Appendix A – Interview Guide for Case Study Research

Project Title: Exploring the Quality and Experience of Patient Care in ICU: A Multiple Case Study Approach with Family Members of Seriously Ill Muslim Patients

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Opening: Thank you for taking the time to be a part of this research study. I will start by giving you some information on the purpose and structure of this interview.

We are interested in learning more about the quality and experience of care that you and your loved one received at Sunnybrook Health Sciences Centre. Muslims are an under-represented community in health services research and there is little understanding around what constitutes quality care and potential gaps that exist in the medical decision-making process. Our aim is to understand aspects of your loved one's care that you feel were of <u>high and/or low quality</u>; we would like to understand your <u>experience with making decisions</u> about end-of-life care; and we would like to explore how your loved one's <u>goals and preferences for care</u> were achieved or not achieved.

<u>INTERVIEW QUESTIONS WITH FAMILY MEMBERS:</u>

Part I – Introduction

Questions	Probes
1. Can you tell me a little bit about your loved one's <u>medical journey</u>?	Was the illness something that was <u>sudden/unexpected</u> or more <u>gradual</u> (i.e., developed over time)?
2. Can you tell me about you and your loved one's <u>racial, ethnic, cultural, and religious background</u>?	Were you and your loved one <u>born</u> inside or outside of Canada? ○ (If outside) what is the <u>country of origin</u>? How <u>important was culture or religion</u> in your loved one's and in your day-to-day life?

3. How long was your loved one's stay in ICU at Sunnybrook Hospital?	Was that the first time that your loved one was admitted into ICU? Did your loved one receive care in other units at Sunnybrook Hospital?

Part II – Aim 1: Quality and Experience of Patient Care

Questions	**Probes**
4. During your experience in ICU, what aspects of your loved one's care would you describe as being high quality? Can you describe specific examples of how this helped you? How about in other places outside the ICU? (i.e., communication, spiritual care workers, emotional support, pain management, kept informed, able to access doctor/nurses, timely updates, etc.)	What was least helpful in your experience? Would you say that the care your loved one received in ICU was respectful? Would you say that your loved one's pain and symptoms were adequately managed? Would you say that you had trust in the healthcare team that was looking after your loved one?
5. Can you describe aspects of care in the ICU that you felt reduced the quality of care for you and your loved one? How about in other places outside the ICU?	What aspects of your loved one's care would you describe as being low quality? **For COVID-19 participants:** Can you describe specific examples of how the quality of care in ICU was impacted by the COVID-19 pandemic? How were you supported or not supported during this time? From your perspective, how can quality of care in ICU have been better? Can you describe specific examples?
6. How would you describe overall communication with the healthcare team (including allied health workers such as social workers or palliative care) in ICU? How about in other places outside the ICU?	Do you feel that you were able to fully express your thoughts and concerns with the healthcare team? Do you feel that information around your loved one's illness was communicated to you in an understandable way? Do you feel that you were kept informed about your loved one's condition in a timely and honest manner? What made communication with the healthcare

	team more or less difficult? **For COVID-19 participants:** How did the COVID-19 pandemic impact communication between you and the healthcare team?
7. If you had to explain to someone with no experience in ICU what it was like to receive care at SBH, what would you tell them? How about in other places outside the ICU?	How could your experience have been better?

Part III – Aim 2: Experience with Making End-of-Life Decisions

Questions	**Probes**
8. Can you tell me about your experience making end-of-life decisions for your loved one's care?	In what ways did the healthcare team support you during the end-of-life decision-making process? Can you describe any other supports (inside or outside of the hospital) that helped you with making end-of-life decisions for your loved one? Do you feel that you had all the information that you needed to make decisions for your loved one's care (i.e., risks/benefits)? Can you describe any challenges or barriers that you experienced with making decisions for your loved one's care (i.e., personal limitations, health literacy, etc.)? Do you feel like you had control over decisions for your loved one's care? **For COVID-19 participants:** How did the COVID-19 pandemic impact your experience with making decisions for your loved one?
9. Do you feel that you were able to address your loved one's values and preferences around medical care during the decision-making process? Can you describe specific examples?	Did you or the healthcare team have an opportunity to speak with your loved one about their values and preferences for care? Can you tell me about any challenges or barriers that you experienced with addressing your loved one's values and preferences for care?

10. There are different ways that people like to be involved in decision-making when it comes to their healthcare or care of their loved one. Some people like to be very involved in the decision-making process, while other people prefer that doctors and other healthcare providers take the lead on decision-making by making recommendations. How do you describe your style of how you prefer to be involved in the decision-making process?	In what ways did the healthcare team meet or not meet your needs with how you prefer to be involved with making medical decisions for your loved one? Can you describe a specific example?
11. If you had to explain to someone with no experience in the ICU what it was like to make end-of-life decisions for a loved one, what would you tell them? How about in other places outside the ICU?	How could your experience have been improved?

