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Exploring the Quality of End-of-Life Care in the Intensive Care Unit: A Multiple Case Study Approach with Family Members of Muslim Patients

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Complete List of Authors:	Nayfeh, Ayah; University of Toronto Conn, Lesley Gotlib; University of Toronto, Institute of Health Policy, Management and Evaluation Dale, Craig; Sunnybrook Research Institute; University of Toronto, Lawrence S. Bloomberg Faculty of Nursing Fowler, Robert; University of Toronto, Interdepartmental Division of Critical Care Medicine; Sunnybrook Health Sciences Centre
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Exploring the Quality of End-of-Life Care in the Intensive Care Unit: A Multiple Case Study Approach with Family Members of Muslim Patients

Keywords

End-of-Life Care, Satisfaction, Quality of Care, Religion, Culture

ABSTRACT

Background: Muslim patients are an underrepresented community in end-of-life care research, with little evidence around factors that influence the medical decision-making process and quality of care. The aim of this study was to explore the quality of end-of-life care in the intensive care unit (ICU) from the perspective of next-of-kin family members of Muslim patients.

Methods: A qualitative multiple case study design using semi-structured interviews was conducted with family members of Muslim patients who were admitted to ICU and died at a large academic tertiary care hospital in Toronto, Canada between October 2019 to December 2021. Data were analysed using deductive content analysis.

Results: Family members of five Muslim patients of South Asian descent were recruited for this study. Four central themes were identified: 1) trust and confidence in the healthcare team overseen by medical experts; 2) quality communication with medical experts; 3) achieving patient goals of care; and 4) dignity of care through cultural respect and emotional support. Culture, religion and religiosity did not appear to have a major influence on the medical decision-making process. Communication, emotional and psychological well-being for patients, and cultural respect were identified as possible areas for quality improvement.

Conclusions: Our findings identified central themes in quality of end-of-life care for families of seriously ill Muslim patients. These insights can inform clinical processes and interventions to improve quality of care and reduce psychological and emotional burden at the end of life.

What is already known on this topic: Racial and ethnic minorities receive more aggressive care at the end of life compared to other patients.

What this study adds: Communication, cultural respect and patient well-being are important factors for the quality and delivery of end-of-life care for seriously ill Muslim patients.

How this study might affect research, practice or policy: Opportunities exist to improve the quality of care and reduce psychological and emotional burden at the end of life for seriously ill Muslim patients and families, including through intensive communication training for ICU nurses and cultural safety and humility skills for ICU staff.

BACKGROUND

Delivering high quality care at the end of life is an essential component of high-functioning health systems. However, with an increasingly multi-cultural and multi-ethnic patient population, there are also increasingly diverse beliefs and values that inform high quality care at the end of life. Research has shown that Black and Hispanic respondents were more likely to express preferences for intensive care at the end of life and were more likely to prefer to die in hospital (1). Varying expectations around end-of-life care could explain observed variation in healthcare utilization at the end of life. In Ontario, Canada, for example, patients of South Asian descent were more likely to die in an intensive care unit (ICU) and received more aggressive care (i.e., mechanical ventilation, dialysis, artificial nutrition, etc.) in the last six months of life compared to other patients (2). Discordance with individual and cultural expectations of care could be contributing to perceptions of lower quality care at the end of life. A recent survey-based study at a large academic tertiary care hospital in Canada found that family members of Muslim patients were less satisfied with the quality of care at the end of life in comparison to other patients (3). It is not clear whether lower ratings of satisfaction for Muslim patients reflect gaps or disparities in the quality of care, or whether it reflects discordance with goals-of-care based on diverse preferences and expectations at the end of life.

Muslims are an underrepresented community in end-of-life care research, with little evidence around factors that influence the medical decision-making process and quality of care. While there is general consensus among both Sunni and Shia Muslims that the withdrawal or withholding of treatment is acceptable if there is no hope for meaningful recovery (4), there is limited knowledge around how characteristics such as race, ethnicity, culture, religious sect and immigration status intersect to influence the trajectory of care. Existing research on key dimensions that comprise quality end-of-life care primarily reflect patients of Caucasian, Protestant and Roman Catholic backgrounds (5,6) and it is unknown whether seriously ill patients from Muslim backgrounds share a similar experience or give equal importance to these items. We therefore sought to address the following research question: *How do family member substitute decision makers of recently deceased Muslim patients describe the quality and experience of end-of-life care in ICU?*

METHODS

Research design

A multiple case study design was used to understand the quality and experience of end-of-life care from the perspective of family member substitute decision-makers (hereinafter referred to as family members) of seriously ill Muslim patients. Case study designs draw upon principles of naturalistic inquiry to gather rich narrative accounts around the experience of a specific person or group and how it unfolds in a natural setting, while also recognizing the researcher's own

background in understanding the research findings (7). The principal investigator and interviewer for this study (AN) was a Palestinian-Canadian woman from a Muslim background and a long-standing first-generation immigrant (25+ years).

Race and ethnicity are multidimensional social constructs. Whereas *race* is defined as a group of people connected by common descent or ancestral origin, *ethnicity* is a distinct concept that is defined by shared culture, language, religion, norms and practices (8). This study uses a unified term of "race and ethnicity" to explore health disparities as relying on physical traits alone may perpetuate the belief that innate racial differences are the primary cause for disparities in health. This construct will be accompanied by other sociodemographic factors such as age, sex, gender, region or country of origin, immigration status, and years spent in Canada to further interrogate intersectionality in the research.

Research setting

This study was conducted at Sunnybrook Health Sciences Centre – a large academic tertiary care hospital in Toronto, Canada that is comprised of approximately 103 critical care beds across seven ICUs. While also important, this study did not focus upon additional intensive care locations that provide care for very specific patient populations (e.g., burned patients, patients with ischemic or congestive cardiac disease).

Sampling

We included family member substitute decision-makers of Muslim patients (≥ 18 years) who were admitted to ICU and subsequently died in-hospital (either in ICU or another hospital unit). Using purposive sampling, we targeted a varied sample according to gender; age; race; ethnicity; primary language; country of origin; immigration status; number of years in Canada; location of death; and cause of illness. In accordance with case study methodology, we aimed to recruit between four and 10 participants. This sample size is based on recommendations that suggest having fewer than four cases in multi-case research limits the rich description of interactivity among cases, whereas more than 10 cases provide more uniqueness of interactivity than researchers can make sense of (9).

Participant identification and recruitment

We identified Muslim patients who were admitted to ICU before (between July 01 2019 to March 31 2020) and after the emergence of COVID-19 (between July 01 2021 to July 31 2022). Each patient's hospital file on the electronic medical record was examined for evidence of Muslim religion via free text search of all fields in the medical record. Recruitment of participants occurred by telephone in close collaboration with healthcare providers who were in the circle of care. One follow-up request was made two weeks after the initial invitation to those who did not respond. Verbal informed consent was obtained from each participant. Compensation was provided to participants in the form of an e-gift card to a local coffee shop.

Data collection

Semi-structured interviews were held between the interviewer (AN) and each participant for approximately 40-50 minutes via passcode-protected videoconferencing or by telephone. There was no relationship between the participants and the interviewer prior to study commencement. Interviews were conducted in English and were audio-recorded to assist with transcription and data analysis. The interview guide included open-ended questions around five key dimensions of quality end-of-life care, as previously identified (6) (Appendix A). This framework was selected for its focus on quality of end-of-life care for seriously ill patients and families in hospital.

We piloted the interview guide with the first three interviews and adjusted wording in consultation with the research team. All cases were included in the final analysis. Field notes capturing reflexive thinking (such as thoughts, ideas and questions) were recorded during each interview and summarized immediately after. These notes were used as supplementary information during data analysis to eliminate or generate additional lines of inquiry. Healthcare providers' notes from the patient medical record were also used to triangulate data and contextualize the patient care experience and medical journey from the perspective of members of the healthcare team (i.e., intensivist-family meeting notes; palliative care; spiritual care; other medical and surgical specialty notes). Data were extracted using a template to gather key details around the patient care journey, such as discourse around treatment decision-making, prognostication, resuscitation status, patient goals-of-care, and other patient and family interactions (Appendix B).

Data analysis

Data were analysed using deductive content analysis (10). A structured categorization matrix was developed using pre-specified codes (28 elements of care) and categories (five key dimensions) from the existing framework on quality end-of-life care for seriously ill patients in hospital (6). Data obtained from healthcare providers' notes were also coded and categorized according to the matrix. Once a segment of text was *deductively* coded and grouped into a category, the content was *inductively* formulated into overarching themes. Data that did not fit the categorization matrix were used to create new codes and categories following the principles of inductive content analysis.

Analytical frameworks from each interview were compared across and within cases through cross-case analysis in order to highlight common experiences, as well as divergent cases that deviated from the dominant narrative. Extensive analytic memos were recorded throughout the data analysis process to document analytic thinking and the interpretation process. Interviews were transcribed verbatim and NVivo 10 software was used to perform data analysis. This study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ).

RESULTS

Among 20 eligible patient decedents, five family members agreed to participate in the interview. Three patients died in 2021 and two died in 2019. Seven family members could not be reached; five had a wrong phone number or missing contact information; and three family members declined study participation. All patients were identified as being of South Asian descent. Patient demographics are reported in Table 1. Four themes emerged from the cross-case analysis. Additional exemplar quotes can be found in Appendix D.

Theme 1: Trust and confidence in the healthcare team overseen by medical experts.

Family members who expressed having trust and confidence in the healthcare team were very satisfied with the quality of care at the end of life (case 3 to 5). In these cases, family trust was established through perceptions of good medical oversight by senior physicians and sufficient skills to provide quality medical care for their loved one. A unifying pattern was that patients in these cases were dealing with serious traumatic injuries or frailty, and there was little hope for a meaningful recovery.

> *"I had absolute trust [in the healthcare team]… on behalf of my [parent], I think they gave [my loved one] the best care possible." – Case 3*

Two family members expressed low satisfaction with the quality of care, due in part to a belief that issues that arose in the ICU were avoidable and/or inadvertently caused by the healthcare team due to inadequate medical skills (cases 1 and 2). Patients in both cases had a long course in hospital that occurred during the pandemic. There was also a belief among one family member that limited continuity of care among healthcare staff had a negative impact on the medical oversight of the patient's care, and a perception that junior clinicians did not have adequate clinical support from more senior clinicians in the hospital (case 1).

> *"The [medical] resident did not know that [my loved one] was not ready for extubation. All they knew was that the attending [doctor] said we need to extubate tonight. They have no clinical judgement, they are residents. That's not their fault, they are just following the attending's order. Their clinical skills aren't as good as attendings." – Case 1*

Theme 2: Quality communication with medical experts.

