Understanding equitable and affirming communication moments and relationship milestones during the intensive care unit journey: findings from stage 1 of a design thinking project

Comprendre les moments de communication équitables et affirmatifs et les jalons relationnels pendant la trajectoire aux soins intensifs : résultats de la première étape d'un projet de réflexion conceptuelle

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Abstract

Purpose Communication is vital to facilitate patient and family-centred care (PFCC) and to build trusting relationships between intensive care unit (ICU) health care providers, the patient, and their loved ones in the ICU. The focus of this investigation was to identify, define, and refine key moments of communication, connection, and relationship building in the ICU through a lens of Equity, Diversity, Decolonization, and Inclusion (EDDI) to encourage meaningful communication and development of trusting relationships.

Methods We conducted 13 journey mapping interviews with ICU health care providers, patients, and their loved ones as the first stage in a design thinking project. We used directed content analysis to identify intersections where principles of EDDI directly or indirectly impacted communication, relationships, and trust throughout the ICU journey. To serve diverse patients and their loved ones, accessibility, inclusivity, and cultural safety were foundational pillars of the design thinking project.

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Results *Thirteen ICU health care providers, patients, and their loved ones participated in journey mapping interviews. We defined and refined 16 communication moments and relationship milestones in the journey of a patient through the ICU (e.g., admission, crises, stabilization, discharge), and intersections where EDDI directly or indirectly impacted communication and connection during the ICU journey.*

Conclusion *Our findings highlight that diverse intersectional identities impact communication moments and relationship milestones during an ICU journey. To fully embrace a paradigm of PFCC, consideration should be given to creating an affirming and safe space for patients and their loved ones in the ICU.*

Résumé

Objectif *La communication est essentielle pour faciliter les soins axés sur la patientèle et la famille et pour établir des relations de confiance entre les prestataires de soins de santé de l'unité de soins intensifs (USI), la patientèle, et ses proches à l'USI. L'objectif de cette enquête était d'identifier, de définir et de peaufiner les moments clés de communication, de connexion et de création de relation aux soins intensifs sous l'angle de l'équité, de la diversité, de l'inclusion et de la décolonisation (EDID) afin d'encourager une communication profonde et la création de relations de confiance.*

Méthode *Nous avons mené 13 entretiens de cartographie du parcours avec des prestataires de soins et des patient·es de l'USI ainsi qu'avec leurs proches dans le cadre de la première étape d'un projet de réflexion conceptuelle. Nous avons utilisé l'analyse de contenu dirigée pour identifier les intersections où les principes de l'EDID ont eu un impact direct ou indirect sur la communication, les relations et la confiance tout au long du parcours aux soins intensifs. L'accessibilité, l'inclusivité et la sécurité culturelle ont constitué des piliers fondamentaux du projet de réflexion conceptuelle pour desservir une patientèle diverse et ses proches.*

Résultats *Treize prestataires de soins et patient·es de l'USI et leurs proches ont participé à des entrevues de cartographie du parcours. Nous avons défini et affiné 16 moments de communication et jalons de la relation dans le parcours d'un·e patient·e à l'USI (p. ex. admission, crises, stabilisation, congé) et les intersections où l'EDID a eu une incidence directe ou indirecte sur la communication et la connexion pendant le parcours aux soins intensifs.*

Conclusion *Nos résultats soulignent que les diverses identités intersectionnelles ont un impact sur les moments de communication et les jalons de la relation lors d'une trajectoire aux soins intensifs. Pour adopter pleinement un paradigme de soins axés sur la patientèle et sa famille, il faudrait envisager de créer un espace d'affirmation et de sécurité pour les patient·es et leurs proches à l'unité de soins intensifs.*

Background

Patient and family-centred care, communication, and relationships in the intensive care unit

Patient and family-centred care (PFCC) is a paradigm that recognizes the benefits of a mutual partnership between patients, their loved ones, and health care providers.[1] In the PFCC paradigm, the patient and their loved ones are empowered and supported to make decisions and define successful outcomes based on what is important to them.[2] In the intensive care unit (ICU), best practices for PFCC include family presence and participation in bedside care; routine communication to engender trust and reduce conflict; and the use of active listening, expressions of empathy, and statements of support during communication with families.[3,4]

