



# The Canadian Journal of Critical Care Nursing

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# The Canadian Journal of Critical Care Nursing

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P.O. Box 25322, London, Ontario N6C 6B1  
caccn.ca  
email: caccn@caccn.ca  
phone: 519-207-7007  
toll-free: 1-866-477-9077  
fax: 519-649-1458

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# Canadian Association of Critical Care Nurses

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All critical care nurses provide the highest standard of patient- and family-centred care through an engaging, vibrant, educated and research-driven specialized community.

## Mission statement

We engage and inform Canadian critical care nurses through education and networking and provide a strong unified national identity.

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Our core values and beliefs:

- Excellence and Leadership
  - Collaboration and partnership
  - Pursuing excellence in education, research, and practice
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  - Respectful, healing and humane critical care environments
  - Combining compassion and technology to advocate and promote excellence
- Integrity and Honesty
  - Accountability and the courage to speak up for our beliefs
  - Promoting open and honest relationships

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### 1. Leadership:

- Lead collaborative teams in critical care interprofessional initiatives
- Develop, revise and evaluate CACCN Standards of Care and Position Statements
- Develop a political advocacy plan



### 2. Education:

- Provision of excellence in education
- Advocate for critical care certification

### 3. Communication and Partnership:

- Networking with our critical care colleagues
- Enhancement and expansion of communication with our members

### 4. Research:

- Encouraging, supporting, facilitating to advance the field of critical care

### 5. Membership:

- Strive for a steady and continued increase in CACCN membership

# Virtual reality as an adjunctive comfort measure in the intensive care and coronary care unit: A nurse-led quality improvement project

By KATHERINE A. KISSEL, MN, RN, CNCC(C), ACCN, ANDREA SOO, PHD, AND KIMBERLEY TATESON BENNETT, RN

## Abstract

**Background:** Pain, discomfort, and anxiety in critical care units are complex, multifaceted experiences. Nurse-led implementations of adjunctive comfort measures in critical care settings are essential components in the holistic management of these experiences. Virtual reality is gaining popularity as an adjunctive comfort measure across acute care settings to promote patient comfort, though there is limited evidence examining the utility of virtual reality in critical care.

**Purpose:** Firstly, to determine if virtual reality, as a nurse-led adjunctive comfort measure, improved patient self-reported pain, discomfort and relaxation. Secondly, to identify if virtual reality led to significant alterations in patient physiological variables.

**Methods:** A quality improvement project was performed with intensive care and coronary care unit patients receiving virtual reality immersion. Pre- and post-tests measured self-reported pain, relaxation, and general/overall discomfort. We examined pre and post vital signs and adverse outcomes (nausea, dizziness,

eye strain/discomfort). We used paired *t*-tests to compare outcomes pre- and post-virtual reality.

**Results:** Post-virtual reality, patient ( $n = 13$ ) scores showed significant reductions in pain (mean improvement: 1.04, 95% CI [0.45, 1.62]), relaxation (mean improvement: 3.08, 95% CI [0.45, 0.62]), general/overall comfort (mean improvement: 2.08, 95% CI [0.86, 3.30]), and respiratory rate (mean reduction: 1.54, 95% CI [0.22, 2.86]). There were no significant changes in adverse events or other physiological variables.

**Conclusion:** Virtual reality was deemed a safe, effective adjunctive comfort measure within one intensive care unit and coronary care unit. Virtual reality may be a useful tool to reduce pain, discomfort, and improve patient relaxation in critical care settings, though research within this specialized population is needed.

**Keywords:** virtual reality, comfort measure, pain, relaxation, critical care

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## Implications for Nursing

- Virtual reality as an adjunctive comfort measure, as well as a pain distractor, is gaining popularity, though evidence pertaining to its use within critical care is limited.
- This quality improvement project highlights the potential benefits of virtual reality as a nurse-led adjunctive comfort measure, and when used within defined parameters, significant improvements in patient pain, comfort and relaxation were observed.
- Research is needed to examine the use of virtual reality amongst larger, randomized, critical care populations, utilizing validated tools where applicable.

## Background

Pain in the intensive care unit (ICU) is a complex phenomenon: underlying critical illness, chronic and comorbid conditions, the presence of invasive lines, and procedural pain (both related to medical and nursing procedures) all contribute to pain sources within the critical care environment (Devlin et al., 2018; Puntillo et al., 2014; Tracy & Chlan, 2011). Inadequate pain management in the ICU has been demonstrated to have adverse impacts on patients' physiological and mental status. These alterations may negatively impact patient recovery and prolong ICU length of stay (Shahriari et al., 2015). Further, anxiety and pain are often

interrelated. Some studies have found where patients experience increased pain scores, they also experience more severe symptoms of anxiety (Castillo et al., 2016; Filipovic-Grcic et al., 2010). Fear, underlying physiological conditions, sleep disturbance, and inability to communicate, as well as loss of control and the presence of mechanical ventilation, may further contribute to patient anxiety (Meghani et al., 2017; Rotondi et al., 2002; Tracy & Chlan, 2011). Pharmacological pain management in the ICU is often indicated. However, the excessive use of opiate analgesia and sedation are associated with increased risk of adverse patient outcome including respiratory depression, prolonged mechanical ventilation and increased length of stay in the ICU (Balzer et al., 2015; Devlin et al., 2018). In order to reduce such adverse outcomes, Devlin et al. (2018) highlight the need for ongoing, protocolized pain assessment and management, and recommend the use of adjunctive pharmacological and non-pharmacological therapies within the ICU.