Part IV – Aim 3: Goal Concordance at the End of Life

Questions	**Probes**
12. What was most important for you and your loved one from a cultural and/or religious perspective?	Can you describe ways in which yours and your loved one's preferences for care were addressed? Can you describe ways in which yours and your loved one's preferences for care were not addressed? Did your loved one die in their location of choice (at home or hospital or other)? **For COVID-19 participants:** How did the COVID-19 pandemic impact how your loved one's goals-of-care were achieved or not achieved?
13. Can you tell me about any challenges or barriers that you experienced with addressing your loved one's values and beliefs for care?	How can efforts to meet cultural and religious preferences for care at the end of life be improved?

14. Overall, do you feel that the care your loved one received was in line with their values, preferences and needs for care? (i.e., was care more or less aggressive preferred)	Are you satisfied with the overall quality and experience of care provided to your loved one? How could your experience have been better?

Part V – Closing

Is there anything that you would like to add that I did not bring up in the interview?

If we have any follow-up questions or need clarification on the some of the information from this interview today, are you okay if I contact you to follow-up on those questions?

Appendix B: Data Collection Template for Healthcare Providers' Notes

Item	Response
Patient care delivery	
How long was the patient in hospital?	
Does the patient meet criteria for chronic critical illness: ≥ 8 days in ICU and one of six qualifying conditions (prolonged mechanical ventilation, tracheostomy, stroke, traumatic brain injury, sepsis, or severe wounds)?	
What types of healthcare providers were interacting with the patient and family/in the circle of care?	
Advance care planning /goals-of-care	
Did the patient have advance care planning (ACP) or goals-of-care documented in the electronic medical record?	
When did ACP or goals-of-care discussion first occur (i.e., upon admission, towards the end, etc.)?	
Did ACP or goals-of-care discussions occur in the absence of physiologic failure?	
How many times were ACP or goals-of-care conversation revisited during the course of patient's stay in hospital?	
With whom did ACP or goals-of-care conversations occur, and who else was present? What format (i.e., in-person, telephone, etc.).	
Cultural/religious factors	
Was culture or religion raised during ACP, goals-of-care or the medical decision-making process and in what context?	
How did healthcare providers in the circle of care try to address cultural or religious needs at the end of life?	
End-of-life care	
When did the pivot from curative to comfort care occur?	

Were family members and healthcare providers in agreement on the pivot towards end-of-life care?	
Was there any tension between the patient/family and healthcare team during the medical decision-making process? If so, what were potential sources of tension?	
Was the care provided to the patient in line with documented goals-of-care?	
Is there evidence of COVID-19 impact on ICU context and/or delivery of care?	

Appendix C: Demographic Characteristics of Family Members

	Family member 1	**Family member 2**	**Family member 3**	**Family member 4**	**Family member 5**
Gender	Male	Female	Female	Female	Male
Race and ethnicity	South Asian	South Asian	South Asian	South Asian	South Asian
Religious sect	Sunni	Sunni	Sunni	Ahmadi	Sunni
Level of religiosity/spirituality [a]	Somewhat	A little	Not at all	Somewhat	A little
Primary language	English	English	English	Other	Other
Secondary language	Other	Other	N/A	English	English
Education	University diploma at bachelor level or above	College, CEGEP[b], or other non-university diploma	College, CEGEP[b], or other non-university diploma	Secondary (high) school diploma	University diploma at bachelor level or above
Relationship to patient	Brother	Daughter	Daughter	Mother	Brother

[a] *Levels of religiosity/spirituality were self-rated (from most to least): very, somewhat, a little, not at all, or do not know.*

[b] *Collège d'enseignement general et professionnel.*

Appendix D: Qualitative Coding Framework

THEMES AND SUBTHEMES	CODE	DEFINITION	OTHER EXEMPLAR QUOTES
Theme 1: Trust and confidence in the healthcare team overseen by medical experts.	**Medical skills**	To have trust and confidence in the [medical skills] of doctors and nurses looking after the patient.	*“The ICU nurses were really incompetent about the nasal tube thing. It had to be one specific nurse who could do it, otherwise it just wouldn't get done. It wouldn’t get done! There were days and days my [parent] had no food.” – Case 2* *“[The doctors] were pretty skilled and knew what was going on and what the outcome was going to be. They were pretty knowledgeable.” – Case 5*
	Continuity of care	To have the same doctors/nurses looking after the patient.	*“I was trying to update [the healthcare providers] because I know the shifts are changing every week and a new [ICU] attending is coming every week, so I can explain [the patient’s medical history]. But they get offended.” – Case 1*
	Clinical support	Medical residents and fellows have adequate clinical support from senior clinicians.	*“[The ICU attending] is on duty. That’s his responsibility, he is the one who is responsible for all of these patients. He can’t sleep if someone is going downhill. If the patient is coding, he can’t stay home in bed!” – Case 1*
Theme 2: Quality communication with medical experts.	**Doctor availability**	That your doctor is available to discuss the patient’s disease with the family.	*“[There was] one [physician] who has amazing because the way he’s communicating with me on an hourly basis, giving me updates and telling me what he’s doing and why he’s doing it – that is a physician.” – Case 1*