Although effective communication underpins much of PFCC, ICU-specific factors make communication particularly challenging in the critical care setting. The complexity of care, number of health care providers involved, nature and pace of the decisions, and the emotional and physical toll of having a loved one in critical condition are barriers to effective communication in the ICU.[5] Intensive care unit clinicians must attempt to overcome these barriers and create space for empathetic, respectful, and collaborative communication with patients and their loved ones, in a manner that facilitates trust.[6] Ineffective communication in the ICU may hinder relationship development by creating bias, distrust, and social distance.[5] Clinicians have skills in both communication and in therapeutic relationship building, which has the potential to improve the experience of patients and positively affect outcomes.[7] Essential conditions for therapeutic relationship building, such as a present, genuine, receptive, collaborative, and committed health care provider, can provide a foundation for engaging patients and their loved ones in PFCC.[7–9]

Equity, Diversity, Decolonization, and Inclusion

Diversity is inherent in the presence of individual differences that shape lived experiences (e.g., race, gender, ethnicity, place of origin, disability, sexual orientation, age).[10] *Intersectionality* refers to the overlapping nature of an individual's multiple identities

that interact to shape distinct lived experiences of social oppression, privilege, and positional power (e.g., race and gender interact so women of colour experience higher levels of oppression perpetuated by systems of power than either men of colour or White women do).[11,12] *Inclusion* is an ongoing process of building welcoming, respectful, and affirming spaces to support *equity* or parity in policy, process, power, access, opportunity, and outcomes.[10] *Decolonization* is a process of deconstructing systems that prioritize settler ideologies, thoughts, and approaches over those of Indigenous culture, traditional ways of knowing, empowerment, and self-determination across all systems, including health care.[13–15] The acronym EDDI refers to the interconnectedness of process and pursuit of Equity, Diversity, Decolonization, and Inclusion.

Persons representing diverse intersectional identities bring practical, contextual, and historical experiences and realities that can have implications for communication and trust building. For example, Indigenous, Black and people of colour (IBPOC) populations may have experienced systemic racism and oppression, intergenerational trauma, the long-term effects of colonization, and inequitable access to housing, sustainable food, and health care.[16–18] For patients and loved ones whose primary language is not English, communication can impact their experience and mental wellbeing during their ICU stay.[19–28] Diversity in culture, language, and spiritual or religious beliefs can influence expectations of critical care patients and their loved ones.[19–21,23,24] These factors with which diverse patients and loved ones come into health care systems may require specific consideration to create a safe and affirming space for communication and trust building.[5,29]

Health care systems have been developed on a foundation of colonial white supremacy and subsequently, systemic racism, which often negatively impacts IBPOC populations' access to appropriate or even adequate health care. Individuals who are negatively impacted by health disparities and inequity have more complex health needs and often delay seeking medical attention due to racism, discrimination, stigma, sexism, and bias.[30–32] Indigenous populations in Canada continue to be disproportionately affected by colonial health care structures.[32]

Focus of the current investigation

The focus of this investigation was to understand communication, connection, and relationship building in the ICU through a lens of EDDI. By understanding the intersection between PFCC and diverse identities, the ICU can become a more equitable and culturally safe space where patients and their loved ones are empowered to actively participate in shared decision-making, engage the health care team, and feel valued and affirmed.

Methods

Design thinking

Design thinking is an applied, systematic approach to problem solving whereby understanding the current reality leads to identifying real-world problems and practical solutions.[33–35] The design thinking process consists of four stages, which are framed as questions: What is? (stage 1), What if? (stage 2), What wows? (stage 3), and What works? (stage 4). This research was conducted within stage 1: What is? of a larger design thinking project to explore how communication technology might enhance communication and connection between the patients, their loved ones, and the ICU team. In keeping with the real-world focus of design thinking, the current study leveraged a pragmatic approach to inquiry[36–39] that views knowledge as transactional and constructed based on the interaction of people and their environments.[40,41] The emphasis of this approach is on producing useful and actionable solutions to real-world problems. To serve diverse patients and their loved ones, accessibility, inclusivity, and cultural safety were defined *a priori* as foundational pillars of this project. This is consistent with the values-informed axiology of a pragmatic approach.