Timely communication and sufficient information from a medical expert were described as important elements of quality communication and end-of-life care by all family members. This was particularly experienced by family members of patients who were dealing with serious traumatic injuries or frailty and had short stays in hospital (cases 3 to 5). Quality communication between family members and medical experts helped to establish trust with the healthcare team and enabled making decisions to shift from curative to comfort care.

> *"[The doctors] told us what the consequences of this accident could be and what the outcomes could be, whether it was positive or negative. They put us in the right direction of what we could expect in a few days based on [our loved one's] condition." – Case 5*

Among some patients who had prolonged stays in hospital, some family members felt that they did not receive sufficient information on patient prognostication during their stay in hospital (case 1). The patient in this case was dealing with a chronic critical illness (i.e., ≥ 8 days in an ICU), and medical notes indicated that informational insufficiency may have been a result of some uncertainty with patient prognosis.

> *"I asked [the doctors] why did kidney function shutdown? They said we don't know. I said what happened from last night until tonight, did something happen? They said it's possible because [the patient] has leukemia. They're blaming everything on leukemia." – Case 1*

Direct and honest communication with the medical team was also described as an element of good quality care by most family members (cases 2 to 5). For family members of patients who were dealing with serious traumatic injuries or frailty, information on the severity of illness and chances for survival helped with decision-making for life-prolonging treatment (cases 3 to 5).

> *"[The doctor] didn't give us false hope that [my loved one] was going to survive. He gave us a direct answer, with no confusion, on why he thinks [the patient] might not survive. He was pretty clear with his message to us. It made our decision easier." – Case 5*

One family member shared a divergent perspective on the desire for more hope from the healthcare team when dealing with severity and uncertainty in the patient's medical situation (case 1). A distinguishing feature of this case was the family member's clinical background and their preference for transmitting hope in patient-family communication.

> *"I'm a physician (family member)…when I see a patient and they don't have any hope, I give them hope." – Case 1*

Language barriers were also raised as a hindrance to communication by one family member (case 5). Upon admission and throughout the patient's course in hospital, the patient's younger sibling supported language translation between the parent/substitute decision-maker and members of the healthcare team. This was described as being very difficult for this family member.

> *"I was the translator at the time. I didn't know what to tell my [parent] because the doctor was talking to me. At the time, I was sixteen I think, and I was trying to translate that to my [parent] and [they] were freaking out." – Case 5*

There was an appreciation for the professional language translator that was provided by the healthcare team to support the final conversation around the withdrawal of life-prolonging treatment. Language barriers were not raised by other family members whose primary language was not English.

Theme 3: Achieving patient goals-of-care.

Patient goals-of-care were focused on maintaining patient quality of life across most cases through limited use of aggressive treatment when there was little hope for meaningful recovery (cases 2 to 4). A unifying pattern was that patients in these cases were dealing with serious traumatic injuries or frailty. Two frail older patients had a documented do-not-resuscitate (DNR) directive on their medical record (cases 2 and 3) and one patient (45-60 years old) had a documented preference for no limitations in care (case 1). All family members were engaged in goals-of-care conversations when treatments were not meeting the indicated physiological goals. Perceptions of exhaustive medical care seemed to enable concordance between the family and healthcare team around decisions to shift from curative to comfort care.

> *"The doctor came and talked to us and explained that is the decision we have to make. He said if 2-3 doctors say there's no brain activity, then it's called brain death. There is no point to keep the ventilator on. We asked for one extra day and there was no improvement." – Case 4*

For one family, there appeared to be varying expectations around the provision and use of life-prolonging and organ-supporting care for their loved one (case 1). Despite the patient's documented preferences for full care, the family believed that healthcare providers did not utilize all medical options to treat the patient's acute critical condition due to a pre-existing cancer diagnosis. There was a perception that, compared to the US health system, Canada's universal healthcare limited the amount of life-prolonging and organ-supporting treatment that a patient could receive.

> *"I think the healthcare system is very difficult in Canada…because if the outcome is not going to be good, they try to limit resources and let the patient die. This is all covered by government funds." – Case 1*

All family members described seeking support from family, friends and extended relatives to help with making end-of-life decisions. This form of support provided family members with reassurance around plans for care, particularly in cases where relatives had medical backgrounds and could offer a second opinion.

> *"We have two doctors in our family. We sent them all the reports to [another country]. And they said the same thing like what the doctor said…They all said there is no chance [for our loved one] to survive." – Case 4*

Across all cases, family members did not feel that culture or religion were major influential factors in the end-of-life decision-making process or for achieving patient goals-of-care, including among patients who were described as being 'very' or 'somewhat' religious.

> *"Cultural and religious [factors] were not [an important part of the process]. We talked about treatment…We never talked about religion or culture. When [my loved one] was in palliative care, then at that point it became important [for us]. For example, they gave us the Quran and we played the [religious audio]." – Case 1*

Theme 4: Dignity of care through cultural respect and emotional support.

Family members of patients who had a short stay in hospital before death, including one that was admitted during COVID-19, believed that their loved ones were treated with full dignity and respect (cases 3 to 5). In two cases where patients had a prolonged stay in hospital, family members believed that their loved ones were not treated in a respectful or compassionate way (cases 1 and 2). Both of these cases occurred after the emergence of COVID-19 and it was noted by one family member that dignity of care may have been impacted by the pandemic and strains on healthcare staff.

> *"I would go very often and [my loved one's] toes would be sticking out, and I'd cover the toes. Sometimes [the patient's] gown would be undone, like you know, if it's slipping, and I'll come and tighten it around the neck. It was things like that." – Case 2*

This family member also described several instances where the care provided by the healthcare team was not in line with the patient's cultural norms and values (case 2).

> *"There was one nurse who was so horrible... She got me to help change [my parent's] diaper. She wouldn't do it herself, and I mentioned to somebody that you're not supposed to be doing that. My [parent] looked very embarrassed and didn't like that. No, no, his [child]? No, you know the culture." – Case 2*

All family members felt that their religious needs at the end of life were addressed. Across all cases, family members expressed an appreciation for the religious audio that was provided by the hospital and permitted to be played at the patient's bedside. One family member described challenges with finding an imam to provide religious services for their loved one in a timely manner (case 3). However, this experience did not negatively influence perceptions around the quality and experience of care.

> *"By the time [our imam] found parking and came [to the hospital], [my loved one] was gone. I asked [the hospital] if they had an imam that can come before, but they didn't get back to me in time." – Case 3*

Concerns around emotional and psychological well-being were raised by one family member who felt that the healthcare team did not adequately address the patient's mental health needs (case 2). This was documented in the patient's medical record and the patient was seen by staff from the psychiatric care team and prescribed anti-depressant medication. Despite efforts by the healthcare team to alleviate patient depression, the family still had a desire for more *"handholding"* from providers during the patient's long stay in hospital.

> *"[My loved one] wanted to talk to somebody. [My loved one] would have loved to banter or listen to somebody. That would have been so helpful. There wasn't enough handholding." – Case 2*

Visitor restrictions were also raised as a barrier for emotional support and well-being by all family members who had loved ones admitted to ICU during the pandemic (cases 1 to 3). In contrast, family members of patients who died before the pandemic believed that the large presence of family and friends at the hospital was a major source of emotional strength (cases 4 and 5).

> *"There were so many people in the ICU, [the patient's] whole group of friends. We have a huge family, everyone was in the ICU... They stayed the six/seven days that [our loved one] was in ICU." – Case 4*

DISCUSSION:

In this multiple case study comprising family members of Muslim patients admitted to the ICU, we identified four key themes influencing satisfaction with the quality and experience of care: trust and confidence in the healthcare team overseen by medical experts; quality communication with medical experts; achieving patient goals of care; and dignity of care through cultural respect and emotional support. Culture, religion and religiosity did not appear to have a major influence on the medical decision-making process. Discordance around expectations of care seemed to occur in cases where there was high uncertainty with patient prognosis. Patient goals of care were achieved in most cases; however, there may be a need to improve elements of care pertaining to communication, cultural respect, and emotional and psychological well-being for patients.

Overall, our findings are consistent with prior research which identified the following elements of care as most important for seriously ill patients and families: “to have trust and confidence in the doctors looking after you”; “not to be kept alive on life support when there is little hope for a meaningful recovery”; and “information about [the patient’s] disease is communicated in an honest manner” (6). We found that trust and confidence in the healthcare team were influenced by perceptions of clinical oversight by medical experts and quality communication, particularly with the staff intensivist or attending physician. Access to clear and timely information from expert clinicians was highly valued by all participants in our study. These elements of care appeared to enable concordance with decisions to shift from curative to comfort care.

Among family members of patients who had chronic critical illnesses and/or prolonged stays in hospital, we found that there was lower satisfaction with the quality and experience of care in the ICU, due in part to unmet needs for more clear and direct communication with attending physicians. These findings are consistent with prior research which has shown that family members of patients with chronic critical illnesses often describe distress due to perceived diminishing communication with the medical team as the ICU stay became protracted (11). Clinicians who have difficulty managing and communicating uncertainty may also have difficulty calibrating prognostic communication with family, leading to discordance and conveying either overly optimistic or pessimistic messages in relation to their prior expectations (12). Where there was discordance and varying expectations around life-prolonging and organ-supporting treatment in our study, there was indication of unmet communication needs around patient prognosis that could lead to perceptions of less than exhaustive medical care. This finding is consistent with research that suggests that perceived gaps in communication related to prognostic uncertainty can influence perceptions around exhaustive care (13). Clinical practice guidelines recommend that healthcare providers in the ICU target communication skills as a key priority area for quality improvement. For example, ICU nurses can help address family members' desires for more communication around resuscitation goals and prognostic timelines through intensive communication training, particularly in settings where family contact with intensivists can be limited (13).

Patient goals of care in our study were driven primarily by patient quality of life and limited use of life-prolonging treatment when there was little hope for meaningful recovery. When prompted to speak more about the influence of their cultural and religious beliefs on the medical decision-making process and experience of care, there did not appear to be a major impact. This might be explained by acculturation of health behaviors – all patients recruited for this study were long-standing immigrants who had spent at least 15 years in Canada. That we did not observe any notes in patient medical records that touched on ethnocultural aspects around goals of care may also reflect limited knowledge on religious or spiritual needs by the healthcare team; however, our study design does not provide more insight into this possibility. There may be opportunities to enhance cultural safety and humility among healthcare staff to prompt for and document cultural considerations important to the patient and family while engaging in advance care planning or goals-of-care discussions. Language barriers were identified as an additional element of quality end-of-life care that was not previously defined in the existing framework (6). The use of professional language interpreters have been shown to improve clinical outcomes and patient satisfaction compared to ad-hoc interpreters, such as family members or bilingual staff (14).