In accordance with the Canadian Association of Critical Care Nurses (2017), critical care nurses play a key role in facilitating "optimal comfort and well-being in a highly technical environment" (p. 4). One way in which critical care nurses may independently promote patient comfort, reduce pain, or enhance the effectiveness of pharmacological approaches is through the implementation of adjunctive, or

non-pharmacological, therapies (Meghani et al., 2017; Tracy & Chlan, 2011). An interest in the utility of specific adjunctive therapies to enhance patient outcomes is growing within the literature. In particular, the use of virtual reality (VR) is expanding across the acute care setting, with potential benefits cited as originating from the immersive nature of the VR environment (Dascal et al., 2017; Tashjian et al., 2017).

VR is defined as “an artificial environment... experienced through sensory stimuli... and in which one’s actions partially determine what happens in the environment” (Merriam-Webster, 2018). Within the inpatient healthcare setting, head mounted VR devices are becoming increasingly popular, as they are easy to use and allow the user to customize their own experience through interaction with the virtual environment (Dascal et al., 2017; Mallari et al., 2019). Though numerous studies examine the impact of VR on patient outcomes, the level of evidence varies. Within two recent systematic reviews, it was noted that VR was a useful tool in the inpatient setting to provide pain distraction and reduce pain levels during painful procedures (Dascal et al., 2017; Mallari et al., 2019). VR may have further benefit in the reduction of chronic pain during or immediately post-VR usage. However, evidence is limited regarding lasting analgesic effect (Jin et al., 2016). Additionally, few studies noted significant reduction in opiate use in patients undergoing painful procedures who utilized VR distraction compared to those who did not (McSherry et al., 2018; Pandya et al., 2017). Though Tashjian et al. (2017) also found VR to be an effective adjunctive therapy to reduce patient pain, they highlight that additional research is required to determine if VR, as a meditative intervention, may further promote patient comfort in acute care settings where patients often experience lack of control and routine.

Despite the growing body of literature, evidence regarding VR use as an adjunctive comfort measure within critical care remains limited (Devlin et al., 2018). To date, three publications were located which examined VR use in a critical care environment, though they lack transferability specific to the patient population within this project. At the time of project inception, one study reported that patients post cardiac surgery ( $n = 67$ ) experienced reductions in pain levels (88%), and improvements in physiological variables post VR intervention (Mosso-Vázquez et al., 2014). These authors highlight VR was an effective method to safely reduce pain as an “additional support mechanism” through its distractive properties (p. 377). Two additional publications were located post project completion, including one case report in which VR was utilized to reduce patient anxiety while undergoing extracorporeal membrane oxygenation (Blair et al, 2019). The final noted in a feasibility study that VR was generally well tolerated by patients, provided environmental distraction, and promoted patient relaxation (Gerber et al., 2019). Recognizing the limited body of evidence examining VR application within critical care, it is important to further examine the use of VR within this setting.

## Purpose

The overarching purpose of this quality improvement (QI) project was to determine if the use of virtual reality as an adjunctive

comfort measure improved patient comfort in one ICU and one coronary care unit (CCU). Specific aims included whether the use of VR would lead to improvements in: patient self-reported pain, levels of overall discomfort, and relaxation. Secondary outcomes included whether the use of VR in the ICU and CCU would lead to reductions in physiological variables including heart rate, respiratory rate, and mean arterial pressure. Results of the project would be used to determine if a VR program could be immediately implemented within the ICU/CCU, as an adjunctive patient comfort measure.

## Methods

### Quality Improvement Framework and Project Approval

The project was formulated utilizing a Plan, Do, Study, Act (PDSA) improvement framework (Institute for Healthcare Improvement, 2021). Though the project met criteria for QI (including goal of immediate practice improvement in the defined setting), to further identify if a formal ethics committee review was required, the Project Ethics Community Consensus Initiative (ARECCI) *Ethics Guideline* and *Screening Tools* were completed (Alberta Innovates, 2017). The purpose of these tools is to aid teams in identifying the ethical risks and management strategies associated with non-research projects (Alberta Innovates, 2017). Based on scoring recommendation, a formal ARECCI second opinion review was obtained. This second opinion review further determined project submission to a formal ethics review board was not required.