Data collection

Journey mapping is a tool frequently employed in design thinking that facilitates the mapping of events, actions, and processes from different perspectives.[33] Following approval by the Behavioural Research Ethics Board of the University of Saskatchewan (Saskatoon, SK, Canada; 15 June 2021), we used journey mapping to understand the experiences of patients, their loved ones, and health care professionals as a patient moves in, through, and out of the ICU. In phase 1, we engaged our larger research team of knowledge users (consisting of patient and family partners, health care providers, and Indigenous scholars to identify *key moments* and *milestones* in the journey of a patient through the ICU where trust was built or threatened, relationships were affirmed or challenged, and communication was effective, ineffective, or absent [e.g., admission, crises, stabilization, discharge]). Team members engaged in phase 1 had lived experiences in ICU. We held informal discussions with the team and visually mapped ideas during the conversation. After the discussions were complete, two authors (S. S., S. K.) met to synthesize the ideas and identified 16 distinct moments. As the purpose of the synthesis was to inform the next phase of the process, the researchers focused on summarizing a robust list of moments and milestones from the visual mapping that were generated during the conversations.

Notes from these discussions were circulated to the team for additions and input. After this process, we defined *communication moments* as an opportunity or event where information is given or received and *relationship milestones* as a time when there was a shift or change in trust or bond.

In phase 2, we conducted semistructured interviews guided by these *key moments and milestones* to better understand and explore lived experiences in patients' ICU journey (Electronic Supplementary Material eAppendix).

Sampling and recruitment

We used maximum variation purposeful sampling to recruit participants including: 1) members of the ICU health care team, including physicians, nurses, and allied health professionals; and, 2) patients and their loved ones with diverse cultural, linguistic, sexual, gender, age, and regional (i.e., rural) identities and intersections of identities. This sampling technique was appropriate in attracting information-rich cases—participants with a diverse range of backgrounds and ICU experiences. Health care providers were recruited through e-mail invitations, posters, and social media. Patient and family participants were recruited through the Saskatchewan Centre for Patient-Oriented Research, posters in Saskatchewan ICUs, and inviting participants from a prior related study.[42,43]

Analysis

We used directed content analysis,[44–46] a deductive approach to qualitative analysis, with the *moments* and *milestones* identified in phase 1 as the coding framework, with an additional code for EDDI examples. As per Hsieh and Shannon's approach to directed content analysis, we also looked for new themes arising that were not represented in the framework.[44] We aimed to 1) further define and refine the 16 moments and milestones identified in stage 1 of the journey mapping; 2) identify any additional moments or milestones; and 3) identify instances where EDDI directly or indirectly impacted the ICU journey. After immersion in the data (memos, transcripts, and audio recordings), the first two authors (S. S., J. O.) coded three transcripts together to ensure common interpretation and application of the coding framework. Then, each researcher independently coded five remaining transcripts. After coding was completed, the researchers met to review and understand intersections of EDDI with the *moments and milestones*. During this meeting, we critically reflected on the identification of EDDI moments in relation to our individual identities. We noticed that the context identified by the participant was often critical to understanding the intersection between EDDI and the moments and milestones. Therefore, we incorporated context into the presentation of findings. Given the deductive nature of this inquiry, our goal was to confirm that the moments and milestones were comprehensive and applicable across ICU journeys. Therefore, confirmation of the framework was achieved when more than one participant described distinct experiences related to each moment and milestone, and no new moments and milestones arose.

Results

In phase 1, we identified 16 key moments and milestones in the ICU journey where trust can be built, relationships can be affirmed, and effective communication can enhance the lived experience of patients and their loved one(s): 1) initial interaction(s) between any member of the ICU team and the patient/loved one(s); 2) transition into the ICU; 3) moments when the loved one(s) were asked to step out of the room; 4) moments when the patient(s) needed to be relocated; 5) loved one(s)' experience during the period of patient stabilization; 6) huddles with health care team (e.g., morning rounds, shift change, hand-off); 7) moments when a patient/loved one requests one-on-one communication with a member of the health care team (e.g., looking for information or insight); 8) patient/loved one(s) gives critical health information to ICU team; 9) ICU team gives health information, education, and plan to patient/loved one(s); 10) decision-making junctions (i.e., opportunity for shared decision-making); 11) moments of connection (e.g., physical touch, attention to comfort—emotional and physical, emotional engagement); 12) moments of acknowledgement and respect for identity and values; 13) moments where patient/loved one(s) feels safe and comfortable to be vulnerable (e.g., ask to pray or smudge, request a dreamcatcher, grieve openly, ask for what they need); 14) moments where health care team connects and is vulnerable with the patient/loved one(s) (e.g., share aspects of their identity, personal experiences); 15) moments leading up to and including transition from the ICU to another hospital ward and/or home (e.g., transition planning); and 16) coordination of follow-up communication and care with community-based supports (e.g., family doctor, specialist[s]), patient(s), and/ or loved one(s).