Overall, our findings align with previous research which suggests that quality ICU care is characterized by high degrees of communication, patient comfort, and having a sense that the medical team provided exhaustive care (6,13). Insights from this research can inform clinical processes and interventions to improve quality of care and reduce psychological and emotional burden at the end of life. Future research should explore additional areas unaddressed in this research, such as how beliefs and attitudes around end-of-life care are influenced by region or country of origin, racial/ethnic background, or level or religiosity/spirituality, and how these factors work in conjunction to influence medical decisions at the end of life.

Strengths and limitations:

The strengths of this study are the use of multiple case study design which enabled rich, detailed narrative understanding of the medical decision-making process and quality-of-care experience for seriously ill Muslim patients. Patients' medical notes were also used to triangulate the medical journey and care context from the perspective of the healthcare providers in the circle of care. Archived patient medical records were important for providing an 'in-the-moment' view of the patient/family encounter.

The positionality of the principal investigator and interviewer for this study is also a strength; being from an Islamic background helped with understanding nuances in the Muslim religion and norms/culture in Muslim-dominant regions to prompt further. Family members may have also felt more comfortable sharing their patient care experience with an interviewer who shared a similar ethnocultural background. The interviewer's role and experience as an end-of-life care researcher was also a strength.

A limitation of this study is that patient religion is not always documented in the patient medical record and eligible participants may have been missed in the screening process. It was also difficult to reach family members of patients who died before the COVID-19 pandemic due to missing or changed contact information. By coincidence, all patients recruited for this study were of South Asian descent and long-standing immigrants who had spent at least 15 years in Canada. We were not able to recruit recent immigrants or Muslim patients from other racial/ethnic backgrounds, religious sects or regions of origin. While theoretical saturation appeared to be achieved at five patient cases with deductive content analysis, we are cognizant of some homogeneity in our sample population and growing debate about the concept of saturation within qualitative research (15). Findings from this study cannot be extended too far beyond their context or generalized to other populations; however, the rich description of participants' perceptions around the patient care experience may be transferable to other healthcare contexts and used to inform future research.

We also did not have access to staffing information before or after the emergence of COVID-19 to help describe the ICU context during specific points in time; however, we know that between July 1 2021 and December 31 2021, visitor restrictions and healthcare human resource shortages may have impacted the quality of communication compared to pre-pandemic practices.

CONCLUSION:

Opportunities exist to improve the quality of care and reduce the psychological and emotional burden at the end of life for seriously ill Muslim patients and families. Future research should explore nuanced areas unaddressed in this research, such as how beliefs and attitudes around end-of-life care are influenced by region or country of origin, racial/ethnic background, or level or religiosity/spirituality, and how these factors work in conjunction to influence medical decisions at the end of life.

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Tables

Table 1 – Demographic and Other Characteristics of Patient Decedents

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5
Age	45-60 years	90+ years	90+ years	20-25 years	20-25 years
Gender	Female	Male	Male	Male	Male
Race/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	Very	A little	Somewhat
Primary language	English	Other	English	Other	Other
Secondary language	Other	English	N/A	English	English
Place of birth	South Asia	South Asia	South America	North America	North America
Immigration status	25+ years	25+ years	25+ years	10-15 years	15-20 years
Education	University diploma at bachelor level or above	University diploma at bachelor level or above	College, CEGEP[c], or other non-university diploma	Secondary (high) school diploma	University diploma at bachelor level or above
Cause of illness	Cancer	Frailty	Frailty	Trauma	Trauma
Type of critical illness [b]	Chronic	Acute	Acute	Acute	Acute
Location of death	ICU	Palliative care	Palliative care	ICU	ICU

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

[b] *Chronic critical illness (CCI) was based on a consensus definition of: ≥ 8 days in an ICU and one of six qualifying conditions (prolonged mechanical ventilation, tracheostomy, stroke, traumatic brain injury, sepsis, or severe wounds).*

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

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

Principal Investigator: Robert Fowler, Sunnybrook Health Sciences Centre, 2075 Bayview Avenue, Office D478, (416) 480-6100 ext. 7471

PhD Student/Sub-Investigator: Ayah Nayfeh, University of Toronto, Dalla Lana School of Public Health, Institute of Health Policy, Management and Evaluation (IHPME), (613) 407-7727

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 high and/or low quality; we would like to understand your experience with making decisions about end-of-life care; and we would like to explore how your loved one's goals and preferences for care were achieved or not achieved.

INTERVIEW QUESTIONS WITH FAMILY MEMBERS:

Part I – Introduction

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

[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 healthcare team provided the patient with exhaustive medical care.	*"I wanted to see if she had acute brain injury... 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 spiritual needs	To have your spiritual or religious needs met.	*"Because we're a Muslim family, the hospital allowed 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*

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Exploring the Quality of End-of-Life Care in the Intensive Care Unit: A Qualitative Multiple Case Study Approach with Family Members of Muslim Patients

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Exploring the Quality of End-of-Life Care in the Intensive Care Unit: A Qualitative Multiple Case Study Approach with Family Members of Muslim Patients

Keywords

End-of-Life Care, Satisfaction, Quality of Care, Religion, Culture

ABSTRACT

Objective: Muslim patients are an underrepresented community in end-of-life care research, with little evidence around factors that influence the quality and experience of care. The aim of this study was to explore the quality of end-of-life care in the intensive care unit (ICU) from the perspective of next-of-kin family members of Muslim patients.

Design: A qualitative multiple case study design using semi-structured interviews with family members of Muslim patients. Healthcare providers' notes from the patient medical record were also used to contextualize the patient care experience and medical journey. Data were analysed using deductive content analysis.

Participants: Next-of-kin family members of Muslim patients (≥ 18 years) who were admitted to ICU and died in hospital between October 2019 to December 2021.

Setting: A large academic tertiary care hospital in Toronto, Canada.

Results: Family members of five Muslim patients of South Asian descent were recruited for this study. Four central themes were identified: 1) trust and confidence in the healthcare team overseen by medical experts; 2) quality communication with medical experts; 3) achieving patient goals of care; and 4) dignity of care through cultural respect and emotional support. Culture, religion and religiosity did not appear to have a major influence on the medical decision-making process. Communication, emotional and psychological well-being for patients, and cultural respect were identified as possible areas for quality improvement.

Conclusions: Our findings identified central themes in quality of end-of-life care for families of seriously ill Muslim patients. These insights can inform clinical processes and interventions to improve quality of care and reduce psychological and emotional burden at the end of life.

Strengths and limitations of this study:

- The use of a qualitative multiple case study design and multiple sources of data enabled a deep dive into the quality and experience of care for Muslim patients and families.
- Archived patient medical records were important for providing an 'in-the-moment' view of the patient/family encounter from the perspective of healthcare providers who were in the circle of care.
- Patient religion was not always documented in the patient medical record and eligible participants may have been missed in the screening and identification process.
- There is limited demographic variability in the sample population for this study to explore related concepts. Future research should explore areas unaddressed in this research, including how beliefs and values around end-of-life care are influenced by region or country of origin, racial/ethnic background, or level or religiosity/spirituality.

BACKGROUND

Delivering high quality care at the end of life is an essential component of high-functioning health systems. However, with an increasingly multi-cultural and multi-ethnic patient population, there are also increasingly diverse beliefs and values that inform high quality care at the end of life. Research has shown that Black and Hispanic respondents were more likely to express preferences for intensive care at the end of life and were more likely to prefer to die in hospital [1] . Varying expectations around end-of-life care could explain observed variation in healthcare utilization at the end of life. In Ontario, Canada, for example, patients of South Asian descent were more likely to die in an intensive care unit (ICU) and received more aggressive care (i.e., mechanical ventilation, dialysis, artificial nutrition, etc.) in the last six months of life compared to other patients [2]. Discordance with individual and cultural expectations of care could be contributing to perceptions of lower quality care at the end of life. A recent survey-based study at a large academic tertiary care hospital in Canada found that family members of Muslim patients were less satisfied with the quality of care at the end of life in comparison to other patients [3]. It is not clear whether lower ratings of satisfaction for Muslim patients reflect gaps or disparities in the quality of care, or whether it reflects discordance with goals-of-care based on diverse preferences and expectations at the end of life.

Muslims are an underrepresented community in end-of-life care research, with little evidence around factors that influence the medical decision-making process and quality of care. While there is general consensus among both Sunni and Shia Muslims that the withdrawal or withholding of treatment is acceptable if there is no hope for meaningful recovery [4], there is limited knowledge around how characteristics such as race, ethnicity, culture, religious sect and immigration status intersect to influence the trajectory of care. Existing research on key dimensions that comprise quality end-of-life care primarily reflect patients of Caucasian, Protestant and Roman Catholic backgrounds [5,6] and it is unknown whether seriously ill patients from Muslim backgrounds share a similar experience or give equal importance to these items. We therefore sought to address the following research question: *How do family member substitute decision makers of recently deceased Muslim patients describe the quality and experience of end-of-life care in ICU?*

METHODS

Research design

A multiple case study design was used to understand the quality and experience of end-of-life care from the perspective of family member substitute decision-makers (hereinafter referred to as family members) of seriously ill Muslim patients. Case study designs draw upon principles of naturalistic inquiry to gather rich narrative accounts around the experience of a specific person or group and how it unfolds in a natural setting, while also recognizing the researcher's own

background in understanding the research findings [7]. The principal investigator and interviewer for this study (AN) was a Palestinian-Canadian woman from a Muslim background and a long-standing first-generation immigrant (25+ years).

Race and ethnicity are multidimensional social constructs. Whereas *race* is defined as a group of people connected by common descent or ancestral origin, *ethnicity* is a distinct concept that is defined by shared culture, language, religion, norms and practices [8]. This study uses a unified term of "race and ethnicity" to explore health disparities as relying on physical traits alone may perpetuate the belief that innate racial differences are the primary cause for disparities in health. This construct will be accompanied by other sociodemographic factors such as age, sex, gender, region or country of origin, immigration status, and years spent in Canada to further interrogate intersectionality in the research.

Research setting

This study was conducted at Sunnybrook Health Sciences Centre – a large academic tertiary care hospital in Toronto, Canada that is comprised of approximately 103 critical care beds across seven ICUs. We deliberately focused on the ICU setting to explore end-of-life decision-making at its most pointed relevance. Patients admitted in ICU typically experience a more sudden or acute illness trajectory which often requires timely decision-making around life-prolonging measures such as CPR and mechanical ventilation. While also important, this study did not focus upon additional intensive care locations that provide care for very specific patient populations (e.g., burned patients, patients with ischemic or congestive cardiac disease).

In terms of demographic make-up, foreign-born immigrants (46.6%) and visible minorities (55.7%) comprised nearly half of the Toronto population [9]. South Asian (14%), Chinese (10.7%) and Black (9.6%) were the three largest visible minority groups in Toronto. After Christianity (46.2%), Muslim (9.6%), Hindu (6.2%) and Jewish (3.6%) were the three largest religious groups in Toronto [9].