Senior administrative leadership within Alberta Health Services and the medical directors for both Intensive Care and Coronary Care within the departmental portfolios provided approval for this project. Consideration of patients’ safety, dignity, anonymity, and protection from coercion was incorporated into the project design. Informed consent was obtained prior to commencing individual trial. Consent script was utilized to ensure consistency and to ensure all information was covered prior to eliciting consent from patients.

### Design

We utilized a pre-post survey for the project to determine if use of a VR application reduced pain and discomfort, and improved relaxation in the critical care patient population. Through the PDSA framework, each patient survey was reviewed. Based upon survey results and patient-reported experience, it was deemed no further PDSA cycles were required.

### Sample

Convenience sampling from the patients admitted to the ICU or CCU occurred between May 2018 and January 2020. In order to be able to validate results from the data collected, we had originally aimed to include approximately 30 patients for this project. However, due to time restraints, and unanticipated barriers to VR application (device access, facilitator model, workload, environmental demands and priority needs of the ICU/CCU), we were only able to survey a smaller sample of patients.

### Recruitment

Initially, unit nurses were provided education regarding the VR project in order to support patient recruitment and enrollment,

with a trained volunteer to support device setup one day per week. However, when patients were identified, volunteers were unavailable, and no patients were enrolled. Subsequently, to ensure suitable enrollment into the project, patients were approached and verbally invited to participate by a Clinical Nurse Educator (CNE) or Clinical Resource Nurse (CRN) based on their knowledge of inclusion and exclusion criteria and device training. Patients were given a brief description of the VR intervention and if they were interested in participating, verbal consent was obtained (as deemed appropriate through the ARECCI second opinion review). A single page of information was shared with prospective patients to provide an image of the VR environment as well as potential triggers within the environment (e.g., fire burning in fire pit, animals found in the forest). Patients were informed of the purpose of the trial as well as potential adverse effects in order to make an informed decision.

### **Inclusion/exclusion criteria**

Inclusion criteria will encompass the patient being awake, alert, oriented, cooperative, hemodynamically stable, and must be able to sit in high-fowlers position and have trunk/abdominal control, ability to interact with the VR environment, operate the VR remote (or at minimum remove the device from their face), and identify relevant fears/triggers to avoid within the VR environment.

In addition to absence of inclusion criteria, the following excluded patients from VR usage for project purposes: hemodynamic instability including active chest pain, pre-existing or predisposition to nausea/vertigo, motion sickness for any intubated patient or patient deemed an aspiration risk, susceptibility to claustrophobia, presence of active dementia, alternative neurological/cognitive disturbances including delirium, recent stroke, seizure disorder, psychiatric disorders, facial injury rendering the patient unable to wear the VR device, absence of audiovisual aids (i.e., hearing aids/glasses), isolation precautions, or non-English speaking.

Consideration of inclusion and exclusion criteria were established to control for confounding variables. For example, timing of VR was intentionally delayed around administration of analgesia to avoid possible attribution of analgesia to change in self-reported scores. Further, the pre-test was performed immediately prior to intervention and the post-test completed immediately after intervention in an effort to capture changes in self-reported scores.

### **Setting**

The project was performed in the participant's room within the ICU or CCU. Patients were required to be either in bed, sitting in high-fowlers position, or in a stationary chair for the duration of the trial. VR immersion lasted between 10–20 minutes with the option to discontinue at any time.

### **Intervention**

The intervention was the VR application environment consisting of an animated, interactive, virtual space that also included guided meditation and background music. The VR experience featured a quiet nature scene and was selected for three main

reasons. Firstly, the overall theme of the app was promoted as calm and relaxing. Secondly, simplicity of the experience did not pose some of the issues that other more realistic or game-based VR experiences may provide (e.g., rapid profile movements, fear of heights/water submersion, interaction with natural elements, etc.). Thirdly, minimal patient engagement with the environment was required due to the presence of invasive lines (e.g., avoiding significant head movements).

### **Procedure**

After verbal consent was obtained, the pre-test questionnaire was completed by the patient, with vital signs being completed by the CNE or CRN. Orientation to the remote control was provided prior to the patient donning the VR headset. Once the VR headset was placed, the patient was guided through setup on the VR app. Unless the patient had requested to stop the immersion, the nurse would ask them at the 10-minute mark if they wanted to continue for up to an additional 10 minutes (20 minutes total immersion time). After completion of the VR immersion, the post-test questionnaire was completed and the CNE or CRN obtained a second set of vital signs. In order to ensure patient safety and monitor for adverse effects of immersion (nausea, eye strain, dizziness) the CNE or CRN continuously monitored the patient for the duration of the trial.

