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"He is so much more than just his illness" using the Patient Dignity Question (PDQ) to elicit personhood and enhance dignity in the intensive care unit (ICU): A feasibility study examining family and healthcare professional feedback

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ABSTRACT

Purpose: To test the feasibility of a novel approach for eliciting personhood in ICUs.
Materials and methods: A multi-method study in ICUs examining the Patient Dignity Question (PDQ): "What do I need to know about you/your family member as a person to take the best care of you/them as possible?". The PDQ was used with family members of critically ill ICU patients. Brief interview summaries were placed at the bedside for the healthcare team to read. Feedback was obtained from families and staff through surveys utilizing Likert scales (1 strongly disagree, 5 strongly agree) and open-ended questions.
Results: Thirty-three family members reported PDQ participation was highly meaningful (Mean 4.8, SD 0.4), should be offered to other patients and families (Mean 4.8, SD 0.5), the PDQ information was accurate (Mean 4.9, SD 0.3), provided important information for the health care team (Mean 4.8, SD 0.4), and would impact their loved one's care (Mean 4.3, SD 0.8). Thirty-six ICU staff members reported the PDQ told them new information (Mean 4.5, SD 0.8), influenced their empathy (Mean 3.7 SD 1.1) and connectedness to the patient (Mean 3.9 SD 0.7). Despite this shift in tone of care, most felt it did not influence their physical care (Mean 2.8 SD 1.1). Qualitative themes from staff feedback include: 1) Knowing the whole person, tailoring care; 2) Increased empathy; and 3) Beyond the patient, impacting family interactions.
Conclusions: Families and staff reported PDQs were highly valued, providing a novel way of improving dignity conserving care in ICUs.

1. Background

Patient and family centered care (PFCC) is an integral element of critical care; however, the intensive care unit (ICU) environment poses challenges to the provision of person-centered dignity conserving care. Illness imposes vulnerability, while modern medicine and technology emphasizes biological dysfunction where patients are seen as synonymous with their disease [1]. Sociologist Nancy Kentish-Barnes stated "in the ICU, the patient becomes a body whose organs must be maintained, and this body in turn disappears behind the machines" [2]. Family

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visitation restrictions during the Coronavirus (COVID-19) pandemic further widened this gap between patients and healthcare team [3,4].

The ICU experience can be life-altering and traumatic. Critical illness has a high mortality and morbidity, and is associated with stress encompassing physical, emotional, existential, social and financial domains [5]. Families and patients experience multiple dehumanizing behaviors including poor or disrespectful communication, lack of compassion and separation from one another [6–9]. A prospective cohort study of nine American ICUs located within tertiary care academic medical centers reported that amongst more than 1500 respondents, about 20 % of patients or family members received inadequate respect, with more than half reporting a lack of control over their loved one's care [8]. A study of ICUs in an urban academic medical center in Baltimore reported that more than 30 % of 57 surveyed patients and/or family members experienced disrespect [10]. According to a large multicenter survey of ICUs in Europe and the United States, more than one-third of ICUs had a poor "climate of mutual respect," and only 18 % highly valued a respectful environment [11–13]. A review by Brown et concluded that, 1) dignity and respect are interrelated, 2) ICU patients and families are vulnerable to disrespect, and 3) violations of respect and dignity are common in the ICU and overlap substantially with dehumanization, 4) disrespect may be associated with both primary and secondary harms; and 5) systemic barriers complicate understanding and the reliable practice of respect in the ICU [9].

Post-ICU mental health burden includes anxiety, depression, post-traumatic stress disorders, and complicated bereavement [5,14–16]. The ICU is an emotionally challenging workplace with high rates of health care worker burnout [17], which were amplified during the COVID-19 pandemic [18]. Dehumanization, the disengagement from human qualities of patients, is sometimes used by staff to mitigate distress, as acknowledging patients' personhood can be emotionally evocative [19]. Dehumanization comes at the expense of person-centred care [20], and may be linked to professional burnout, feelings of clinical futility [21,22] and increased medical litigation [23].