Sampling

We included family member substitute decision-makers of Muslim patients (≥ 18 years) who were admitted to ICU and subsequently died in-hospital (either in ICU or another hospital unit). Using purposive sampling, we targeted a varied sample according to gender; age; race; ethnicity; primary language; country of origin; immigration status; number of years in Canada; location of death; and cause of illness. In accordance with case study methodology, we aimed to recruit between four and 10 participants, or until data reached theoretical saturation whereby the incorporation of new data provided no new theoretical insights. This sample size is based on recommendations that suggest having fewer than four cases in multi-case research limits the rich description of interactivity among cases, whereas more than 10 cases provide more uniqueness of interactivity than researchers can make sense of [10].

Participant identification and recruitment

We identified Muslim patients who were admitted to ICU before (between July 01 2019 to March 31 2020) and after the emergence of COVID-19 (between July 01 2021 to July 31 2022). Each patient's hospital file on the electronic medical record was examined for evidence of Muslim religion via free text search of all fields in the medical record. Recruitment of participants occurred by telephone in close collaboration with healthcare providers who were in the circle of care. One follow-up request was made two weeks after the initial invitation to those who did not respond. Verbal informed consent was obtained from each participant. Compensation was provided to participants in the form of an e-gift card to a local coffee shop.

Data collection

Semi-structured interviews were held between the interviewer (AN) and each participant for approximately 40-50 minutes via passcode-protected videoconferencing or by telephone. Interviews took place between August and November 2022. There was no relationship between the participants and the interviewer prior to study commencement. Interviews were conducted in English and were audio-recorded to assist with transcription and data analysis. The interview guide included open-ended questions around five key dimensions of quality end-of-life care, as previously identified [6] (Appendix A). This framework was selected for its focus on quality of end-of-life care for seriously ill patients and families in hospital.

We piloted the interview guide with the first three interviews and adjusted wording in consultation with the research team. All cases were included in the final analysis. Field notes capturing reflexive thinking (such as thoughts, ideas and questions) were recorded during each interview and summarized immediately after. These notes were used as supplementary information during data analysis to eliminate or generate additional lines of inquiry. Healthcare providers' notes from the patient medical record were also used to triangulate data and contextualize the patient care experience and medical journey from the perspective of members of the healthcare team (i.e., intensivist-family meeting notes; palliative care; spiritual care; other medical and surgical specialty notes). Following each interview, data were extracted from the patient medical record using a template to gather key details around the patient care journey, such as discourse around treatment decision-making, prognostication, resuscitation status, patient goals-of-care, and other patient and family interactions (Appendix B).

Data analysis

Data were analysed using deductive content analysis [11]. A structured categorization matrix was developed using pre-specified codes (28 elements of care) and categories (five key dimensions) from the existing framework on quality end-of-life care for seriously ill patients in hospital [6]. Data obtained from healthcare providers' notes were also coded and categorized according to the matrix. These lines of data were used to expand upon and provide complementary insight into the patient care journey and healthcare experience gathered during the interview process. Once a segment of text was *deductively* coded and grouped into a category, the content was *inductively* formulated into overarching themes. Data that did not fit the categorization matrix were used to create new codes and categories following the principles of inductive content analysis.

Analytical frameworks from each interview were compared across and within cases through cross-case analysis in order to highlight common experiences, as well as divergent cases that deviated from the dominant narrative. Extensive analytic memos were recorded throughout the data analysis process to document analytic thinking and the interpretation process. Feedback from the research team also helped to expand the analytical process. Interviews were transcribed verbatim and NVivo 10 software was used to perform data analysis. This study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) [12].

Ethics approval

Ethical review and approval were received from Sunnybrook's Research Ethics Board in May 2020 (#025-2020) and the University of Toronto in April 2021 (#40926).

Patient and public involvement

Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans as it pertains to this research.

RESULTS

Among 20 eligible patient decedents, five family members agreed to participate in the interview (Appendix C). Three patients died in 2021 and two died in 2019. Seven family members could not be reached; five had a wrong phone number or missing contact information; and three family members declined study participation. All patients were identified as being of South Asian descent. Patient demographics are reported in Table 1. Four themes emerged from the cross-case analysis. Additional exemplar quotes can be found in Appendix D.

Theme 1: Trust and confidence in the healthcare team overseen by medical experts.

Family members who expressed having trust and confidence in the healthcare team were very satisfied with the quality of care at the end of life (case 3 to 5). In these cases, family trust was established through perceptions of good medical oversight by senior physicians and sufficient skills to provide quality medical care for their loved one. A unifying pattern was that patients in these cases were dealing with serious traumatic injuries or frailty, and there was little hope for a meaningful recovery.

> *"I had absolute trust [in the healthcare team]… on behalf of my [parent], I think they gave [my loved one] the best care possible." – Case 3*

Two family members expressed low satisfaction with the quality of care, due in part to a belief that issues that arose in the ICU were avoidable and/or inadvertently caused by the healthcare team due to inadequate medical skills (cases 1 and 2). Patients in both cases had a long course in hospital that occurred during the pandemic. There was also a belief among one family member that limited continuity of care among healthcare staff had a negative impact on the medical oversight of the patient's care, and a perception that junior clinicians did not have adequate clinical support from more senior clinicians in the hospital (case 1).

> *"The [medical] resident did not know that [my loved one] was not ready for extubation. All they knew was that the attending [doctor] said we need to extubate tonight. They have no clinical judgement, they are residents. That's not their fault, they are just following the attending's order. Their clinical skills aren't as good as attendings." – Case 1*

Theme 2: Quality communication with medical experts.

Timely communication and sufficient information from a medical expert were described as important elements of quality communication and end-of-life care by all family members. This was particularly experienced by family members of patients who were dealing with serious traumatic injuries or frailty and had short stays in hospital (cases 3 to 5). Quality communication between family members and medical experts helped to establish trust with the healthcare team and enabled making decisions to shift from curative to comfort care.

> *"[The doctors] told us what the consequences of this accident could be and what the outcomes could be, whether it was positive or negative. They put us in the right direction of what we could expect in a few days based on [our loved one's] condition." – Case 5*

Among some patients who had prolonged stays in hospital, some family members felt that they did not receive sufficient information on patient prognostication during their stay in hospital (case 1). The patient in this case was dealing with a chronic critical illness (i.e., ≥ 8 days in an ICU), and medical notes indicated that informational insufficiency may have been a result of some uncertainty with patient prognosis.

> *“I asked [the doctors] why did kidney function shutdown? They said we don’t know. I said what happened from last night until tonight, did something happen? They said it’s possible because [the patient] has leukemia. They’re blaming everything on leukemia.” – Case 1*

Direct and honest communication with the medical team was also described as an element of good quality care by most family members (cases 2 to 5). For family members of patients who were dealing with serious traumatic injuries or frailty, information on the severity of illness and chances for survival helped with decision-making for life-prolonging treatment (cases 3 to 5).

> *“[The doctor] didn't give us false hope that [my loved one] was going to survive. He gave us a direct answer, with no confusion, on why he thinks [the patient] might not survive. He was pretty clear with his message to us. It made our decision easier.” – Case 5*

One family member shared a divergent perspective on the desire for more hope from the healthcare team when dealing with severity and uncertainty in the patient’s medical situation (case 1). A distinguishing feature of this case was the family member’s clinical background and their preference for transmitting hope in patient-family communication.

> *“I’m a physician (family member)…when I see a patient and they don’t have any hope, I give them hope.” – Case 1*

Language barriers were also raised as a hindrance to communication by one family member (case 5). Upon admission and throughout the patient’s course in hospital, the patient’s younger sibling supported language translation between the parent/substitute decision-maker and members of the healthcare team. This was described as being very difficult for this family member.

> *“I was the translator at the time. I didn't know what to tell my [parent] because the doctor was talking to me. At the time, I was sixteen I think, and I was trying to translate that to my [parent] and [they] were freaking out.” – Case 5*

There was an appreciation for the professional language translator that was provided by the healthcare team to support the final conversation around the withdrawal of life-prolonging treatment. Language barriers were not raised by other family members whose primary language was not English.

Theme 3: Achieving patient goals-of-care.

Patient goals-of-care were focused on maintaining patient quality of life across most cases through limited use of aggressive treatment when there was little hope for meaningful recovery (cases 2 to 4). A unifying pattern was that patients in these cases were dealing with serious traumatic injuries or frailty. Two frail older patients had a documented do-not-resuscitate (DNR) directive on their medical record (cases 2 and 3) and one patient (45-60 years old) had a documented preference for no limitations in care (case 1). All family members were engaged in goals-of-care conversations when treatments were not meeting the indicated physiological goals. Perceptions of exhaustive medical care seemed to enable concordance between the family and healthcare team around decisions to shift from curative to comfort care.

> *"The doctor came and talked to us and explained that is the decision we have to make. He said if 2-3 doctors say there's no brain activity, then it's called brain death. There is no point to keep the ventilator on. We asked for one extra day and there was no improvement." – Case 4*

For one family, there appeared to be varying expectations around the provision and use of life-prolonging and organ-supporting care for their loved one (case 1). Despite the patient's documented preferences for full care, the family believed that healthcare providers did not utilize all medical options to treat the patient's acute critical condition due to a pre-existing cancer diagnosis. There was a perception that, compared to the US health system, Canada's universal healthcare limited the amount of life-prolonging and organ-supporting treatment that a patient could receive.

> *"I think the healthcare system is very difficult in Canada…because if the outcome is not going to be good, they try to limit resources and let the patient die. This is all covered by government funds." – Case 1*

All family members described seeking support from family, friends and extended relatives to help with making end-of-life decisions. This form of support provided family members with reassurance around plans for care, particularly in cases where relatives had medical backgrounds and could offer a second opinion.

> *"We have two doctors in our family. We sent them all the reports to [another country]. And they said the same thing like what the doctor said…They all said there is no chance [for our loved one] to survive." – Case 4*

Across all cases, family members did not feel that culture or religion were major influential factors in the end-of-life decision-making process or for achieving patient goals-of-care, including among patients who were described as being ‘very’ or ‘somewhat’ religious.

> *“Cultural and religious [factors] were not [an important part of the process]. We talked about treatment…We never talked about religion or culture. When [my loved one] was in palliative care, then at that point it became important [for us]. For example, they gave us the Quran and we played the [religious audio].” – Case 1*

Theme 4: Dignity of care through cultural respect and emotional support.