Thirteen health care providers, patients, and their loved ones participated in journey mapping interviews (phase 2). Participant characteristics are presented in Table 1. We defined and refined the 16 moments and milestones identified in phase 1 and identified instances where EDDI directly or indirectly impacted the ICU journey (Table 2).

Table 1 Journey mapping interviews: participant characteristics

	Gender	Ethnicity	Languages spoken (in addition to English)	Education	Additional self-identified diversity considerations
Patient's loved ones n = 3	2 female 1 male	1 Indigenous 2 Caucasian	1 Plains Cree	2 post-secondary 1 high school	1 low income[a] 1 demisexual 1 rural resident[c]
Physicians n = 3	2 female 1 male	1 Chinese 1 South Asian 1 Caucasian	1 Cantonese 1 Punjabi 2 French	3 post-secondary	1 English not first language
Nurses n = 2	2 female	2 Caucasian	n/a	2 post-secondary	
Allied health professionals[b] n = 5	4 female 1 male	4 Caucasian 1 European, Caribbean, Métis	2 French 1 German	5 post-secondary	2 with disability 1 rural resident

[a] Defined as any person in a household with income less than the Canadian Low-income measure, after tax (LIM-AT)

[b] Includes dieticians, physiotherapists, pharmacists, and social workers

[c] Defined by Canada Post as having a rural forward sortation area

No new moments or milestones emerged in phase 2. However, throughout the ICU journey, participants described how the COVID-19 pandemic and technology interact with equity, inclusion, communication and relationship building. To ensure these ideas were captured, we inductively created two new themes and developed working definitions for each (Table 3).

All participants explored the interaction between diverse identities and the lived experience of moving through the ICU. Participants described impacts and implications of having, accommodating, and affirming the following identities (listed alphabetically):

- Access to technology, technological skills
- Age
- Body size and weight
- Cognitive-communicative ability and/or impairment
- Cultural and religious beliefs and values
- Education
- Family structure (e.g., parents with children)
- Gender
- Geographic location (e.g., residents of rural or remote communities)
- Health literacy
- Indigenous identity
- Linguistic proficiency (e.g., English language learners)
- Mental health and addictions
- Sexual orientation

Affirming identity can build trust, relationships, and communication as illustrated by Physician 1 describing their experience with an LGBTQ2S+ couple:

… her partner came up to me … and she said, "You know what? I think we have to stop." She said "It's not going anywhere … she's suffering … she's not going to get better to a point where you know she would find it meaningful. I think we have to just make her comfortable"… I really appreciated that moment … she [the partner] was able to take some of the information that I was giving her … And put it into context of someone who loves and knows this person

Affirming identity can build trust and decolonize the ICU journey for Indigenous patients and their loved ones. This can include creating opportunities for patients and their loved ones to embrace traditional healing and beliefs, as is shown in one Loved One 3's example about the importance of the patient wearing a protection prayer pouch while in the ICU:

… my first experience … was a good one … we were given these little pouches. Sometimes it's for like protection, like a protection prayer pouch. And when I was with my loved one in [City 1], they allowed that protection pouch to be around my loved ones neck and be close to him … they should be open with culture and beliefs and allow things like that, because … it makes the ones that love the person feel more comfortable. And especially if that person is into their beliefs. Them too. It'll be good for them too.