Person-centered care incorporates patient's values, preferences and care needs, while dignity in care bestows a state wherein patients feel worthy of honor and respect [24]. Many ICU PFCC recommendations [25] attempt to mitigate distress associated with critical illness by addressing the needs of patients and families. Families need to be assured that the healthcare team looks after their loved ones [26]; acknowledging personhood assures them that their loved one is cared for and seen as a human being over and above their ailments [27,28]. Affirming patients' value upholds their dignity [24], while acknowledging personhood facilitates trust between medical staff and mitigates dissatisfaction [29]. As surrogate decision-makers, family inform high-stakes decisions, which require a clear understanding of the patient's wishes, beliefs and values [30,31]. Poor decision-making processes can result in goal discordant care, family distress, and is associated with expensive, inappropriately aggressive end-of-life care [32,33].

Various novel approaches have been tried in ICUs to optimize PFCC. The 3 Wishes Project is an ICU end-of-life program designed to mitigate human suffering by fostering connections and deepening relationships between patients, family members, and clinicians [34]. Clinicians honor patients in the last moments of life by carrying out wishes, such as creating word clouds, plaster casts of clasped hands, or thumbprint keychains or jewelry; a visit by the family pet, favorite music playing in the room, a final toast, or surrounding the patient by things and people that they love. Another approach, The Footprints Project, facilitates holistic patient-centered care, humanizing patients for clinicians [35]. It uses a 16-item structured questionnaire to elicit personal information about a patient's story (e.g., preferred name, language, family members, beliefs, values, hobbies, personality traits, etc.). Key information is transcribed onto a dedicated Footprints Whiteboard in each patient's room. Bedside whiteboards such as Get To Know Me Boards (GTKMB) enable patients and/or families to provide information, which is displayed in the patient's room denoting things like nicknames, favorite activities, hobbies, likes and dislikes, and information about relationships and achievements. Entries are typically a few words or short phrases, aimed at helping ICU care teams know the human side of patients [36,37].

The Patient Dignity Question (PDQ) is unique in being a narrative based intervention. It is designed to elicit personhood in medical settings through a short conversation framed by the question "what do we need to know about you as a person to take the best care of you possible?" [29,38,39]. PDQs focus on how someone defines themselves as a person, their core values, critical relationships, and responsibilities and how they wish to be seen or known by their healthcare professionals. Summaries of these conversations are placed on the patient's chart or at their bedside. The PDQ has been well received in palliative care by patients, families, and healthcare workers [39–42], providing healthcare providers with new information about patients exceeding routine clinical practice [29]. In an outpatient setting, it helped individuals with early-stage cancer express their values, desires and needs over the course of their disease trajectory [42].

This study is the first to examine PDQs completed by family members of critically ill ICU patients [43]. The objectives of this study were to test the feasibility of the PDQ in the ICU environment and elicit feedback from both family members and healthcare providers.

2. Methods

This study was approved by University of Manitoba Health Research Ethics Board (Dignity in Care during the COVID-19 Pandemic, H2020:423, October 16, 2000) and was conducted in concordance with ethical standards regarding human research and the Helsinki Declaration of 1975. It was part of a program of research examining the experience of death and dying during pandemic, hence the focus on ICU patients who were at high risk of death [44–47].

We chose a descriptive multi-method design for this exploratory feasibility study. We recruited family members of critically ill adult patients admitted to one of four ICUs (57 beds over 3 hospitals) located in Winnipeg, Manitoba, Canada between July 1, 2021, to August 31, 2022. Patients were eligible if their prognosis was guarded, defined as either an anticipated life expectancy <6 months (as determined by the ICU physician) or a high acute severity of illness score (sequential organ failure (SOFA) score of >12 or an increase in 4 over time). To enhance referrals, the SOFA score requirement was subsequently removed at the end of December 2021; instead, clinicians were asked to refer if they thought the patient had a high chance of dying during the current hospitalization. Family members of patients expected to die prior to completion of the protocol weren't asked to participate; nor were those unable to converse in English, or based on clinical consensus, lacked the cognitive ability to do so. The ICU physician referred families of eligible patients to the research team. Due to public health restrictions, families were then contacted mainly by telephone to obtain informed consent. Given this was a feasibility study and the challenges of recruitment during the COVID-19 pandemic, we did not track the number of patients admitted to the ICUs within the study timeframe.