### **Outcomes**

The primary outcomes were self-reported scores regarding: pain, relaxation, and discomfort. Pre-test, post-test questionnaires were created for ease and usability. Pain assessment and relaxation were placed on the zero to 10-point scale (McSherry et al., 2018). The term relaxation was used instead of anxiety to avoid clinically implicit language as well as effects of polarizing terminology with patients (Tate et al., 2012). There are many validated tools to measure anxiety, relaxation, and mindfulness. However, given the scope of this QI project, none were deemed appropriate due to complexity. The self-reported measure of discomfort was placed on a Likert scale of 7 based on agreement with a statement (1 = strongly disagree, 2 = disagree, 3 = somewhat disagree, 4 = neither agree nor disagree, 5 = somewhat agree, 6 = agree, 7 = strongly agree). A seven-point Likert scale was selected for simplicity, ease of use, and increased accuracy of reporting (Finstad, 2010).

Secondary outcomes were monitoring for adverse events including nausea, dizziness, and eye strain/discomfort, as well as changes to vital signs before and after a VR intervention. A seven-point Likert scale based on degree of agreement with a statement (as outlined above) was used to measure adverse event outcomes. In addition to the self-rating component of the survey, patients were given the option to capture thoughts, feelings, or comments in an optional free text response. Utilization of current literature was used to guide and develop appropriate criteria and consideration to ensure safety of patients (Bruck & Watters, 2011; Nichols & Patel, 2002; Tashjian et al., 2017).

On the post-test questionnaire, four additional questions were asked (seven-point Likert scale); three questions specifically targeted the VR environment (realness of environment, interest in further VR experiences, and recommendation to others) and one addressed sense of overall comfort.

## Data Analysis

Descriptive statistics were utilized to report results using frequencies with percentages, means with standard deviations (SD) or medians with interquartile ranges (IQR), as appropriate. Data was analyzed using R, version 4.0.0 (R Core Team, 2020). Paired t-tests were used to compare primary and secondary outcomes pre- and post-VR. Boxplots were utilized to review the distributions of differences in pre- and post-VR scores. As not all distributions were relatively symmetrical, sensitivity analyses were also done using Wilcoxon signed ranked tests.

## Results

Thirteen patients met the eligibility criteria and consented to participate in the VR trial between May 2018 and January 2020. As this was a QI initiative, the number of individuals excluded or whom declined to participate were not tracked. Reasons for exclusion included presence of isolation precautions, and on one occasion, patient reported fear of environmental triggers. Of the 13 patients, 4 (31%) were male with a mean age of 68.5

years ( $SD = 7.33$ ), and 7 (69%) were female with a mean age of 58.3 years ( $SD = 11.77$ ). Primary admission diagnoses were 46% cardiac ( $n = 6$ ), 23% respiratory ( $n = 3$ ), 23% sepsis ( $n = 3$ ), and 8% gastro-intestinal bleed ( $n = 1$ ) (Table 1).

### VR Immersion

Mean duration in VR was 15.5 minutes ( $SD = 4.7$ ). Six (46%) patients completed the full 20-minute immersion. Of the seven sessions discontinued prior to maximal allotted time, where recorded ( $n = 3$ ), reasons cited for early discontinuation were: interruption for patient rounds ( $n = 1$ ), toileting requirements ( $n = 1$ ), and post session report of inability to hear audio ( $n = 1$ ). No patient requested early discontinuation due to undesired effects including presence of, or increase in nausea, dizziness, or eye strain/discomfort. Post survey results reported no occurrence of other adverse event or patient deterioration.

### Primary Results

Analyses comparing outcomes pre-post VR are in Tables 2 and 3, respectively. All three primary outcomes (pain, relaxation and general/overall comfort scores) demonstrated statistically significant improvement post VR. Pain scores improved in 8 (61.5%) patients with a mean improvement of 1.04 (95% confidence interval [CI], (0.45, 1.62),  $p = 0.002$ ). Relaxation scores improved in 12 (92.3%) patients with a mean improvement of 3.08 (95% CI [1.66, 4.50],  $p = 0.001$ ). General/overall comfort scores improved in 9 (69.2%) patients with a mean improvement of 2.08 (95% CI [0.86, 3.30],  $p = 0.003$ ). No significant changes were noted to the secondary (adverse) outcomes including nausea ( $p = 0.22$ ), eye discomfort or strain ( $p = 0.83$ ), and dizziness ( $p = 0.10$ ). Any report of condition improvement or worsening within these secondary outcomes was a result of minor progression along the Likert scale, with no large swings from the disagreement to agreement categories, or vice versa. Of the physiological variables, respiratory rate was the only variable in which a significant change was noted (7.5% reduction, or mean decrease of 1.54, 95% CI [0.22, 2.86],  $p = 0.026$ ). No significant change was noted to heart rate ( $p = 0.65$ ) or mean arterial pressure ( $p = 0.84$ ) post VR. There was an observed trend towards increasing SpO<sub>2</sub> post VR, though this was not statistically significant ( $p = 0.058$ ). The analysis of SpO<sub>2</sub> was based upon a sample of 11, as SpO<sub>2</sub> recordings were incomplete for two patients.