Family members of patients who had a short stay in hospital before death, including one that was admitted during COVID-19, believed that their loved ones were treated with full dignity and respect (cases 3 to 5). In two cases where patients had a prolonged stay in hospital, family members believed that their loved ones were not treated in a respectful or compassionate way (cases 1 and 2). Both of these cases occurred after the emergence of COVID-19 and it was noted by one family member that dignity of care may have been impacted by the pandemic and strains on healthcare staff.

> *“I would go very often and [my loved one’s] toes would be sticking out, and I'd cover the toes. Sometimes [the patient’s] gown would be undone, like you know, if it’s slipping, and I’ll come and tighten it around the neck. It was things like that.” – Case 2*

This family member also described several instances where the care provided by the healthcare team was not in line with the patient’s cultural norms and values (case 2).

> *“There was one nurse who was so horrible… She got me to help change [my parent's] diaper. She wouldn't do it herself, and I mentioned to somebody that you're not supposed to be doing that. My [parent] looked very embarrassed and didn't like that. No, no, his [child]? No, you know the culture.” – Case 2*

All family members felt that their religious needs at the end of life were addressed. Across all cases, family members expressed an appreciation for the religious audio that was provided by the hospital and permitted to be played at the patient’s bedside. One family member described challenges with finding an imam to provide religious services for their loved one in a timely manner (case 3). However, this experience did not negatively influence perceptions around the quality and experience of care.

> *"By the time [our imam] found parking and came [to the hospital], [my loved one] was gone. I asked [the hospital] if they had an imam that can come before, but they didn't get back to me in time." – Case 3*

Concerns around emotional and psychological well-being were raised by one family member who felt that the healthcare team did not adequately address the patient's mental health needs (case 2). This was documented in the patient's medical record and the patient was seen by staff from the psychiatric care team and prescribed anti-depressant medication. Despite efforts by the healthcare team to alleviate patient depression, the family still had a desire for more *"handholding"* from providers during the patient's long stay in hospital.

> *"[My loved one] wanted to talk to somebody. [My loved one] would have loved to banter or listen to somebody. That would have been so helpful. There wasn't enough handholding." – Case 2*

Visitor restrictions were also raised as a barrier for emotional support and well-being by all family members who had loved ones admitted to ICU during the pandemic (cases 1 to 3). In contrast, family members of patients who died before the pandemic believed that the large presence of family and friends at the hospital was a major source of emotional strength (cases 4 and 5).

> *"There were so many people in the ICU, [the patient's] whole group of friends. We have a huge family, everyone was in the ICU... They stayed the six/seven days that [our loved one] was in ICU." – Case 4*

DISCUSSION:

In this multiple case study comprising family members of Muslim patients admitted to the ICU, we identified four key themes influencing satisfaction with the quality and experience of care: trust and confidence in the healthcare team overseen by medical experts; quality communication with medical experts; achieving patient goals of care; and dignity of care through cultural respect and emotional support. Culture, religion and religiosity did not appear to have a major influence on the medical decision-making process. Discordance around expectations of care seemed to occur in cases where there was high uncertainty with patient prognosis. Patient goals of care were achieved in most cases; however, there may be a need to improve elements of care pertaining to communication, cultural respect, and emotional and psychological well-being for patients.

Overall, our findings are consistent with prior research which identified the following elements of care as most important for seriously ill patients and families: "to have trust and confidence in the doctors looking after you"; "not to be kept alive on life support when there is little hope for a meaningful recovery"; and "information about [the patient's] disease is communicated in an honest manner" [6]. We found that trust and confidence in the healthcare team were influenced by perceptions of clinical oversight by medical experts and quality communication, particularly with the staff intensivist or attending physician. Access to clear and timely information from expert clinicians was highly valued by all participants in our study. These elements of care appeared to enable concordance with decisions to shift from curative to comfort care.

Among family members of patients who had chronic critical illnesses and/or prolonged stays in hospital, we found that there was lower satisfaction with the quality and experience of care in the ICU, due in part to unmet needs for more clear and direct communication with attending physicians. These findings are consistent with prior research which has shown that family members of patients with chronic critical illnesses often describe distress due to perceived diminishing communication with the medical team as the ICU stay became protracted [13]. Clinicians who have difficulty managing and communicating uncertainty may also have difficulty calibrating prognostic communication with family, leading to discordance and conveying either overly optimistic or pessimistic messages in relation to their prior expectations [14]. Where there was discordance and varying expectations around life-prolonging and organ-supporting treatment in our study, there was indication of unmet communication needs around patient prognosis that could lead to perceptions of less than exhaustive medical care. This finding is consistent with research that suggests that perceived gaps in communication related to prognostic uncertainty can influence perceptions around exhaustive care [15]. Clinical practice guidelines recommend that healthcare providers in the ICU target communication skills as a key priority area for quality improvement. For example, ICU nurses can help address family members' desires for more communication around resuscitation goals and prognostic timelines through intensive communication training, particularly in settings where family contact with intensivists can be limited [15].

Patient goals of care in our study were driven primarily by patient quality of life and limited use of life-prolonging treatment when there was little hope for meaningful recovery. When prompted to speak more about the influence of their cultural and religious beliefs on the medical decision-making process, there did not appear to be a major impact. This might be explained by acculturation of health behaviors – all patients recruited for this study were long-standing immigrants who had spent at least 15 years in Canada. That we did not observe any notes in patient medical records that touched on ethnocultural aspects around goals of care may also reflect limited knowledge on religious or spiritual needs by the healthcare team; however, our study design does not provide more insight into this possibility.

While culture, religion and religiosity did not appear to have a major influence on the medical decision-making process, respect for cultural and religious values was identified as an important element of quality care for Muslim patients and families. Perceived failure to acknowledge or address ethnocultural beliefs and values at the end of life appeared to have contributed to loss of trust and lower satisfaction with the quality and experience of care. There may be opportunities to enhance cultural safety and humility among healthcare staff to prompt for and document cultural considerations important to the patient and family while engaging in advance care planning or goals-of-care discussions. Language barriers were identified as an additional element of quality end-of-life care for Muslim patients that was not previously defined in the existing framework [6]. The use of professional language interpreters have been shown to improve clinical outcomes and patient satisfaction compared to ad-hoc interpreters, such as family members or bilingual staff [16].

Overall, our findings align with previous research which suggests that quality ICU care is characterized by high degrees of communication, patient comfort, and having a sense that the medical team provided exhaustive care [6,15]. Insights from this research can inform clinical processes and interventions to improve quality of care, enhance cultural safety and humility, and reduce psychological and emotional burden at the end of life. Future research should explore additional areas unaddressed in this research, such as how beliefs and attitudes around end-of-life care are influenced by region or country of origin, racial/ethnic background, or level or religiosity/spirituality, and how these factors work in conjunction to influence medical decisions at the end of life.

Strengths and limitations:

The strengths of this study are the use of multiple case study design which enabled rich, detailed narrative understanding of the medical decision-making process and quality-of-care experience for seriously ill Muslim patients. Patients' medical notes were also used to triangulate the medical journey and care context from the perspective of the healthcare providers in the circle of care. Archived patient medical records were important for providing an 'in-the-moment' view of the patient/family encounter.

The positionality of the principal investigator and interviewer for this study is also a strength; being from an Islamic background helped with understanding nuances in the Muslim religion and norms/culture in Muslim-dominant regions to prompt further. Practicing reflexivity was particularly important for surfacing personal experience, values and beliefs and acknowledging areas where responses could be interpreted in a certain way. For example, topics that resonated or triggered emotional reactions were noted and enabled labelling of experience (i.e., seeing sick parent in a disheveled state). Family members may have also felt more comfortable sharing their patient care experience with an interviewer who shared a similar ethnocultural background. The interviewer's role and experience as an end-of-life care researcher was also a strength.

A limitation of this study is that patient religion is not always documented in the patient medical record and eligible participants may have been missed in the screening process. It was also difficult to reach family members of patients who died before the COVID-19 pandemic due to missing or changed contact information. By coincidence, all patients recruited for this study were of South Asian descent and long-standing immigrants who had spent at least 15 years in Canada. We were not able to recruit recent immigrants or Muslim patients from other racial/ethnic backgrounds, religious sects or regions of origin. Most patient decedents were also male and most were highly educated which may have also had an impact on the end-of-life care experience and delivery of care. While theoretical saturation appeared to be achieved at five patient cases with deductive content analysis, we are cognizant of some homogeneity in our sample population and growing debate about the concept of saturation within qualitative research [17]. Findings from this study cannot be extended too far beyond their context or generalized to other populations; however, the rich description of participants' perceptions around the patient care experience may be transferable to other healthcare contexts and used to inform future research.

We also did not have access to healthcare worker demographics or staffing information before or after the emergence of COVID-19 to help describe the ICU context during specific points in time; however, we know that between July 1 2021 and December 31 2021, visitor restrictions and healthcare human resource shortages may have impacted the quality of communication compared to pre-pandemic practices.

CONCLUSION:

Opportunities exist to improve the quality of care and reduce the psychological and emotional burden at the end of life for seriously ill Muslim patients and families. Future research should explore nuanced areas unaddressed in this research, such as how beliefs and attitudes around end-of-life care are influenced by region or country of origin, racial/ethnic background, or level or religiosity/spirituality, and how these factors work in conjunction to influence medical decisions at the end of life.

CONTRIBUTORS

AN, RF, LGC and CD conceptualized the study. AN, RF, LGC and CD developed the methodology and analytical plan. AN undertook data analysis assisted by RF, LGC and CD. AN, RF, LGC, and CD contributed to final analysis and interpretation of the data. RF acted as guarantor. All authors read and approved the final manuscript.

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COMPETING INTERESTS

None declared.

DATA AVAILABILITY

No additional data available.

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Tables

Table 1 – Demographic and Other Characteristics of Patient Decedents

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5
Age	45-60 years	90+ years	90+ years	20-25 years	20-25 years
Gender	Female	Male	Male	Male	Male
Religious sect	Sunni	Sunni	Sunni	Ahmadi	Sunni
Level of religiosity/spirituality [a]	Somewhat	A little	Very	A little	Somewhat
Primary language	English	Other	English	Other	Other
Secondary language	Other	English	N/A	English	English
Immigration status	25+ years	25+ years	25+ years	10-15 years	15-20 years
Education	University diploma at bachelor level or above	University diploma at bachelor level or above	College, CEGEP[c], or other non-university diploma	Secondary (high) school diploma	University diploma at bachelor level or above
Cause of illness	Cancer	Frailty	Frailty	Trauma	Trauma
Type of critical illness [b]	Chronic	Acute	Acute	Acute	Acute
Location of death	ICU	Palliative care	Palliative care	ICU	ICU

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

[b] *Chronic critical illness (CCI) was based on a consensus definition of: ≥ 8 days in an ICU and one of six qualifying conditions (prolonged mechanical ventilation, tracheostomy, stroke, traumatic brain injury, sepsis, or severe wounds).*

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

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

Principal Investigator: Robert Fowler, Sunnybrook Health Sciences Centre, 2075 Bayview Avenue, Office D478, (416) 480-6100 ext. 7471

PhD Student/Sub-Investigator: Ayah Nayfeh, University of Toronto, Dalla Lana School of Public Health, Institute of Health Policy, Management and Evaluation (IHPME), (613) 407-7727

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 high and/or low quality; we would like to understand your experience with making decisions about end-of-life care; and we would like to explore how your loved one's goals and preferences for care were achieved or not achieved.

