

Research in Progress: What do “We” Care About at Our End-of-Life? A Qualitative Study Exploring Culturally Inclusive End-of-Life Care in Critical Care Settings

Kathy Le, Ron Shiu, Jennifer Hamera, Kim Woody, Tanya De Leon, and Vininder K. Bains



Background

- Culture influences many parts of end-of-life care¹
- Canada is increasingly culturally-diverse²
- Limited studies on culture and end-of-life in critical care³⁻⁴

Research Questions

- How do patients' and patients' families' culture contribute or influence their experiences of end-of-life in the critical care setting?
- What are recommendations for improving culturally sensitive and inclusive end-of-life care?

Methodology

What: Semi-structured interviews
Who: Families of patients who have died in the last five years
Where: St. Paul's Hospital Critical Care Program in Vancouver, British Columbia
When: August 2022 to present
Why: A Providence Health Care Research Challenge project which aimed to improve culturally sensitive and inclusive end-of-life care in critical care settings

- **Interpretive Description:** a qualitative methodology that allows us to look for the “why” but in a way that makes it easier to inform practice
- It allows us to be flexible and borrow elements of different methodologies to meet our practical needs⁵

Study Design

- **Goal:** At least 10 interviews with culturally-diverse family members of patients who have died in St. Paul's Hospital critical care units within the last five years
- **Recruitment:** Send out a recruitment letter in multiple languages plus a follow-up phone call
- **Semi-structured interviews:** Three main questions include:
 - Can you tell me your experiences with your loved one here in the hospital?
 - How did your cultural background influence your experience with your loved one's end of life care?
 - What can we do to adapt our critical care program to be more inclusive and welcoming?
- Interviews can be conducted in person or virtually, using translation services for over 180 languages
- Interviews are professionally transcribed
- **Transcriptions** are analyzed and discussed by our research team and patient family partners

Timeline and Recruitment

- **ICU:** Intensive Care Unit
- **LOS:** Length of Stay in critical care units
- **NoK:** Next of Kin
- **CICU:** Cardiac Intensive Care Unit
- **CSICU:** Cardiac Surgery Intensive Care Unit

Recruitment Wave 1 (Aug 2022)

- Practice interviews with 2 patient family partners
- 99 deaths in ICU from Aug 1, 2021 to May 31, 2022 with LOS ≥ 2 days
- 47 NoK addresses found in chart review and letters sent
- 3 interviews completed

Broadening the Date Range: Recruitment Wave 2 (Jan 2023)

- 271 death in ICU from **Aug 1, 2019 to July 31, 2022** with LOS ≥ 2 days
- 99 of which were from previous recruitment; 172 new cases
- 34 recruitment letters sent
- 1 interview completed

To date we currently have 4 participant interviews and 2 patient family partner interviews completed and transcribed.

Next Steps: Recruitment Wave 3 (Sept 2023)

- Expanded recruitment to include CICU and CSICU
- 105 CICU and CSICU deaths from Aug 1, 2019 to July 31, 2022 with LOS ≥ 2 days
- Received approval from Privacy Office for follow-up phone call after letter
- Translated recruitment letter to 11 languages to improve recruitment of those who don't speak English
- Increased participant honorarium from \$20 to \$75 gift card to improve recruitment

Equity, Diversity, and Inclusion

- Our **team** includes persons of different ethnicities and cultures
- We view our results both as clinicians and as persons of diverse cultural backgrounds
- Many of us have family members who may speak English as a second or third language, so we have these perspectives when trying to understand the impact of culturally-sensitive (or insensitive) care
- For **recruitment**, our letter of invitation is available in 11 different languages
- For our **interviews**, we have 24/7 translation services for over 180 languages
- For **Sex- and Gender-Based Analysis**, all our interviews have been conducted with women (mom/partner/wife)
- Throughout history, women have traditionally been in the caregiver role⁶
- What can we do to also include men's voices as family members of patients who pass away?
- **How can we elicit more diversity in our participants and their contexts?** Participants all have a Euro-Canadian background but there is socioeconomic diversity (Downtown Eastside (DTES), middle-class, and upper-middle class)
- Marginalized populations that historically are not reflected in research are being unfairly excluded due to the barrier of limiting initial contact to addresses only⁷ - are there other strategies we can use to address this inequity?



We (Critical Care/Healthcare System) Have a Culture

A family's worst day versus a critical care nurse's “normal” day

I thought when they meant turn off the machines, they turned off the machines. I didn't realize they extubated...So, that one caught me off guard, I have to say...I couldn't figure out why that guy was standing there the whole time, waiting. I was like, “What are we doing?” “What are we waiting for?” But then I realized afterwards that he had to take the tube out and I was like, “Oh...!”

It is not uncommon to bury one's critical care experience with diagnosis, prognosis, and treatments...but do we as clinicians not only hold space, but hold enough space - enough safe space for cultural practices? How it is so easy to overlook.

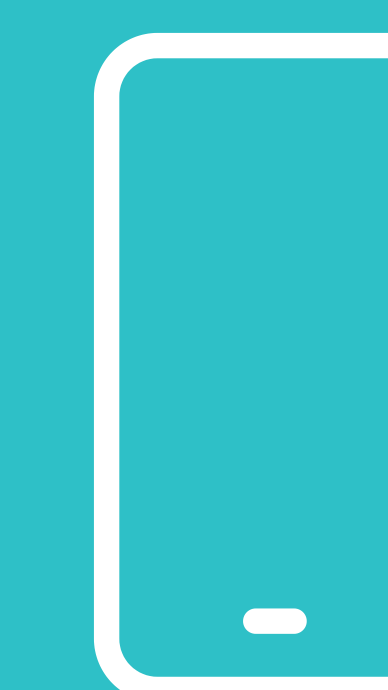
It's Hard to Ask About Culture

- Culture is not visible; it's innate, and is expressed not only in what we say, but in how we tell our stories
- Cultures can be blended
 - a participant was a non-practicing Jehovah's Witness, and the patient had strong connections to his Indigenous background
- Culture and common community
 - both patient and participant were from the DTES community, and shared the common experience of marginalization, stigmatization, judgement, and drug use culture.

ASKING ABOUT CULTURE...
IS LIKE ASKING A FISH ABOUT WATER
– Sheila Lindfield, Patient Family Partner

Acknowledgements

- Patient family partners Sheila Lindfield and Prachi Khanna
- Providence Health Care Practice-Based Research Challenge Award
- Canadian Association of Critical Care Nurses Research Grant



SCAN ME
FOR CONTACT
INFORMATION
AND
REFERENCE LIST