### Post-Only Survey Results

Of post-survey data results, questions pertaining to immersion, and the general VR experience are summarized in Table 4. In alignment with self-reported findings of improved general/overall discomfort post VR, 92.3% of patient agreed that their VR experience *improved [their] sense of overall comfort* (some-what agree, agree, strongly agree). Finally, participants were offered to provide additional comments or feedback regarding their virtual reality experience. Responses, where provided, are summarized in Table 5. Key themes included annotated experiences of relaxation, distraction/escape, and nostalgia in relation to past experiences.

**Table 1**

#### Demographics

Participant Characteristics	N = 13
Sex, <i>n</i> (%)	
Male	4 (31)
Female	9 (69)
Age (years), mean (SD)	
Male	68.5 (7.3)
Female	58.3 (11.8)
Unit, <i>n</i> (%)	
ICU	7 (54)
CCU	6 (46)
Artificial airway, <i>n</i> (%)	
Yes	3 (23)
No	10 (77)
Admission Diagnosis, <i>n</i> (%)	
Infection / Sepsis	3 (23)
Primary Respiratory	3 (23)
Cardiac	6 (46)
GI Bleed	1 (78)
LOS* at time of VR (hours), mean (SD)	
Male	58 (33)
Female	113 (136)
LOS* at time of VR (hours), median (IQR)	
Male	56 (33, 80)
Female	53 (48, 96)

*Note.* LOS = length of stay on unit, rounded to the nearest hour. SD = standard deviation. IQR = interquartile range.

**Table 2***Paired t-test Analysis of Primary and Secondary Outcomes*

	Pre Mean	Post Mean	Mean difference (95% CI)	SD of difference	p-value	n (%) improved score	n (%) no change in score	n (%) worsening score	Direction, Percentage (%) of Change
Pain	3.04	2.00	-1.04 [-1.62, -0.45]	0.97	0.002	8 (61.5%)	5 (38.5%)	0 (0.0%)	↓ 34%
Relaxation	4.96	1.88	-3.08 [-4.50, -1.66]	2.35	0.001	12 (92.3%)	1 (7.7%)	0 (0.0%)	↑ 62%
General or overall discomfort	4.92	2.85	-2.08 [-3.30, -0.86]	2.02	0.003	9 (69.2%)	3 (23.1%)	1 (7.7%)	↓ 42%
Nausea	2.31	2.00	-0.31 [-0.82, 0.21]	0.85	0.22	2 (15.4%)	11 (84.6%)	0 (0.0%)	—
Dizziness	2.92	2.31	-0.62 [-1.38, 0.15]	1.26	0.10	4 (30.8%)	8 (61.5%)	1 (7.7%)	—
Eye discomfort or strain	2.46	2.38	-0.08 [-0.84, 0.68]	1.26	0.83	1 (7.7%)	9 (69.2%)	3 (23.1%)	—
Heart rate	81.3	80.5	0.85 [-3.16, 4.85]	6.63	0.65				—
Respiratory rate	20.5	19.0	-1.54 [-2.86, -0.22]	2.18	0.026				↓ 7.5%
SpO <sub>2</sub>	95.8	96.8	1.00 [-0.04, 2.04]	1.55	0.058				—
MAP	95.9	95.5	-0.46 [-5.48, -4.56]	8.31	0.84				—

Note. SpO<sub>2</sub> = oxygen saturation. MAP= mean arterial pressure. (—) = no significant change

## Discussion

The overarching purpose of this project was to determine if the use of virtual reality as an adjunctive comfort measure improved patient comfort in the ICU and CCU setting. Our findings demonstrated that utilizing VR as a nurse-led adjunctive comfort measure did reduce self-reported levels of pain and discomfort, while improving relaxation. No adverse events, including significant increases in nausea, dizziness, or eye strain/discomfort were reported. No significant change was noted to the vital signs (with the exception of respiratory rate) post VR. Self-reported findings were further reinforced by anecdotal post-session comments. These comments further align with previous VR literature including improved sense of well-being, increased relaxation, environmental distraction, and a decrease in pain.

VR applications are expanding across the acute care setting. While current gaps exist within the critical care literature pertaining to the use of VR as a comfort measure, this quality improvement project highlights the potential utility of VR in these specific critical care environments. Given the linkages between physiological and environmental alterations that occur within the critical care unit and patient experiences of pain and anxiety, implementation of non-pharmacological interventions is essential to support patient well-being (Meghani et al., 2017; Tracy & Chlan, 2011). Critical care nurses play an integral role in supporting this provision of non-pharmacological interventions (Canadian Association of Critical Care Nurses, 2017; Tracy & Chlan, 2011). Through this project, VR may be considered as a potential non-pharmacological measure in promoting patient comfort. Although our