In contrast, not affirming identity can have damaging effects that break trust and relationships, as Loved One 3 describes another experience at another hospital where the patient was prohibited from wearing the protection prayer pouch:

… at this other hospital, it seemed like it was a problem for them … they said, "Well, he just can't have nothing around his neck because he has all these

Table 2 Moments of communication and relationship-building in a patient's ICU journey

Moment and/or milestone	Definition	Quote about interaction between EDDI at this moment and/or milestone	Summary of context
First ICU interaction	The first time the ICU team, the patient, and/or a loved one meets, communicates, and/or interacts.	"… an Indigenous man who was stabbed … I remember the physician went up to the family and … said … 'I don't think there is anything that we can do here.' And the dad was like, 'That is my son, you will talk to me' … He [the father] said ' … Be professional, you need to introduce yourself' … You need to treat these people with respect." (Nurse 2)	A nurse described a scenario where a physician informed an Indigenous family that their loved one was dying without introducing himself first.
Transition into the ICU	Moments leading up to and including the transition period into the ICU, including very early moments of the ICU admission.	" … especially with Indigenous [peoples] … it's like … 'Why didn't you call me and tell me, my loved one was being moved to ICU?' … when people have a bad experience with the health care system … that just can keep filtering down … " (Allied Health 3)	An allied health professional described a situation where an Indigenous loved one was not informed about a patient being moved into the ICU and reflected upon how bad experiences using the health care system can influence perceptions and trust.
When the loved one(s) are asked to step out of the room	The health care team requires the loved one(s) to be physically distanced and/or separated from the patient. Loved one(s) may be required to leave or not enter the patient's room while the ICU team completes a procedure or provides care.	"I had this one experience where they told us to step out of the room, and … they didn't tell me why it just seemed like such a big rush … I understand that … was an emergency … even after … that happened, nobody really explained to us what really happened …" (Loved One 3)	An Indigenous loved one described a situation where they were asked to step out of the room without clear communication as to why.
When the patient needs to be relocated	The patient is moved from a familiar location to another (new) location for a definite or indefinite period of time, during the patient's stay in the ICU (i.e., distinct from transition out of the ICU).	" … sometimes moving a patient, in my opinion isn't always necessary. And it depends on the person in charge … usually, it's a good reason you need an empty … private room, and your patient is the only one that can move somewhere … and then there's other times where you might feel that it's not necessary for your move to be made … maybe there's a family situation … that needs to be sorted out before we can move them …" (Nurse 1)	A nurse described the potential for inequitable decisions about which patients are given private rooms.
Period of patient stabilization	Interval of time that occurs after the ICU team has addressed acute life-threatening conditions, but the patient remains in critical condition and long-term health outcomes remain unknown.	"I sat [child] down and we had a pretty deep and honest conversation about what our next few days could look like … The possibility of mom not making it … Can't imagine any father wanting to have that conversation." (Loved One 2)	A loved one describes having difficult conversations with a patient's child when outcomes were unknown.
Huddles with ICU team	Regularly scheduled or unscheduled information-sharing gatherings, which include the ICU team, patients, and/or loved one(s) and may occur in-person or at-a-distance with technology (e.g., phone).	" … there's still elderly individuals that would never know how to … login on a WebEx or Zoom to talk about their elderly partner who's in ICU." (Allied Health 4)	An allied health provider describes difficulties in connecting with elderly loved ones using video conferencing technology during rounds.