INTERVIEW QUESTIONS WITH FAMILY MEMBERS:

Part I – Introduction

Questions	Probes
1. Can you tell me a little bit about your loved one's medical journey?	Was the illness something that was sudden/unexpected or more gradual (i.e., developed over time)?
2. Can you tell me about you and your loved one's racial, ethnic, cultural, and religious background?	Were you and your loved one born inside or outside of Canada? ○ (If outside) what is the country of origin? How important was culture or religion 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 healthcare team provided the patient with exhaustive medical care.	*"I wanted to see if she had acute brain injury... 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 spiritual needs	To have your spiritual or religious needs met.	*"Because we're a Muslim family, the hospital allowed 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*

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Exploring the quality of end-of-life care in the intensive care unit: a qualitative multiple case study approach with family members of Muslim patients

ABSTRACT

Objective: Muslim patients are an underrepresented community in end-of-life care research, with little evidence around factors that influence the quality and experience of care. The aim of this study was to explore the quality of end-of-life care in the intensive care unit (ICU) from the perspective of next-of-kin family members of Muslim patients.

Design: A qualitative multiple case study design using semi-structured interviews with family members of Muslim patients. Healthcare providers' notes from the patient medical record were also used to contextualize the patient care experience and medical journey. Data were analysed using deductive content analysis.

Setting: A large academic tertiary care hospital in Toronto, Canada.

Participants: Next-of-kin family members of Muslim patients (≥ 18 years) who were admitted to ICU and died in hospital between October 2019 to December 2021.

Results: Family members of five Muslim patients of South Asian descent were recruited for this study. Four central themes were identified: 1) trust and confidence in the healthcare team overseen by medical experts; 2) quality communication with medical experts; 3) achieving patient goals of care; and 4) dignity of care through cultural respect and emotional support. Culture, religion and religiosity did not appear to have a major influence on the medical decision-making process. Communication, emotional and psychological well-being for patients, and cultural respect were identified as possible areas for quality improvement.

Conclusions: Our findings identified central themes in quality of end-of-life care for families of seriously ill Muslim patients. These insights can inform clinical processes and interventions to improve quality of care and reduce psychological and emotional burden at the end of life.

Keywords
End-of-Life Care, Satisfaction, Quality of Care, Religion, Culture

Strengths and limitations of this study

- The use of a qualitative multiple case study design and multiple sources of data enabled a deep dive into the quality and experience of care for Muslim patients and families.
- Archived patient medical records were important for providing an 'in-the-moment' view of the patient/family encounter from the perspective of healthcare providers who were in the circle of care.
- Patient religion was not always documented in the patient medical record and eligible participants may have been missed in the screening and identification process.

- There is limited demographic variability in the sample population for this study to explore how the end-of-life care experience is influenced by region or country of origin, racial/ethnic background, or level or religiosity/spirituality.

INTRODUCTION

Delivering high quality care at the end of life is an essential component of high-functioning health systems. However, with an increasingly multi-cultural and multi-ethnic patient population, there are also increasingly diverse beliefs and values that inform high quality care at the end of life. Research has shown that Black and Hispanic respondents were more likely to express preferences for intensive care at the end of life and were more likely to prefer to die in hospital [1] . Varying expectations around end-of-life care could explain observed variation in healthcare utilization at the end of life. In Ontario, Canada, for example, patients of South Asian descent were more likely to die in an intensive care unit (ICU) and received more aggressive care (i.e., mechanical ventilation, dialysis, artificial nutrition, etc.) in the last six months of life compared to other patients [2]. Discordance with individual and cultural expectations of care could be contributing to perceptions of lower quality care at the end of life. A recent survey-based study at a large academic tertiary care hospital in Canada found that family members of Muslim patients were less satisfied with the quality of care at the end of life in comparison to other patients [3]. It is not clear whether lower ratings of satisfaction for Muslim patients reflect gaps or disparities in the quality of care, or whether it reflects discordance with goals-of-care based on diverse preferences and expectations at the end of life.

Muslims are an underrepresented community in end-of-life care research, with little evidence around factors that influence the medical decision-making process and quality of care. While there is general consensus among both Sunni and Shia Muslims that the withdrawal or withholding of treatment is acceptable if there is no hope for meaningful recovery [4], there is limited knowledge around how characteristics such as race, ethnicity, culture, religious sect and immigration status intersect to influence the trajectory of care. Existing research on key dimensions that comprise quality end-of-life care primarily reflect patients of Caucasian, Protestant and Roman Catholic backgrounds [5,6] and it is unknown whether seriously ill patients from Muslim backgrounds share a similar experience or give equal importance to these items. We therefore sought to address the following research question: *How do family member substitute decision makers of recently deceased Muslim patients describe the quality and experience of end-of-life care in ICU?*

METHODS

Research design

A multiple case study design was used to understand the quality and experience of end-of-life care from the perspective of family member substitute decision-makers (hereinafter referred to as family members) of seriously ill Muslim patients. Case study designs draw upon principles of naturalistic inquiry to gather rich narrative accounts around the experience of a specific person or group and how it unfolds in a natural setting, while also recognizing the researcher's own

background in understanding the research findings [7]. The principal investigator and interviewer for this study (AN) was a Palestinian-Canadian woman from a Muslim background and a long-standing first-generation immigrant (25+ years).

Race and ethnicity are multidimensional social constructs. Whereas *race* is defined as a group of people connected by common descent or ancestral origin, *ethnicity* is a distinct concept that is defined by shared culture, language, religion, norms and practices [8]. This study uses a unified term of “race and ethnicity” to explore health disparities as relying on physical traits alone may perpetuate the belief that innate racial differences are the primary cause for disparities in health. This construct will be accompanied by other sociodemographic factors such as age, sex, gender, region or country of origin, immigration status, and years spent in Canada to further interrogate intersectionality in the research.

Study setting

This study was conducted at Sunnybrook Health Sciences Centre – a large academic tertiary care hospital in Toronto, Canada that is comprised of approximately 103 critical care beds across seven ICUs. We deliberately focused on the ICU setting to explore end-of-life decision-making at its most pointed relevance. Patients admitted in ICU typically experience a more sudden or acute illness trajectory which often requires timely decision-making around life-prolonging measures such as CPR and mechanical ventilation. While also important, this study did not focus upon additional intensive care locations that provide care for very specific patient populations (e.g., burned patients, patients with ischemic or congestive cardiac disease).

In terms of demographic make-up, foreign-born immigrants (46.6%) and visible minorities (55.7%) comprised nearly half of the Toronto population [9]. South Asian (14%), Chinese (10.7%) and Black (9.6%) were the three largest visible minority groups in Toronto. After Christianity (46.2%), Muslim (9.6%), Hindu (6.2%) and Jewish (3.6%) were the three largest religious groups in Toronto [9].

Sampling

We included family member substitute decision-makers of Muslim patients (≥ 18 years) who were admitted to ICU and subsequently died in-hospital (either in ICU or another hospital unit). Using purposive sampling, we targeted a varied sample according to gender; age; race; ethnicity; primary language; country of origin; immigration status; number of years in Canada; location of death; and cause of illness. In accordance with case study methodology, we aimed to recruit between four and 10 participants, or until data reached theoretical saturation whereby the incorporation of new data provided no new theoretical insights. This sample size is based on recommendations that suggest having fewer than four cases in multi-case research limits the rich description of interactivity among cases, whereas more than 10 cases provide more uniqueness of interactivity than researchers can make sense of [10].

Participant identification and recruitment

We identified Muslim patients who were admitted to ICU before (between July 01 2019 to March 31 2020) and after the emergence of COVID-19 (between July 01 2021 to July 31 2022). Each patient's hospital file on the electronic medical record was examined for evidence of Muslim religion via free text search of all fields in the medical record. Recruitment of participants occurred by telephone in close collaboration with healthcare providers who were in the circle of care. One follow-up request was made two weeks after the initial invitation to those who did not respond. Verbal informed consent was obtained from each participant. Compensation was provided to participants in the form of an e-gift card to a local coffee shop.

Data collection

Semi-structured interviews were held between the interviewer (AN) and each participant for approximately 40-50 minutes via passcode-protected videoconferencing or by telephone. Interviews took place between August and November 2022 (ranging from nine to 36 months after patient death). There was no relationship between the participants and the interviewer prior to study commencement. Interviews were conducted in English and were audio-recorded to assist with transcription and data analysis. The interview guide included open-ended questions around five key dimensions of quality end-of-life care, as previously identified [6] (Appendix A). This framework was selected for its focus on quality of end-of-life care for seriously ill patients and families in hospital.

We piloted the interview guide with the first three interviews and adjusted wording in consultation with the research team. All cases were included in the final analysis. Field notes capturing reflexive thinking (such as thoughts, ideas and questions) were recorded during each interview and summarized immediately after. These notes were used as supplementary information during data analysis to eliminate or generate additional lines of inquiry. Healthcare providers' notes from the patient medical record were also used to triangulate data and contextualize the patient care experience and medical journey from the perspective of members of the healthcare team (i.e., intensivist-family meeting notes; palliative care; spiritual care; other medical and surgical specialty notes). Following each interview, data were extracted from the patient medical record using a template to gather key details around the patient care journey, such as discourse around treatment decision-making, prognostication, resuscitation status, patient goals-of-care, and other patient and family interactions (Appendix B).

Data analysis

Data were analysed using deductive content analysis [11]. A structured categorization matrix was developed using pre-specified codes (28 elements of care) and categories (five key dimensions) from the existing framework on quality end-of-life care for seriously ill patients in hospital [6]. Data obtained from healthcare providers' notes were also coded and categorized according to the matrix. These lines of data were used to expand upon and provide complementary insight into the patient care journey and healthcare experience gathered during the interview process. Once a segment of text was *deductively* coded and grouped into a category, the content was *inductively* formulated into overarching themes. Data that did not fit the categorization matrix were used to create new codes and categories following the principles of inductive content analysis.

Analytical frameworks from each interview were compared across and within cases through cross-case analysis in order to highlight common experiences, as well as divergent cases that deviated from the dominant narrative. Extensive analytic memos were recorded throughout the data analysis process to document analytic thinking and the interpretation process. Feedback from the research team also helped to expand the analytical process. Interviews were transcribed verbatim and NVivo 10 software was used to perform data analysis. This study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) [12].