**Table 3***Analysis Utilizing Wilcoxon Signed Ranked Test*

	Pre Median	Post Median	Median difference (post - pre) (IQR of median difference)	p-value from Wilcoxon signed rank test
Pain	3	2	-1 (-2, 0)	0.002
Relaxation	6	1	-2 (-5.5, -1.0)	0.001
General or overall discomfort	5	2	-2 (-4, 0)	0.003
Nausea	2	1	0 (0, 0)	0.22
Dizziness	3	2	0 (-1, 0)	0.10
Eye discomfort or strain	1	2	0 (0, 0)	0.83
Heart rate	79	76	-1 (-2, 0)	0.65
Respiratory rate	20	18	-1 (-2, 0)	0.026
SpO <sub>2</sub>	96	97	0 (0, 1.5)	0.058
MAP	98	93	1 (-4, 5)	0.84

Note. SpO<sub>2</sub> = oxygen saturation. MAP = mean arterial pressure. IQR = interquartile range

**Table 4***Post Survey Results*

Question	Strongly Disagree (Likert = 1)	Disagree (Likert = 2)	Somewhat Disagree (Likert = 3)	Neither Agree nor Disagree (Likert = 4)	Somewhat Agree (Likert = 5)	Agree (Likert = 6)	Strongly Agree (Likert = 7)	Median, (IQR)
Did the VR environment seem real?	0%	7.7%	7.7%	30.8%	7.7%	23.1%	23.1%	5.0 (4.0, 6.5)
If available, I would be interested in experiencing VR again?	0%	7.7%	0%	7.7%	23.1%	23.1%	38.5%	6.0 (5.0, 7.0)
I would recommend virtual reality to others?	0%	0%	0%	0%	7.7%	53.9%	38.5%	6.0 (6.0, 7.0)
The VR experience improved my sense of overall comfort?	0%	0%	0%	7.7%	15.4%	53.9%	23.1%	6.0 (5.5, 6.5)

Note. All percentages rounded to the first decimal place. IQR = interquartile range.

**Table 5**

*Post Survey Responses to Request for Comments/Feedback Regarding the VR Experience*

*Please provide any additional comments or feedback you wish regarding your virtual reality experience.*

Patient 1	“Reminds me of [a location]. Great colours and settings. Mask got hot on face. Great distraction.”
Patient 2	“Because I am on bedrest I had a bit of trouble turning my head certain directions (downward), but what I could see was really interesting. It helped me to relax and forget where I am for 20 minutes. It was nice it takes you out of the room. Not really reality, more like fantasy. Would have been nice to have sat higher up as there was a lot of activity going on down below that was difficult to see. Very peaceful. Commentator was very relaxing. If you hover over the book it will start again.”
Patient 3	“Very relaxing. Felt like a dream.”
Patient 4	“Relaxing.”
Patient 5	Cute to look at.
Patient 6	Takes your mind off everything. Better distraction because environment keeps changing and it’s unlike anything you have seen before. New to the senses. Can see the benefit to using this for procedures.
Patient 7	“I would have loved more of the rain and fog and more water lapping noises. I find them relaxing.” Next time would prefer to sit in a chair to be able to look around more. The happy place environment brought back some positive memories from childhood and early adulthood.”
Patient 8	When told [they] had been in the environment for 10 minutes [they] said it felt like [they] had just gotten in there. Said it felt like [they] left the ICU environment for the time — really enjoyed it.
Patient 9	“Calming. Did not see or hear people. Only 10 minutes of myself on campsite. Nothing else. Total relaxation, no frog on unicycle or weird stuff. Just campfire by lake, wildlife.”
Patient 10	VR did not look real but brought up all the “feelings” of feeling good and relaxed as if looking at it in real life. Neat experience. Calming, relaxing. Brought [them] memories of happiness, reminded [them] of being at the lake with [their spouse].
Patient 11	“I saw the rain and I could feel it on my legs. I would like to see things move more. It was super cool.”
Patient 12	“More realistic scenes. More music to accompany (classical music). I would recommend to other patients.”
Patient 13	“It definitely took my mind off everything.”

Direct written patient comments are highlighted with quotations, and content transcribed or summarized by the facilitator is recorded verbatim without quotations (except to remove sex or identifiable locations where brackets noted).

sample was small, the data supports expanded implementation of a VR program in this ICU/CCU.

This QI project has numerous limitations. The small convenience sample obtained for purposes of this project within one ICU and CCU limits generalizability. The priority demands of the critical care unit and time required to facilitate VR (50-60 minutes per participant) led to missed VR opportunities. It was identified that device location (i.e., increased accessibility on unit), training related to device setup, and a quick reference tool were essential to facilitate project enrollment.

Unlike the other physiological variables, the reduction of respiratory rate was noted to be statistically significant (mean reduction 1.54 breaths per minute). However, the clinical significance of this reduction is unknown. Research examining the relationship between VR, pain, comfort, relaxation, and respiratory rate in the critical care setting is warranted. Though

the term relaxation was used for the purposes of this project, additional investigation regarding the impact of VR on patient anxiety utilizing a validated anxiety assessment tool would be beneficial. Of interest are also the subjective or annotated comments, which speak to key themes of: relaxation, calmness, and environmental distraction or escape. Research would be beneficial to explore the relationships between pain and environmental distraction in a highly technical care environment. Finally, though significant improvements were noted to patient-reported pain, discomfort, and relaxation scores post VR, long-term benefit of these outcomes remain unknown.