Table 2 continued

Moment and/or milestone	Definition	Quote about interaction between EDDI at this moment and/or milestone	Summary of context
Request for one-on-one communication with ICU team (member)	A patient and/or loved one requests in-person or technology-enabled at-a-distance communication with a specific member of the ICU team, any member of the ICU team, and/or the ICU team as a whole.	" … we get a lot of patients … from northern communities … or rural and, people can't just make it to come to [City] and be at the bedside … just finances and the distance can be a barrier … " (Allied Health 3)	An allied health provider describes finances and distance as barriers to ICU bedside presence for loved ones residing in northern and rural areas.
Patient and/or loved one(s) gives health information or advanced directive to ICU team	A patient and/or loved one(s) provide information about the patient's health history, health beliefs, and/or end of life wishes (i.e., advanced directives), which directly impact health planning, intervention, and decisions.	"About a month ago, there was a family that their health literacy … was not very high … they were having a tough time even understanding the question itself … trying to figure out … what medications the patient had been taking." (Allied Health 5) "… you have to be able to build relationships and rapport very quickly, so people are willing to share that information … especially if there's things around … substance abuse …, addiction … mental health … that you're asking, and some of those pieces are critical to the patient's … ICU stay or where things are at." (Allied Health 3)	An allied health professional described how low health literacy can make collecting important health information challenging. An allied health professional described how it is important to build relationships to understand health conditions, particularly conditions that are stigmatized (mental health, additions), to ensure ICU care is responsive.
ICU team gives health information to patient and/or loved one(s)	The ICU team provides information and related education about the patient's status, prognosis, treatment/intervention plan, and/or options.	"… [a] language barrier can be very, very challenging … in a sense, there's already a language barrier when … we're talking … the language of … health care words and health care discussions … you throw on top of that … someone who doesn't have English as their first language, it becomes very, very difficult." (Physician 3)	A physician identifies how medical jargon is a general language barrier which could be made more challenging if the patient and/or loved one(s) are English language learners.
Decision-making junctions	The ICU team and the patients and/or loved one(s) must make (shared) decisions and/or set direction for care, which could be especially challenging given the life-or-death nature of the decisions to be made.	"… if you have someone that's used to having … their cultural basis, their family experience is to have five or six people in the room making a decision supporting each other all the time, if they're now by themselves doing this, because they're, you know, legally, the person that's been decided is the decision maker … that that can be very challenging to … watch." (Allied Health 5)	An allied health professional describes a disconnect between the legal requirements for substitute decision-making and the process of making health care decisions in differing cultural contexts.

Table 2 continued

Moment and/or milestone	Definition	Quote about interaction between EDDI at this moment and/or milestone	Summary of context
Meaningful connection (e.g., physical, emotional, communication)	The patient, loved one(s), and ICU team are connected physically (touch), verbally/nonverbally (communication), and/or emotionally. This moment is not specifically related to an aspect of identity.	"… depending on how confused the patient is, sometimes it [a video call] can make it worse. … especially … for people with children … the children come on the video and their family member is … sedated and paralyzed and tubes and everything coming [out] … so we tried our best to say, 'Dad can still hear you' and … 'Maybe you want to sing Dad's favourite song' … or 'Tell us about what Dad likes' … But it can be a scary experience." (Allied Health 2)	An allied health professional describes video calls between patients and their children and how the team tries to encourage children to share about their parents to make the experience less scary for the children.
		"… I needed to … we were all missing being able to touch her to tell her that we love her … I'm a farm boy, we used to AI [artificially inseminate] cows all the time … if there would have been like a hole in the wall and they could have taped that glove [long rubber glove from fingers to elbows used in AI]. And I could have stuck my arm through it sterile on that side. And I could have just held her [the patient's] hand or … if [child's name] could have just held her hand and had a little speaker box or something to be able to talk directly to her … " (Loved One 2)	A loved one applies his experience from artificially inseminating livestock to try to find a creative solution to hold his wife's hand while she had to stay in sterile conditions.
Affirming patient and/or loved one identity, beliefs, and/or values	Specific aspects of cultural, religious, social, intersectional identity, values, and beliefs are acknowledged, and/or affirmed.	"Smudging is tricky because our beds don't fit in the smudge room. So, we can't get them up there. But I will ask if that's something that they want. They can smudge a pillowcase and then I'll put the pillowcase on the pillow. And then at least they have the smell of the sage and stuff so … it's not ideal, but … it's something … " (Nurse 2)	A nurse describes barriers to smudging for Indigenous patients and how the team respectfully tries to incorporate cultural beliefs.
		"Don't medicalize everything. Understand that Indigenous population has their own type of healing and try to incorporate that into … their health care, and that includes diet … a local Indigenous diet when people are in the hospital … and traditional healers … Indigenous medicines to be open to that … " (Physician 2)	A physician describes how ways of Indigenous healing can be incorporated into health care.