Consented family members were guided through a telephone or in person conversation by one of three research team members, each with a background in the health sciences or health psychology. This conversation was framed by the PDQ adapted for family respondents; "What do we need to know about your loved one as a person to take the best care of them possible?". Research staff were trained to do so by the senior author (HMC), who also reviewed every PDQ summary to provide quality assurance and supervision. The PDQ allows family members to describe how they feel their loved one would want to be seen or known. Various prompts were used, such as inquiry about important personal qualities, critical relationships, key roles and accomplishments, core beliefs or values, along with ongoing worries and concerns. These conversations were not recorded or transcribed; but notes were taken to help facilitate the writing process. Immediately after the interview,

important conversation elements focused on personhood were summarized into a few paragraphs, no more than one-page. The interviewer then read this summary to the family to determine if corrections were required. Once completed, family were asked permission to have the PDQ summary placed on the front of the medical chart or posted at the bedside to maximize visibility to the entire healthcare team. Typical time for the entire PDQ intervention was 30 min, with interviews lasting 10–15 min.

Family was offered a copy of the PDQ summary and asked to provide feedback regarding the PDQ, rating their agreement with statements on a Likert Scale (see results, Table 2). Feedback was obtained immediately after completion of the PDQ, either verbally over the phone or through an emailed survey link. Online surveys were hosted and stored on the University of Manitoba's REDCap survey server, while all other collected data was de-identified and manually entered onto the server. Paper copies were securely stored in the Department of Psychiatry's research laboratory. All ICU clinical staff were invited to read the PDQ and provide feedback. Using a quick response (QR) code located on the PDQ summary, staff could access an online survey (see results, Table 3). Providers rated their agreement with statements regarding the PDQ using Likert scales; and responding to two open-ended questions on their impressions of using the PDQ in the ICU and how it impacted their care.

2.1. Analytic strategy

Quantitative data were analyzed descriptively. Continuous variables are reported using means and standard deviations (SD).We analyzed the quantitative data using the Statistical Package for the Social Sciences (SPSS, Version 27). Open-ended text responses were analyzed using conventional content analysis [48]. This analytic approach was selected to stay close to the data, using an inductive approach to coding, ensuring that we captured the unique perspectives of providers on their use of this novel approach in the ICU. This allowed us to code provider feedback iteratively to generate clear thematic categories. The coding process consisted of familiarization (i.e., reviewing the open-ended questions and all responses twice, while taking analytic notes); generating initial codes (i.e., highlighting key words and creating a word map with similar concepts); labeling concepts and sorting them into clusters of main and sub-themes; finalizing the names of themes and subthemes according to their meaning. The analytic process was led by one of the team's co-investigators (KR) and reviewed by the lead and senior authors. Qualitative rigor was enhanced by the analytic method followed, documentation of coding notes (audit trail), and involvement of several lenses and perspectives in the final development of the thematic framework.

3. Results

A total of 33 families (one member per patient) were approached and consented for study enrollment (consent rate 100 %). Each of these family members responded to the PDQ and provided feedback. The number of healthcare providers who read patient's PDQ is unknown, however 36 staff members consented to provide feedback by accessing the QR code displayed with the PDQ summary.

3.1. Family and patient characteristics

Patients were 48 % male with a mean age of 64 years (SD 15), while family participants were 21 % male with a mean age of 53 years (SD 14). Family participants included adult children (42.4 %), spouses (30.3 %), siblings (18.2 %) and parents (9.1 %). The racial background of families included 70 % white and 21 % indigenous. Patients were admitted to ICU with a variety of illnesses. All patients were incapacitated with either coma (74 %) or delirium (26 %). Overall hospital mortality was 84 % (28/33) with 64 % (21/33) dying in the ICU and 20 % (7/33) dying on the ward. Patient and family characteristics are summarized in Table 1.

Table 1
Demographics of patients and their family members.