Ethics approval

Ethical review and approval were received from Sunnybrook's Research Ethics Board in May 2020 (#025-2020) and the University of Toronto in April 2021 (#40926).

Patient and public involvement

None.

RESULTS

Among 20 eligible patient decedents, five family members agreed to participate in the interview (Appendix C). Three patients died in 2021 and two died in 2019. Seven family members could not be reached; five had a wrong phone number or missing contact information; and three family members declined study participation. All patients were identified as being of South Asian descent. Patient demographics are reported in Table 1. Four themes emerged from the cross-case analysis (Figure 1). Additional exemplar quotes can be found in Appendix D.

Theme 1: Trust and confidence in the healthcare team overseen by medical experts

Family members who expressed having trust and confidence in the healthcare team were very satisfied with the quality of care at the end of life (case 3 to 5). In these cases, family trust was established through perceptions of good medical oversight by senior physicians and sufficient skills to provide quality medical care for their loved one. A unifying pattern was that patients in these cases were dealing with serious traumatic injuries or frailty, and there was little hope for a meaningful recovery.

> *"I had absolute trust [in the healthcare team]… on behalf of my [parent], I think they gave [my loved one] the best care possible." – Case 3*

Two family members expressed low satisfaction with the quality of care, due in part to a belief that issues that arose in the ICU were avoidable and/or inadvertently caused by the healthcare team due to inadequate medical skills (cases 1 and 2). Patients in both cases had a long course in hospital that occurred during the pandemic. There was also a belief among one family member that limited continuity of care among healthcare staff had a negative impact on the medical oversight of the patient's care, and a perception that junior clinicians did not have adequate clinical support from more senior clinicians in the hospital (case 1).

> *"The [medical] resident did not know that [my loved one] was not ready for extubation. All they knew was that the attending [doctor] said we need to extubate tonight. They have no clinical judgement, they are residents. That's not their fault, they are just following the attending's order. Their clinical skills aren't as good as attendings." – Case 1*

Theme 2: Quality communication with medical experts

Timely communication and sufficient information from a medical expert were described as important elements of quality communication and end-of-life care by all family members. This was particularly experienced by family members of patients who were dealing with serious traumatic injuries or frailty and had short stays in hospital (cases 3 to 5). Quality communication between family members and medical experts helped to establish trust with the healthcare team and enabled making decisions to shift from curative to comfort care.

> *"[The doctors] told us what the consequences of this accident could be and what the outcomes could be, whether it was positive or negative. They put us in the right direction of what we could expect in a few days based on [our loved one's] condition." – Case 5*

Among some patients who had prolonged stays in hospital, some family members felt that they did not receive sufficient information on patient prognostication during their stay in hospital (case 1). The patient in this case was dealing with a chronic critical illness (i.e., ≥ 8 days in an

ICU), and medical notes indicated that informational insufficiency may have been a result of some uncertainty with patient prognosis.

> *"I asked [the doctors] why did kidney function shutdown? They said we don't know. I said what happened from last night until tonight, did something happen? They said it's possible because [the patient] has leukemia. They're blaming everything on leukemia." – Case 1*

Direct and honest communication with the medical team was also described as an element of good quality care by most family members (cases 2 to 5). For family members of patients who were dealing with serious traumatic injuries or frailty, information on the severity of illness and chances for survival helped with decision-making for life-prolonging treatment (cases 3 to 5).

> *"[The doctor] didn't give us false hope that [my loved one] was going to survive. He gave us a direct answer, with no confusion, on why he thinks [the patient] might not survive. He was pretty clear with his message to us. It made our decision easier." – Case 5*

One family member shared a divergent perspective on the desire for more hope from the healthcare team when dealing with severity and uncertainty in the patient's medical situation (case 1). A distinguishing feature of this case was the family member's clinical background and their preference for transmitting hope in patient-family communication.

> *"I'm a physician (family member)…when I see a patient and they don't have any hope, I give them hope." – Case 1*

Language barriers were also raised as a hindrance to communication by one family member (case 5). Upon admission and throughout the patient's course in hospital, the patient's younger sibling supported language translation between the parent/substitute decision-maker and members of the healthcare team. This was described as being very difficult for this family member.

> *"I was the translator at the time. I didn't know what to tell my [parent] because the doctor was talking to me. At the time, I was sixteen I think, and I was trying to translate that to my [parent] and [they] were freaking out." – Case 5*

There was an appreciation for the professional language translator that was provided by the healthcare team to support the final conversation around the withdrawal of life-prolonging treatment. Language barriers were not raised by other family members whose primary language was not English.

Theme 3: Achieving patient goals-of-care

Patient goals-of-care were focused on maintaining patient quality of life across most cases through limited use of aggressive treatment when there was little hope for meaningful recovery (cases 2 to 4). A unifying pattern was that patients in these cases were dealing with serious traumatic injuries or frailty. Two frail older patients had a documented do-not-resuscitate (DNR) directive on their medical record (cases 2 and 3) and one patient (45-60 years old) had a documented preference for no limitations in care (case 1). All family members were engaged in goals-of-care conversations when treatments were not meeting the indicated physiological goals. Perceptions of exhaustive medical care seemed to enable concordance between the family and healthcare team around decisions to shift from curative to comfort care.

> *"The doctor came and talked to us and explained that is the decision we have to make. He said if 2-3 doctors say there's no brain activity, then it's called brain death. There is no point to keep the ventilator on. We asked for one extra day and there was no improvement." – Case 4*

For one family, there appeared to be varying expectations around the provision and use of life-prolonging and organ-supporting care for their loved one (case 1). Despite the patient's documented preferences for full care, the family believed that healthcare providers did not utilize all medical options to treat the patient's acute critical condition due to a pre-existing cancer diagnosis. There was a perception that, compared to the US health system, Canada's universal healthcare limited the amount of life-prolonging and organ-supporting treatment that a patient could receive.

> *"I think the healthcare system is very difficult in Canada…because if the outcome is not going to be good, they try to limit resources and let the patient die. This is all covered by government funds." – Case 1*

All family members described seeking support from family, friends and extended relatives to help with making end-of-life decisions. This form of support provided family members with reassurance around plans for care, particularly in cases where relatives had medical backgrounds and could offer a second opinion.

> *"We have two doctors in our family. We sent them all the reports to [another country]. And they said the same thing like what the doctor said…They all said there is no chance [for our loved one] to survive." – Case 4*

Across all cases, family members did not feel that culture or religion were major influential factors in the end-of-life decision-making process or for achieving patient goals-of-care, including among patients who were described as being ‘very’ or ‘somewhat’ religious.

> *“Cultural and religious [factors] were not [an important part of the process]. We talked about treatment…We never talked about religion or culture. When [my loved one] was in palliative care, then at that point it became important [for us]. For example, they gave us the Quran and we played the [religious audio].” – Case 1*

Theme 4: Dignity of care through cultural respect and emotional support

Family members of patients who had a short stay in hospital before death, including one that was admitted during COVID-19, believed that their loved ones were treated with full dignity and respect (cases 3 to 5). In two cases where patients had a prolonged stay in hospital, family members believed that their loved ones were not treated in a respectful or compassionate way (cases 1 and 2). Both of these cases occurred after the emergence of COVID-19 and it was noted by one family member that dignity of care may have been impacted by the pandemic and strains on healthcare staff.

> *“I would go very often and [my loved one’s] toes would be sticking out, and I'd cover the toes. Sometimes [the patient’s] gown would be undone, like you know, if it’s slipping, and I’ll come and tighten it around the neck. It was things like that.” – Case 2*

This family member also described several instances where the care provided by the healthcare team was not in line with the patient’s cultural norms and values (case 2).

> *“There was one nurse who was so horrible… She got me to help change [my parent's] diaper. She wouldn't do it herself, and I mentioned to somebody that you're not supposed to be doing that. My [parent] looked very embarrassed and didn't like that. No, no, his [child]? No, you know the culture.” – Case 2*

All family members felt that their religious needs at the end of life were addressed. Across all cases, family members expressed an appreciation for the religious audio that was provided by the hospital and permitted to be played at the patient’s bedside. One family member described challenges with finding an imam to provide religious services for their loved one in a timely manner (case 3). However, this experience did not negatively influence perceptions around the quality and experience of care.

> *"By the time [our imam] found parking and came [to the hospital], [my loved one] was gone. I asked [the hospital] if they had an imam that can come before, but they didn't get back to me in time." – Case 3*

Concerns around emotional and psychological well-being were raised by one family member who felt that the healthcare team did not adequately address the patient's mental health needs (case 2). This was documented in the patient's medical record and the patient was seen by staff from the psychiatric care team and prescribed anti-depressant medication. Despite efforts by the healthcare team to alleviate patient depression, the family still had a desire for more *"handholding"* from providers during the patient's long stay in hospital.

> *"[My loved one] wanted to talk to somebody. [My loved one] would have loved to banter or listen to somebody. That would have been so helpful. There wasn't enough handholding." – Case 2*

Visitor restrictions were also raised as a barrier for emotional support and well-being by all family members who had loved ones admitted to ICU during the pandemic (cases 1 to 3). In contrast, family members of patients who died before the pandemic believed that the large presence of family and friends at the hospital was a major source of emotional strength (cases 4 and 5).

> *"There were so many people in the ICU, [the patient's] whole group of friends. We have a huge family, everyone was in the ICU... They stayed the six/seven days that [our loved one] was in ICU." – Case 4*

DISCUSSION

In this multiple case study comprising family members of Muslim patients admitted to the ICU, we identified four key themes influencing satisfaction with the quality and experience of care: trust and confidence in the healthcare team overseen by medical experts; quality communication with medical experts; achieving patient goals of care; and dignity of care through cultural respect and emotional support. Culture, religion and religiosity did not appear to have a major influence on the medical decision-making process. Discordance around expectations of care seemed to occur in cases where there was high uncertainty with patient prognosis. Patient goals of care were achieved in most cases; however, there may be a need to improve elements of care pertaining to communication, cultural respect, and emotional and psychological well-being for patients.

Overall, our findings are consistent with prior research which identified the following elements of care as most important for seriously ill patients and families: "to have trust and confidence in the doctors looking after you"; "not to be kept alive on life support when there is little hope for a meaningful recovery"; and "information about [the patient's] disease is communicated in an honest manner" [6]. We found that trust and confidence in the healthcare team were influenced by perceptions of clinical oversight by medical experts and quality communication, particularly with the staff intensivist or attending physician. Access to clear and timely information from expert clinicians was highly valued by all participants in our study. These elements of care appeared to enable concordance with decisions to shift from curative to comfort care.