Table 2 continued

Moment and/or milestone	Definition	Quote about interaction between EDDI at this moment and/or milestone	Summary of context
Patient and/or loved one(s) are or are not safe or comfortable to be emotionally vulnerable	The patient and/or loved one(s) are comfortable to communicate, engage (or disengage), and/or act in a manner that is meaningful and/or aligned with their emotions/ emotional state.	"… they had an Elder on call … And I just felt like I had a.. person there to talk to when I was feeling really low … I was able to call this Elder anytime of the day … And they would come to me and talk to me … we'd meet in this … special room, and we smudge … And it really helped my spirit be strong through that time … " (Loved One 3)	A loved one describes how having an Elder on call helped them feel safe and able to connect with their beliefs when they were navigating a challenging time alone.
ICU team connects their own emotions and identity to patients and/or loved one(s)	The intersectional identity of a member of the ICU team facilitates meaningful engagement, personal connection, emotional investment, self/team reflection, and/or closer relationships with the patient and/or loved one(s).	"… she [the patient] was maybe five or 10 years older than me. And she had two daughters. And I remember … just feeling like, this could be me." (Allied Health 4)	An allied health professional reflects on similarities between themselves and a patient.
Transition from the ICU	Preparation, planning, coordination, and decision-making related to a period of transition out of the ICU to either a step down unit, palliative care, another unit/ward, another facility, death, and/or home.	"… culture has a huge part of grieving … some are very vocal, some are very quiet. Some are communities, some are very isolated … it's so interesting to see … the ritual after that person passes … depending on their faith, what that looks like and what you can … do and can't do with that person once they go." (Nurse 2)	A nurse describes diversity in grieving practices and rituals surrounding death and dying.
Follow-up communication after ICU stay	Communication and coordination that occur after the patient has left the ICU with loved one(s), caregivers, health care professionals, and/or community-based supports.	"… they [the health care team] communicated information to him [the patient] … And I was his next to kin … I don't know why they told him because he was still not feeling too well … I think they should have told me instead of him, because … I don't think he was thinking clear about a lot of things.. they did kind of write down … his after plan, but they weren't really detailed. So, I … had to phone in and … get more details from them." (Loved One 3)	A loved one describes how a patient's cognitive capacity was a barrier to them understanding discharge plans, which resulted in the loved one having to follow up with the team to get more information.

EDDI = Equity, Diversity, Decolonization and Inclusion; ICU = intensive care unit

things hooked up to him." And then I asked if I could put it [traditional protection pouch] by their bed and they said, "No, in case there's an emergency," they don't want to … knock it over or anything like that … I felt like they were judging me … I felt like they were being racist to me … It felt like they're making up excuses or something to me. I don't know. But that's just the way I took it in.

Particularly for Indigenous patients, historical injustice and intergenerational trauma may affect patient trust in the health care team and willingness to provide information. For example, Indigenous Peoples may be unwilling to share information about familial circumstances due to ongoing fears related to the forced removal of children from Indigenous homes and communities, as is illustrated by Allied Health 3:

Table 3 Emerging themes from phase 2 analysis

Emerging theme	Definition	Quote about interaction between EDDI and the emerging theme	Summary of context
COVID-19	Impact of the COVID-19 pandemic and subsequent visitor restrictions on communication, relationships, and connection in the ICU	"… you have all these stressors. And then you have this poor little … wife standing outside the room, and you're just like, that lady just needs a hug … she just need someone to stand beside her … But when it was full blown with COVID, there was nobody … there was pumps ringing … there was care that needed to be done … we lost a lot there …" (Nurse 2)	A nurse describes a spouse experiencing the ICU during COVID-19, how the team was stretched and unable to build meaningful connection.
Technology	The current and potential use of communication technology to support communication, relationships, and connection in the ICU	"… not everyone has a computer that they have access to that they can download these apps on, so they can see and talk to their family member." (Nurse 2)	A nurse discusses how lack of access to technology could hinder connection between patients and their loved ones.

EDDI = Equity, Diversity, Decolonization and Inclusion; ICU = intensive care unit

I think a lot of people associate social work with … taking people's children away … especially with Indigenous [peoples], … when they hear social worker, it's like … "Why are you asking about the children?" Like, "What, what do you want to know that for?" …

Discussion

Main findings

Through this investigation, we confirmed 16 key moments and milestones in the ICU journey where trust can be built, relationships can be affirmed, and effective communication can enhance the lived experience of patients and their loved one(s). We also began to understand how affirming or not affirming diverse, intersectional identities can interact with experiences throughout the ICU journey.[5] Some participants identified examples of how affirming identities through principles of EDDI can improve communication, relationships, trust, and connection during the ICU journey. Some participants identified examples of how denying or negating identities could disrupt, damage, or even destroy trust and relationships during an ICU stay. These preliminary findings open the opportunity for further investigation into the ways in which affirming or not affirming aspects of identity can directly or indirectly affect the provision of PFCC.[1,3,4]