Characteristic	Patient	Family
Age (years, mean +/− SD)	64 ± 15	64 ± 15 (27–90)
Male Gender (N, %)	16 (48)	7 (21)
Ethnicity (N, %)		
White	23	23 (69.6)
Black	1	1 (3.0)
Indigenous	7	7 (21.2)
South Asian	1	1 (3.0)
Other	1	1 (3.0)
Marital Status (N, %)		
Married/ Common-Law	17 (51.5)	23 (69.7)
Widowed	10 (30.3)	2 (6.1)
Separated/Divorced	3 (9.1)	2 (6.0)
Single	3 (9.1)	6 (18.2)
Education (N, %)		
None or Primary	4 (12.1)	1 (3.0)
High School	20 (60.6)	13 (39.4)
Undergraduate	9 (27.3)	17 (51.5)
Postgraduate	0	2 (6.1)
Employment (N, %)		
Retired	14 (42.4)	7 (21.2)
Employed	3 (9.1)	20 (60.6)
Not Employed	13 (39.4)	4 (12.1)
Disability	3 (9.1)	2 (6.1)
Income Level (N, %)		
Below $20,000	3 (10.0)	1 (3.4)
$20,000-39,999	4 (16.6)	3 (10.3)
$40,000-59,999	9 (30.0)	8 (27.6)
$60,000-79,999	5 (16.6)	9 (31.0)
$80,000+	8 (26.6)	8 (27.6)
Diagnosis* (N, %)		
COVID	8 (24)	–
Liver Failure	5 (15)	–
Coma	5(15)	–
Respiratory Failure	6(18)	–
Sepsis	5(15)	–
Other	4(12)	–
Religion (N, %)		
Christian	23 (70.0)	–
No religion	9 (27.0)	–
Spiritualist	1 (3.0)	–
Living Arrangement (N, %)		
Alone	6 (18.1)	–
Spouse	11 (33.3)	–
Others	13 (39.3)	–
Combination	3 (9.0)	–
Relationship to Patient N%		
Spouse or Partner	–	10 (30.3)
Parent	–	2 (6.0)
Sibling	–	7 (21.2)
Adult Child	–	14 (42.4)

3.2. Family feedback on patient dignity question summary

All families (100 %) agreed to share the patient dignity summary with the healthcare team, while 54 % (18/36) also requested a copy of the summary for themselves. Families were extremely positive about PDQ summary and experience. Using Likert scale (1 = strongly disagree, 5 = strongly agree), every participant felt the summary was accurate (mean 4.9 SD 0.3) and contained important information for the health

care provider (mean 4.8 SD 0.4). Ninety-seven percent of families felt that PDQ participation was a meaningful experience for them (mean 4.8 SD 0.5) and should be offered to other patients and families in similar circumstances (mean 4.8 SD 0.5). Eighty-eight percent of families agreed (42 %) or strongly agreed (46 %) that the PDQ summary would influence the way health care providers cared for their loved ones (mean 4.3 SD 0.4) [Table 2].

3.3. Provider feedback on patient dignity question summary

The 36 staff survey respondents were 68 % female with a mean age of 39 years (SD 9.3). They included nursing (61 %), physicians (25 %) and allied health (14 %), with a wide range of ICU work experience (1–5 years [18 %], 5 to 10 years [29 %], 10 to 20 years [39 %] and greater than 20 years [14 %]). Ninety-two percent of staff learned something new from the PDQ (mean 4.5 SD 0.8) and 86 % were emotionally affected by the PDQ (mean 4.1, SD 0.8). Staff reported that the PDQ influenced their sense of connectedness (81 %; mean 4.0, SD 0.7) and empathy (66 %; mean 3.7, SD 1.0). Half of the staff respondents reported the PDQ affected their satisfaction in caring for their patient (mean 3.5, SD 1.0). Besides influencing the overall tone of care, 25 % reported the PDQ influenced the physical care they provided (mean 2.8, SD 1.1).

