had a prior conversation about donation with Pt, or was a donor card signed (and found), or donation decision registered.	

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