			"[They called us] literally like every day. If there is something going on, they let us know that [the patient's] condition is getting worse." – Case 5
	Informational sufficiency	To receive adequate information about the patient's disease and the risks/benefits of treatment	*"The last few days, they were telling us [that our loved one] was having too much medicine which was causing some of his organs to fail or malfunction. They let us know that [the patient's] condition was getting worse, and informed us that [our loved one] might pass away in like a day." – Case 5*
	Honesty	That information about the patient's disease be communicated by the doctor in an honest manner.	*"[The doctor] said to me 'I have the remedy, I'm going to come and fix [your loved one] tomorrow. You'll be fine, inshallah'. Okay, you shouldn't give me that hope. That was really horrible." – Case 2* *"When we reached the hospital, the doctor told us straight. They took us into the room, and told us [your loved one] can't survive. There were too many injuries." – Case 4*
	Language barriers	That information about the patient be communicated in a way that addresses language and communication barriers.	*"The doctor knew this was going to be a hard decision to be made [by our family], so he got somebody to translate it for my [parent]." – Case 5*
Theme 3: Achieving patient goals-of-care.	**Life support**	Not to keep the patient alive on life support when there is little hope for a meaningful recovery.	*"That's one of the first thing they asked me when [my loved one] went to hospital, maybe because of [my parent's] age and everything. They asked if [my loved one] wanted CPR or not. I asked my [parent] and [they] said [they] didn't want it. From that point of*

			view, [their] values and preferences around medical care were addressed." – Case 2 *"Ultimately, my [parent] made [the final] decision because the doctors said there was basically no point of having the ventilator on because the brain was dead… My [parent] said let my [sibling] have a natural death, remove the ventilator and let his heart beat go to zero." – Case 5*
	Relief of symptoms	The patient has relief of physical symptoms such as pain, shortness of breath, nausea.	*"[My loved one] couldn't breathe anymore. Even the highest level of oxygen wasn't helping [the patient] and we didn't want to resuscitate…[My loved one] didn't want that." – Case 2* *"I know [my loved one] was going through a lot of pain, and [the doctors] tried the best... They said without all of these painkillers, [my loved one] would be suffering." – Case 5*
	Decisional support	To receive help to make difficult treatment decisions.	*"I had my brother and my husband there, so they helped me make a decision …I don't believe in sort of taking somebody's life. I would do everything and anything to make that person live." – Case 2* *"[My mom] had some of her family relatives come over to help her think about it... She had my friend, a family friend, and one of her relatives to help her make that decision." – Case 5*
	Exhaustive care	To have a sense that the	*"I wanted to see if she had acute brain injury...*

		healthcare team provided the patient with exhaustive medical care.	*Chances are very minimal, but this is acute brain damage so we can see for a couple of weeks [if there is] any chance to reverse [the injury]. If she has some improvement, then there's a chance. If there's no improvement, then there's no chance." – Case 1*
Theme 4: Dignity of care and respect for cultural and religious values.	**Respect and compassion**	That the care received from healthcare providers is respectful and compassionate.	*"I never ever saw any ICU attending come inside the room and touch my sister. They just stood outside of the door talking to me and then gone. They never looked at her. They were treating the chart and whatever was told to them by the resident and the fellow. I never saw any one of the attendings in ICU remove the sheet and look at her abdomen and other stuff until I asked them to do that." – Case 1*
	Cultural respect	That the care received from healthcare providers is respectful of cultural norms and values.	*"I feel like people from other nationalities might be treated differently… [their] approach is different if it's a different person or a different background. But this should not be [the case], especially in the clinical care." – Case 1* *"In our culture - be it Muslim or South Asian or Oriental - respecting elders is really important, right? Elder respect. The [Canadian] culture does not have that kind of hierarchy where you respect an elder person. When you become an older person, you automatically you get that respect, and my [loved one] was used to that, you see. [My loved one] wasn't treated with that respect at all." – Case 2*
	Religious and	To have your spiritual or	*"Because we're a Muslim family, the hospital allowed*

	spiritual needs	religious needs met.	*us to pray, say the Quran out loud, even though there were other patients, they allowed us to continue because of the final moments of [our loved one]. They respected our culture and allowed us to do whatever is best in our religion and for [our loved one].” – Case 5*
Subtheme 4a: Access to emotional support systems.	**Psychological support**	To have someone listen to the patient/family and be with them when they are feeling sad, frightened, anxious or confused.	*“[My loved one] kept saying: I want a social worker. I want to speak to somebody. I want a psychologist. Please help me. I want to speak to somebody. I'm getting depressed. I'm suffering from depression.” – Case 2*
	Visitor restrictions	To have visitor and family presence in the hospital as a support system for the patient and family.	*“My mother was really saddened that she couldn’t go [visit the patient] as frequently as she wanted to because there was restrictions [on visitors]. It was just me and my [sibling]. I think not seeing my mother was really problematic for [the patient]... Only when [the patient] was dying did they give permission for the entire family [to visit].” – Case 2*