Using conventional content analysis, we categorized the open-ended text-based comments from the healthcare provider survey into three themes: 1) Knowing the whole person, tailoring care; 2) Increased empathy; and 3) Beyond the patient, impacting family interactions. Within the theme of *Knowing the whole person, tailoring care*, healthcare providers documented that the PDQ allowed them to see their patients with renewed, broadened perspective, which promoted their ability to connect, and tailor care to meet their unique needs. For example, one provider wrote, "It states that she likes everything quiet when she sleeps. So I made sure no music was playing." While another noted, "By the summary I understood he spoke French therefore I spoke to him in French occasionally." Further, enhanced patient information provided by the PDQ allowed healthcare providers to offer trauma informed care, maximizing patient benefits while minimizing harms. As one participant wrote, "It was good to know about her history of abuse. This made me more mindful to cover her up properly and to tell her exactly what I'm doing before doing it." As another example of maximizing benefits and minimizing harms, one provider described, "I found out what hobbies he liked and therefore focused more on those topics when he was becoming increasingly upset. This gave me a better tool on interacting with my patient." Finally, providers said the PDQ promoted their ability to understand and advocate for their patients' wishes near the end of their lives. For example, "It was very important to have the knowledge of the religious background and wishes, so that I can advocate for her." A second theme of *Increased empathy*, was an evident impact of the PDQ, with one provider noting, "Now I see her [patient] as a person who is a loving grandmother and mother, not just another ICU/COVID patient." Another participant described the ways they were able to relate to their patient, which in turn, impacted their care provision, when stating, "It made me think of my own mother and father, and how I would want the best for them in the event they got admitted to a critical care unit. I feel I am more patient and loving in terms of how I assist her nurse with caring for her due to my knowledge of the PDQ." In the third theme, *Beyond the patient, impacting family interactions*, providers described how the PDQ supported not only their patient care, but also their family care. For example, one participant noted, "Made my interaction more personal with the patient and their family."

Table 2
Family feedback on ICU patient dignity summary using Likert scales.

	Strongly disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly agree (5)	Mean (SD)
The PDQ summary was accurate	0	0	0	12.1 %	87.9 %	4.9 (0.3)
The PDQ summary provides important information for your healthcare provider	0	0	0	18.2 %	81.8 %	4.81 (0.4)
The PDQ summary will affect the way your healthcare provider cares for you	0	6.1 %	6.1 %	42.4 %	45.5 %	4.3 (0.9)
The PDQ should be offered to other patients or families*	0	0	3.0 %	12.1 %	84.8 %	4.8 (0.5)
Completing the PDQ was a meaningful experience	0	0	3.0 %	12.1 %	84.4 %	4.8 (0.5)

* Missing one response.

4. Discussion

Juxtaposed on the highly technical ICU setting remains the frailty of life and the human experience. The ICU contains multiple barriers to offering person-centered, dignity-conserving care [27]. Minute-to-minute data involving numerous physiologic processes used to make treatment decisions can obscure clinicians from seeing patients and families. An ideal empathic distance is dynamic and must continuously be negotiated and managed within each clinical encounter. Dehumanization can easily occur when patients are surrounded and supported by technology; unable to communicate or participate in their care plans [49]. These dehumanizing aspects of ICU care were particularly salient during the COVID-19 pandemic. While the rational for dehumanization is based on protecting healthcare providers from feeling the patient's pain and distress, it is nevertheless important that they know the patient is suffering [50]. While becoming enmeshed in the patient's anguish can render healthcare providers ineffectual, being too distant can lead to professional burnout and yield deleterious effects on patients and families including difficulty identifying values-based goals of care. This study demonstrated that using PDQs was an effective and feasible way to elicit information from families regarding patient personhood, and valued by families and healthcare workers.

The composition of our cohort suggests PDQ application may be highly generalizable. These general systems ICUs—both medical and surgical—provide service to people living in the province of Manitoba, including its capital Winnipeg; and those from northwestern Ontario. Hence, its catchment subsumes rural and urban populations. Further, our demographic data affirms considerable diversity across age, gender, ethnicity (with 30 % identifying as non-white), socio-economic status (with 57 % reporting less than $60,000 household income and rest more), and educational background (with 61 % reporting high school education, with the remainder split between those with more and less education).

Interventions such as Get to Know Me Boards (GTKMB) and Footprints Whiteboards are designed to promote awareness of personhood in a medical setting [34–37]. They usually contain critical, albeit cryptic information about patients that is displayed for the healthcare team. The

Table 3
Staff ($N = 36$) feedback on ICU patient dignity summary using Likert scales.