Given the timing of this investigation (i.e., during the COVID-19 pandemic), participants also discussed the impact of visitor restrictions and the increased workload on the ICU team on building relationships and trust in the ICU.[43] Some participants identified how technology could

be used to mitigate challenges related to communication. Nevertheless, some participants identified that lack of access and skill in using technology could lead to inequities. These emerging themes of COVID-19 and technology did not represent distinct points along the ICU journey, but appeared to interact with communication and relationship building in significant ways throughout the journey.[43,47–49] Participants suggested that these contemporary, emerging themes may require recognition of EDDI lenses.

Intensive care unit health care providers should consider key *communication moments* and *relationship milestones* influenced by the context, experience, and intersectional identities of patients and their loved ones. For example, when asking information about an Indigenous person's children, understanding the history of colonization, assimilation policies, and practices (residential "schools," sixties scoop). Providing a culturally safe experience requires self-reflection of the positionality, privilege and unconscious biases of the health care provider and how this may affect the intersectional identities of patients and their loved ones.[50–52]

Strengths

We engaged a diverse team that included patient and family partners and health care providers to collaborate and create the foundation for this investigation in phase 1 of journey mapping. Diverse team members actively shaped the study through cocreation among practitioners, patients, and their loved ones, which is consistent with the pragmatic paradigm. This ensured our phase 2 interviews were focused and allowed for a more in-depth exploration of these moments with participants. Our exploratory

semistructured interview approach in phase 2 allowed us to explore the lived experiences of the ICU team, patients, and their loved ones. Almost all of our participants described how at least one aspect of identity could impact the lived experience of navigating the ICU. This suggests that work in understanding trust, relationships, and communication in the ICU should consider principles of EDDI and the role of affirming or not affirming intersectional identities. Our partnerships with an Indigenous community-based research lab and a division of the College of Medicine dedicated to supporting health equity in education, research, service, and advocacy, facilitated engagement and ensured that marginalized voices were represented throughout this project. Work with the Indigenous community-based research lab ensured Indigenous cultural safety was considered while engaging the knowledge base of experiences of this population. We believe our pragmatic approach amplified experiences of marginalized peoples and may contribute to decolonization.

Limitations

This study is limited by the small sample of interview participants; it's likely a larger sample would have collected a greater dimension of diverse identities. Nevertheless, our goal was to confirm and refine the framework we established in phase 1 of the journey mapping process. Our study is limited in our ability to prescribe specific actions to create safe spaces; safety is a personal experience, but by gaining greater understanding of the experiences of diverse patients and their loved ones, health care providers can adapt their behaviour in the ICU journey to increase feelings of personal safety.

Next steps

We recommend that future work should seek to apply the moments and milestones to patients, their loved ones, and the ICU team with diverse and intersectional identities and seek to understand similarities and differences between lived experiences throughout the ICU journey. Quality criteria for pragmatic research ask whether the findings produce *actionable knowledge* and if *research participants are involved in the inquiry process.*[53,54] The list of communication moments and relationship milestones can be used to sensitize health care providers in creating culturally safe environments. Journey mapping personas (e.g., a patient whose first language is not English, a loved one who lives in a rural or remote area, an ICU physician) will be developed into sketch videos to educate ICU health care providers and trainees about what diverse patients may experience as they move through the ICU. For patients'

loved ones, sketch videos will identify opportunities for advocacy and engagement with the ICU health care team. Our inquiry process included health care providers, researchers, patients, and patient family members to generate moments and milestones during phase 1. Next, participants will engage in facilitated workshops in the second stage of design thinking—What If?—to envision communication technology-enabled solutions to support communication, trust, and relationships in the ICU.

Conclusion

This investigation is part of a larger design thinking project that is adopting an agile approach to problem solving to a real-world health care problem. Understanding the ICU journey is an important foundation for envisioning a future of enhanced communication and connection in the ICU. Our findings highlight that diverse intersectional identities impact *communication moments* and *relationship milestones* during an ICU journey. Health advocates, decision-makers, and government officials can use our findings to champion affirming and culturally safe communication for ICU patients and their loved ones.

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