## **Conclusion**

Within one ICU and CCU, virtual reality, as nurse-led adjunctive comfort therapy, was found to be a safe, successful, and desirable tool to reduce patient-reported pain, general/overall discomfort, and improve relaxation. Research, with larger

sample sizes, the use of validated assessment tools (where applicable), and examination of long-term benefit of VR is required within the critical care setting.

## Author Notes

Katherine A. Kissel, MN, RN, CNCC(C), ACCN(C), Clinical Nurse Specialist, Alberta Health Services, Calgary, Alberta.

Andrea Soo, PhD, Senior Biostatistician, Department of Critical Care Medicine, Alberta Health Services, and Adjunct Assistant Professor, Department of Critical Care Medicine, Cumming School of Medicine, University of Calgary, Calgary, Alberta.

Kimberley Tateson Bennett, RN, Director of Health, CUPS, Calgary, Alberta.

## Address for correspondence

Katherine Kissel, Intensive Care Unit, Peter Lougheed Centre, 3500 26 Ave NE, Calgary, AB T1Y 6J4.

Email: [katherine.kissel@albertahealthservices.ca](mailto:katherine.kissel@albertahealthservices.ca); Phone: 403-943-4544

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# Burnout and compassion fatigue among organ donation coordinators: A Canadian perspective

BY VANESSA SILVA E SILVA, PHD, RN, MARYANNE BOURRET, RN, TRICIA CARTA, RN, SHAUNA MATHESON, RN, HAYLEY RIVETT, RN, JANET TAYLOR, RN, BARB VAN RASSEL, RN, HEIDI BUTLER, MScN, RN, JENNA BAKER, RN, ANDREA ROCHON, MScN, RN, AMINA REGINA SILVA, MN, RN, BARTIRA DE AGUIAR ROZA, PHD, AMBER APPLEBY, MM, RN, PEGGY JOHN, JOYCE TROMPETA, PHD, RACHEL STODDARD-MURDEN, MSc, RN, KEN LOTHERINGTON, LAURA HORNBY, MSc, AIMEE SARTI, MD, AND SONNY DHANANI, MD

## Abstract

**Aim:** To understand the experiences and perceptions of burnout and compassion fatigue among Organ and Tissue Donation Coordinators (OTDCs) in Canada.

**Methods:** A series of virtual focus group discussions were held with OTDCs from across Canada to discuss burnout and compassion fatigue as part of a national research project in collaboration with Canadian Blood Services, the organ donation and transplantation community, and experts in the field.

**Results:** Eleven participants, including Canadian OTDCs and experts in the area of burnout, compassion fatigue and organ donation, participated in the discussion. OTDCs agreed that the high pressure and demands of their role challenge their workplace wellbeing and mental health. As a result, some of the OTDCs have recognized signs and symptoms of burnout and compassion fatigue throughout their career. Although OTDCs support each

other and develop their own personal coping and protective strategies, there is a continued need to develop specific strategies to help mitigate work-related issues and increase retention of experienced OTDCs in Canada.

**Conclusion:** The highly demanding role of OTDCs in Canada have challenged their mental health and work-related wellbeing, leaving them more susceptible to experiencing issues such as burnout and compassion fatigue. Future research is needed to investigate the levels of work-related issues among OTDCs, as well as to develop specific interventions to help support the work-related wellbeing and mental health of these professionals.

**Keywords:** tissue and organ procurement, burnout psychological, compassion fatigue, occupational stress, nurses, qualitative research, focus groups

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## Implications for Nursing

- Burnout and compassion fatigue are work-related issues that impact the mental health and wellbeing of Organ and Tissue Donation Coordinator (OTDC) nurses given the demanding and high-stress nature of their daily work.
- OTDCs support each other and develop their own personal coping and protective strategies, but these have not been enough to sustain their work-related wellbeing and further investigations on how to better support the mental health of these professionals are needed.
- Results from this study draw attention to work-related issues such as burnout and compassion fatigue among OTDCs and the consequences of working in a highly demanding environment.
- This study will inform future research to further illustrate our findings and develop strategies to help mitigate those issues, and improve quality of life, work wellbeing and mental health of OTDCs.