	Strongly disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly agree (5)	Mean (SD)
Did you learn something new from the PDQ?	2.8 %	0 %	5.6 %	30.6 %	61.1 %	4.5 (0.8)
Were you emotionally affected by the PDQ?	0 %	5.6 %	8.3 %	58.3 %	27.8 %	4.1 (0.8)
Did the PDQ influence your attitude towards the patient?	2.8 %	13.9 %	27.8 %	36.1 %	19.4 %	3.6 (1.1)
Did the PDQ influence your care of the patient?	13.9 %	25.0 %	36.1 %	16.7 %	8.3 %	2.8 (1.1)
Did the PDQ influence your respect for the patient?	8.3 %	11.1 %	38.9 %	27.8 %	13.9 %	3.3 (1.1)
Did the PDQ influence your empathy for the patient?	5.6 %	5.6 %	22.2 %	44.4 %	22.2 %	3.7 (1.1)
Did the PDQ affect your sense of connectedness with the patient?	0 %	2.8 %	16.7 %	61.1 %	19.4 %	3.7 (1.1)
Did the PDQ affect your satisfaction in caring for the patient?	0	16.7 %	33.3 %	33.3 %	16.7 %	4.0 (0.7)

Table 4
Comparisons of typical whiteboard content versus PDQ exemplars.

Personal characteristic(s)
Typical Whiteboard Example: Considerate

- PDQ exemplar: The patient's wife says she "wants the staff to know that her husband is a good man. He is a loving, caring and devoted husband, brother, father and grandfather. He is so much more than just his illness. He has always helped his community when the opportunity arose, and she is happy that now people are helping him get better.

Family role(s)
Typical Whiteboard Example: Devoted father

- PDQ exemplar: His parents describe their son, "His warm and loving personality is not only felt by friends but also his family. He is a father of five, who spent much of his time sharing his love for sports with his children. He taught them how to play hockey, skate and play baseball to list a few. His love for his children remains strong and unconditional.

Typical Whiteboard Example: Family Provider

- PDQ exemplar: His kids say that their dad was the best provider. He never complained about providing and did it with so much grace.

Vocational role(s)
Typical Whiteboard Example: Farmer

- PDQ exemplar: She says his favorite thing to do is to go on a drive and pass by all the farms to see their crops, "because he's a farmer at heart".

Typical Whiteboard Example: Successful businessman

- PDQ exemplar: After his father unexpectedly passed away at a young age, "J" and his brother took over the family business, and after just a short time, turned it into a successfully business with over 400 employees. His role as a successful business owner is one he takes great pride in. However, he takes the most pride in telling people that his employees are more like family than anything else.

Co-morbid condition(s)
Typical Whiteboard Example: Mental Health Issues

- PDQ exemplar: A patient's sister said of her brother, "his perception of what people are doing is different than how we may interpret it, because of his mental health issues" so this is something she would like the staff to be cognizant of.

Typical Whiteboard Example: Organ transplant recipient

- PDQ exemplar: He has been exceptionally grateful for a second chance to live after receiving a double lung transplant 15 years ago. He has a strong desire to live life to the fullest and ensured that he did not take this opportunity for granted; he exercises faithfully and is always vigilant with his health. He would say "these lungs were given to me by a young man so, I need to take care of them".

Hobbies
Typical Whiteboard Example: A wonderful cook.

- PDQ exemplar: The patient's husband described his wife as "one hell of a cook". He often found humour on the days where she would be watching cooking shows and say "they're doing it all wrong, let me give this a try". She would then re-create those recipes with her personal touch often using vegetables from her garden that she proudly grew herself.

Key biographical information
Typical Whiteboard Example: Grieving loss of parents

- PDQ exemplar: According to the patient's two daughters, "after their mother's parents passed away, she wasn't really the same" Her daughters know their mum is a fighter but cannot help but wonder if mum has seen her parents calling her, and if she wants to be reunited with them again.