Among family members of patients who had chronic critical illnesses and/or prolonged stays in hospital, we found that there was lower satisfaction with the quality and experience of care in the ICU, due in part to unmet needs for more clear and direct communication with attending physicians. These findings are consistent with prior research which has shown that family members of patients with chronic critical illnesses often describe distress due to perceived diminishing communication with the medical team as the ICU stay became protracted [13]. Clinicians who have difficulty managing and communicating uncertainty may also have difficulty calibrating prognostic communication with family, leading to discordance and conveying either overly optimistic or pessimistic messages in relation to their prior expectations [14]. Where there was discordance and varying expectations around life-prolonging and organ-supporting treatment in our study, there was indication of unmet communication needs around patient prognosis that could lead to perceptions of less than exhaustive medical care. This finding is consistent with research that suggests that perceived gaps in communication related to prognostic uncertainty can influence perceptions around exhaustive care [15]. Clinical practice guidelines recommend that healthcare providers in the ICU target communication skills as a key priority area for quality improvement. For example, ICU nurses can help address family members' desires for more communication around resuscitation goals and prognostic timelines through intensive communication training, particularly in settings where family contact with intensivists can be limited [15].

Patient goals of care in our study were driven primarily by patient quality of life and limited use of life-prolonging treatment when there was little hope for meaningful recovery. When prompted to speak more about the influence of their cultural and religious beliefs on the medical decision-making process, there did not appear to be a major impact. This might be explained by acculturation of health behaviors – all patients recruited for this study were long-standing immigrants who had spent at least 15 years in Canada. That we did not observe any notes in patient medical records that touched on ethnocultural aspects around goals of care may also reflect limited knowledge on religious or spiritual needs by the healthcare team; however, our study design does not provide more insight into this possibility.

While culture, religion and religiosity did not appear to have a major influence on the medical decision-making process, respect for cultural and religious values was identified as an important element of quality care for Muslim patients and families. Perceived failure to acknowledge or address ethnocultural beliefs and values at the end of life appeared to have contributed to loss of trust and lower satisfaction with the quality and experience of care. There may be opportunities to enhance cultural safety and humility among healthcare staff to prompt for and document cultural considerations important to the patient and family while engaging in advance care planning or goals-of-care discussions. Language barriers were identified as an additional element of quality end-of-life care for Muslim patients that was not previously defined in the existing framework [6]. The use of professional language interpreters have been shown to improve clinical outcomes and patient satisfaction compared to ad-hoc interpreters, such as family members or bilingual staff [16].

Overall, our findings align with previous research which suggests that quality ICU care is characterized by high degrees of communication, patient comfort, and having a sense that the medical team provided exhaustive care [6,15]. Insights from this research can inform clinical processes and interventions to improve quality of care, enhance cultural safety and humility, and reduce psychological and emotional burden at the end of life. Future research should explore additional areas unaddressed in this research, such as how beliefs and attitudes around end-of-life care are influenced by region or country of origin, racial/ethnic background, or level or religiosity/spirituality, and how these factors work in conjunction to influence medical decisions at the end of life.

Strengths and limitations

The strengths of this study are the use of multiple case study design which enabled rich, detailed narrative understanding of the medical decision-making process and quality-of-care experience for seriously ill Muslim patients. Patients' medical notes were also used to triangulate the medical journey and care context from the perspective of the healthcare providers in the circle of care. Archived patient medical records were important for providing an 'in-the-moment' view of the patient/family encounter.

The positionality of the principal investigator and interviewer for this study is also a strength; being from an Islamic background helped with understanding nuances in the Muslim religion and norms/culture in Muslim-dominant regions to prompt further. Practicing reflexivity was particularly important for surfacing personal experience, values and beliefs and acknowledging areas where responses could be interpreted in a certain way. For example, topics that resonated or triggered emotional reactions were noted and enabled labelling of experience (i.e., seeing sick parent in a disheveled state). Family members may have also felt more comfortable sharing their patient care experience with an interviewer who shared a similar ethnocultural background. The interviewer's role and experience as an end-of-life care researcher was also a strength.

A limitation of this study is that patient religion is not always documented in the patient medical record and eligible participants may have been missed in the screening process. It was also difficult to reach family members of patients who died before the COVID-19 pandemic due to missing or changed contact information. By coincidence, all patients recruited for this study were of South Asian descent and long-standing immigrants who had spent at least 15 years in Canada. We were not able to recruit recent immigrants or Muslim patients from other racial/ethnic backgrounds, religious sects or regions of origin. Most patient decedents were also male and most were highly educated which may have also had an impact on the end-of-life care experience and delivery of care. While theoretical saturation appeared to be achieved at five patient cases with deductive content analysis, we are cognizant of some homogeneity in our sample population and growing debate about the concept of saturation within qualitative research [17]. Our aim with this initial study was to validate and exemplify existing theory with Muslim patients/families rather than to develop new theory; however, there is importance in conducting further research (using inductive approaches and more demographic variability) to explore how the end-of-life care experience is influenced by region or country of origin, racial/ethnic background, or level or religiosity/spirituality. Findings from this study cannot be extended too far beyond their context or generalized to other populations; however, the rich description of participants' perceptions around the patient care experience may be transferable to other healthcare contexts and used to inform future research.

We also did not have access to healthcare worker demographics or staffing information before or after the emergence of COVID-19 to help describe the ICU context during specific points in time; however, we know that between July 1 2021 and December 31 2021, visitor restrictions and healthcare human resource shortages may have impacted the quality of communication compared to pre-pandemic practices.

CONCLUSION

Opportunities exist to improve the quality of care and reduce the psychological and emotional burden at the end of life for seriously ill Muslim patients and families. Future research should explore nuanced areas unaddressed in this research, such as how beliefs and attitudes around end-of-life care are influenced by region or country of origin, racial/ethnic background, or level or religiosity/spirituality, and how these factors work in conjunction to influence medical decisions at the end of life.

CONTRIBUTORS

AN, RF, LGC and CD conceptualized the study. AN, RF, LGC and CD developed the methodology and analytical plan. AN undertook data analysis assisted by RF, LGC and CD. AN, RF, LGC, and CD contributed to final analysis and interpretation of the data. RF acted as guarantor. All authors read and approved the final manuscript.

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COMPETING INTERESTS

None declared.

DATA AVAILABILITY STATEMENT

No additional data available.

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Table 1. Demographic and other characteristics of patient decedents

	Patient 1	**Patient 2**	**Patient 3**	**Patient 4**	**Patient 5**
Age	45-60 years	90+ years	90+ years	20-25 years	20-25 years
Gender	Female	Male	Male	Male	Male
Religious sect	Sunni	Sunni	Sunni	Ahmadi	Sunni
Level of religiosity/spirituality [a]	Somewhat	A little	Very	A little	Somewhat
Primary language	English	Other	English	Other	Other
Secondary language	Other	English	N/A	English	English
Immigration status	25+ years	25+ years	25+ years	10-15 years	15-20 years
Education	University diploma at bachelor level or above	University diploma at bachelor level or above	College, CEGEP[c], or other non-university diploma	Secondary (high) school diploma	University diploma at bachelor level or above
Cause of illness	Cancer	Frailty	Frailty	Trauma	Trauma
Type of critical illness [b]	Chronic	Acute	Acute	Acute	Acute
Location of death	ICU	Palliative care	Palliative care	ICU	ICU

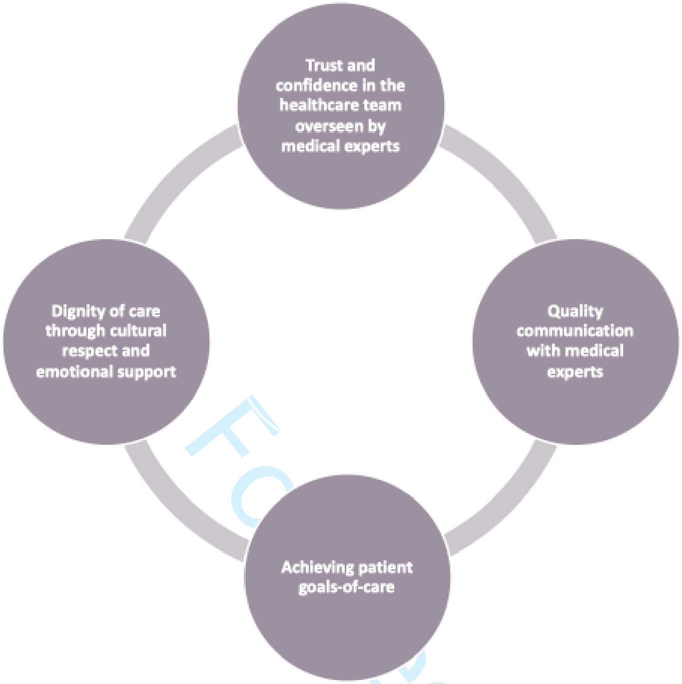
[a] *Levels of religiosity/spirituality were rated by family members (from most to least) : very, somewhat, a little, not at all, or do not know.*

[b] *Chronic critical illness (CCI) was based on a consensus definition of: ≥ 8 days in an ICU and one of six qualifying conditions (prolonged mechanical ventilation, tracheostomy, stroke, traumatic brain injury, sepsis, or severe wounds).*

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

FIGURE TITLE

Figure 1. Key themes influencing perceptions around quality and experience of end-of-life care


Trust and confidence in the healthcare team overseen by medical experts
Dignity of care through cultural respect and emotional support
Quality communication with medical experts
Achieving patient goals-of-care

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

Principal Investigator: Robert Fowler, Sunnybrook Health Sciences Centre, 2075 Bayview Avenue, Office D478, (416) 480-6100 ext. 7471

PhD Student/Sub-Investigator: Ayah Nayfeh, University of Toronto, Dalla Lana School of Public Health, Institute of Health Policy, Management and Evaluation (IHPME), (613) 407-7727

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 high and/or low quality; we would like to understand your experience with making decisions about end-of-life care; and we would like to explore how your loved one's goals and preferences for care were achieved or not achieved.

INTERVIEW QUESTIONS WITH FAMILY MEMBERS:

Part I – Introduction

Questions	Probes
1. Can you tell me a little bit about your loved one's medical journey?	Was the illness something that was sudden/unexpected or more gradual (i.e., developed over time)?
2. Can you tell me about you and your loved one's racial, ethnic, cultural, and religious background?	Were you and your loved one born inside or outside of Canada? ○ (If outside) what is the country of origin? How important was culture or religion 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 is 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 5* *"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 healthcare team provided the patient with exhaustive medical care.	*"I wanted to see if she had acute brain injury... 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 spiritual needs	To have your spiritual or religious needs met.	*"Because we're a Muslim family, the hospital allowed 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*