PDQ on the other hand is unique in being narrative based. While whiteboards, for example, might describe a patient being 'considerate', an exemplar PDQ addressed this characteristic as follows:

> She (the daughter of a 90-year-old ICU patient) says her dad is one of the sincerest people she knows, and even if he cannot communicate his feelings to the staff, she knows he is as concerned about the staff's wellbeing, as they are for his.

Whiteboards may include biographical content, such as 'residential school survivor'. The daughter of an Indigenous patient conveyed her mother's experience by way of the PDQ as follows:

Despite being a residential school survivor, losing her father at a young age and later having her daughter 'go missing; for the past 13 years, "she continued to be present and be the best mother possible to her children. This loss has in some ways strengthened her and has pushed her to become an advocate for young women and girls who have gone missing. She once said, "I want to be the voice for those who cannot speak for themselves" (see Table 4 for other examples).

Given they are brief narratives, PDQs can be more detailed, nuanced and emotionally evocative relative to traditional whiteboards [51,52]. Unlike the latter, the process of eliciting PDQs is conversational and relational; hence, almost without exception, families reported this to be an emotionally meaningful experience. It is also noteworthy that every family member approached to take part in this study consented to do so; hence attesting to the acceptability and feasibility of this approach.

This study differs from previous PDQ research that has taken place in palliative care and outpatient oncology patients [29,40–42]. First, ICU is a very different patient population with respect to illness trajectory, disease, prognosis, and treatment options. Secondly, this study used family as the exclusive source of information regarding patients' personhood. Families reported the PDQ was an accurate reflection of their loved one, containing important information for the healthcare team. Finally, due to COVID-19 pandemic restrictions, almost all PDQ interviews took place by telephone ($N = 27$; 82 %), in contract to the usual in-person ($N = 6$; 18 %) administration.

The PDQ summary may have multiple benefits. It may mitigate feelings of distress and emotional assault by assuring ICU families that their loved one is being cared for in a compassionate and respectful manner and acknowledged as a person beyond their illness [24]. By helping ICU families and the health care team focus on patient's personhood, the PDQ can improve quality and timing of goals of care discussions, ensure treatment directions that are consistent with patient wishes [53], and decrease family burden associated with the surrogate decision-making process. Due to patient incapacity, ICUs frequently rely on shared decision making with the family to elicit direction of care and treatment decisions. The core of this shared decision-making model requires an understanding of the patient as a person to best determine their wishes, but often struggle to include patients' values and preferences [53,54]. Critical care has high rates of health care worker burnout, accentuated during the COVID-19 pandemic [18,55]. In palliative care, receptiveness to PDQ elicited information is associated with improved healthcare professional job satisfaction, meaning in life and overall personal empathy [29]. In this study, staff reported the PDQ summary improved their understanding of and empathy towards patients and their families. Healthcare professionals' empathy and compassion can improve job satisfaction, decrease burnout [56,57], and relieve ICU associated distress [58], while poor communication and lack of empathy is associated with increased medical litigation [23,59,60]. Compassion satisfaction, referring to the pleasure elicited from showing compassion to others, can help prevent healthcare worker burnout [61]. The PDQ may protect healthcare professional from burnout by improving empathy and compassion satisfaction [29,62]; empathetic clinicians are associated with improved patient outcomes [6,63]. Enhanced empathy and awareness resulting from the PDQ can also elicit trauma informed care [64].

As evidence mounts PDQs will need to extend beyond research, finding their way into routine ICU practice. The Society of Critical Care Medicine (SCCM) publishes standards and guidelines on family-centred care for adults in ICUs [65]. Their recommendations include a variety of measures, including liberal family presence, using ICU diaries for ICU families, and identifying and supporting the spiritual needs of families of ICU patients. While they recommend communication skills training to clinicians, there is no mentioned whatsoever of personhood and the importance of knowing who patients are as persons. To redress this absence, professional societies such as the SCCM should include a broad range of studies that reflect the voices of patients and families. Meta-synthesis research summarizing qualitative studies may be one way of integrating those missing and critical perspectives within the guidelines which tend to prioritize quantitative evidence. PDQs are a viable means of eliciting personhood within the ICU setting. They can be completed in relatively little time by people who are good listeners and adept at distilling patient disclosures into a few paragraphs. This skillset could be taught to physicians, residents, nurses, and perhaps more practically, psychosocial clinicians such as ICU social workers or healthcare chaplains. Implementing this approach could help transform the culture of ICUs, wherein attentiveness to personhood, with or without PDQs, becomes an essential element of healthcare.

While our muti-method design was well suited to this feasibility study, there are various limitations worth noting. First and foremost, this was an exploratory study whose intent was to apply a novel means of eliciting personhood in the ICU setting. Only families of ICU patients at high risk of death were approached to participate; we also cannot make any inferences about how the PDQ was perceived by healthcare providers who did not respond to the post-intervention survey. The sample size was relatively small, with clinicians' perhaps hesitant to refer until there was more certainty of death with a definitive plan for transition to comfort focussed care. By then limited life expectancy may have precluded study referral and enrollment. High workloads and staff shortages during the COVID-19 pandemic also impeded study referrals and the number of staff providing feedback. Like most feasibility studies, we did not have a comparison group and cannot comment on the potency of PDQs to elicit empathic connections relative to other approaches such as the Footprints Whiteboards or Get To Know Me Boards. While COVID related public health restrictions limited family presence, it is likely that applying PDQs in person would only enhance easier administration of this personhood eliciting approach. Finally, because this study was one of several within a program of research on death and dying during the pandemic, enrollment was limited to patients at high risk of dying. Personhood is relevant despite prognostic expectations, meaning the PDQ likely has applications that extend beyond patients who are imminently dying.

Future research may engage larger samples and apply more formal experimental designs, comparing various personhood-eliciting approaches. It would be important to study if the PDQ improves mental health for families, and patients able to provide this information on their own. Future studies should also explore the impact of PDQs on ICU survivors' experience and the decision-making process. It is also important to examine if this narrative approach elicits responses from staff that help them engage in humanistic dimensions of medicine, and how this might influence their vulnerability to burnout. Future research may also determine if PDQs have differential effects amongst healthcare professionals across key demographic variables, such as gender, disciplinary affiliation and years of experience.

5. Conclusions

Events during and following the ICU stay can be traumatic for patients, their families and the healthcare team. The provision of person-centered care in the ICU is extremely important, albeit challenging.

The PDQ appears to be a straightforward, low resource intervention that can be implemented in most ICU settings, where usual culture and workflow do not facilitate a process or space for acknowledging personhood. This study found using the PDQ to elicit information related to personhood in the ICU was feasible—with every family approached consenting to take part—and highly valued by families and health care staff. Further rigorous studies are needed to establish the place for PDQs within ICUs, exploring how they improve outcomes for patients, families, and healthcare professionals alike.

CRediT authorship contribution statement

Kendiss Olafson: Writing – review & editing, Writing – original

draft, Supervision, Project administration, Methodology, Investigation, Data curation, Conceptualization. **Salina Pirzada:** Writing – review & editing, Project administration, Data curation. **Lucas Mosienko:** Writing – review & editing, Investigation, Data curation. **Kelsey Papineau:** Writing – review & editing, Investigation, Data curation. **Lily Pankratz:** Writing – review & editing, Investigation, Formal analysis, Data curation. **Gagan Gill:** Writing – review & editing, Formal analysis, Data curation. **Tim Hiebert:** Writing – review & editing, Data curation, Conceptualization. **Maia S. Kredentser:** Writing – review & editing, Formal analysis, Conceptualization. **Kristin Reynolds:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Formal analysis, Data curation, Conceptualization. **James M. Bolton:** Writing – review & editing, Formal analysis, Data curation, Conceptualization. **Renée El-Gabalawy:** Writing – review & editing, Methodology, Formal analysis, Conceptualization. **Christian La Rivière:** Writing – review & editing, Investigation, Data curation, Conceptualization. **Harvey Max Chochinov:** Writing – original draft, Supervision, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Author statement

All authors have approved the final manuscript and agree to be accountable for the work.

Declaration of competing interest

None of the authors have any conflicts of interest to declare.

None of the author have any financial and personal relationships with other people or organizations that could inappropriately influence or bias their work.

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