## Background

Organ donation processes are highly specific and take place in complex, interdependent and inter-professional healthcare settings and are frequently

encountered in critical care areas (Rosen et al., 2018). The success of organ donation programs depends on a combination of process, structural and contextual factors (Silva e Silva et al., 2021), but the most important one is undoubtedly the role of Organ and Tissue Donation Coordinator (OTDC) nurses. This role requires a vast amount of knowledge and skills in order to provide optimal care to organ donors and their families, including excellent therapeutic communication skills, extensive critical care nursing knowledge, ability to engage in interprofessional collaboration, and ethical posture (Silva e Silva et al., 2021). Experienced critical care nurses have the extensive background required to work in the OTDC role. They identify patients who may be suitable organ donors and, thus, play a part in increasing the potential number of organ donors (O’Leary, 2018). Critical care nurses are often tasked with caring for organ donors, maintaining organ viability and preparing them for organ procurement, while simultaneously providing support and reassurance to the donor family (O’Leary, 2018). Although it has not been an absolute requirement for organ donation programs worldwide, the OTDC role is typically filled by skilled, compassionate registered nurses (RNs) with critical care experience (Heredero & Berzosa, 2012), or specific organ donation certification or specialized training (Mendes et al., 2012). The OTDC role is multifaceted and fraught with many

challenges (Danet & Cardoso, 2020; Mercado-Martinez et al., 2013). OTDCs work in high-pressure and demanding environments involving several stressors; dealing with families in their most vulnerable state following tragic events with their loved ones and striving to provide a positive experience throughout the organ donation journey (Danet & Cardoso, 2020; Jesse et al., 2015). The constant exposure to stressors, pressure and grief can lead OTDCs to experience compassion fatigue and/or burnout, which are conditions characterized by emotional, physical and mental exhaustion (Koinis et al., 2015; Mao et al., 2018). Work-related issues, such as burnout and compassion fatigue, can negatively affect workplace wellness, productivity and quality of life for healthcare professionals (HCPs), and leave them more susceptible to errors and/or adverse events that can negatively impact outcomes for organ donation, as it can lead to missed opportunities of donation, reduced quality of organs and elevated costs for the healthcare system (Chandler et al., 2017; Koinis et al., 2015; Mao et al., 2018).

The majority of OTDCs in a Chinese study experienced burnout, with reduced personal accomplishment being the main clinical feature (Mao et al., 2018). Similarly, OTDCs in Turkey reported relatively high levels of burnout with low levels of personal accomplishment (Kader et al., 2013). No studies specifically measuring the incidence of compassion fatigue among OTDCs were found in the literature. However, a recent review of the literature identified a high prevalence of compassion fatigue among critical care nurses (Alharbi et al., 2019). Burnout and compassion fatigue can impact turnover, retention rates, psychological health, and organ donation outcomes (Danet et al., 2019; Fonseca & Tavares, 2016; Kress, 2009; Lima et al., 2009). With a lengthy and intensive training process for new OTDCs, the cost of attrition and turnover can be significant. While no cost information about OTDC turnover is currently available, the majority of OTDCs are RNs; a recent Canadian study estimated that the rate of annual turnover for RNs is 20%, with an estimated cost of \$27,000 per nurse (Rondeau & Wagar, 2016). Although there is evidence to suggest that work-related issues can impact OTDC wellbeing and organ donation outcomes, there is a lack of studies investigating this issue in Canada. While the majority of Canadian provinces have an opt-in system for organ donation, Nova Scotia is the first province to recently adopt an opt-out system. Therefore, the aim of this study was to bring together a sample of OTDCs from Canadian Organ Donation Organizations (ODOs) and experts in the field to discuss and share their experiences on the impact of burnout and compassion fatigue among OTDCs and the importance of further investigation of this topic in Canada.

## Methods

In this study, we used a qualitative descriptive approach to explore the perceptions of a sample of OTDCs related to burnout and compassion fatigue. Qualitative descriptive design allows the researcher to explore issues pertinent to healthcare settings while staying closer to the data (Denzin & Lincoln, 2011; Tong et al., 2007). Additionally, we used focus groups to generate qualitative data from collective views around the topic of interest (Mishra, 2016).

A series of virtual focus group discussions were held with OTDCs from ODOs across Canada to discuss burnout and compassion fatigue, as part of a national research project in collaboration with Canadian Blood Services (CBS), that provided funding for this project through their Centre for Innovation, the organ donation and transplantation community, and other experts in the field. We used a focus group approach as it allows the collection of in-depth data around the experiences and views of a group of people while offering for the participants more control of the interaction (Stewart & Shamdasani, 2017; Tritter & Landstad, 2020). However, in focus groups, participants may also feel uncomfortable to voice their experiences if their thoughts are different from the ones expressed by the rest of the group and, thus, attention is required to ensure that everyone has the opportunity to speak and share their experiences during the discussion process (Stewart & Shamdasani, 2017; Tritter & Landstad, 2020). An invitation letter was sent to the Donation and Transplantation Administrative Advisory Committee (DTAAC) within CBS providing information about the study and requesting the contact of potential participants from the Canadian provinces, as it is DTAAC's responsibility to provide advice to inform and guide the development of national initiatives to support interprovincial activities in the area of organ donation and transplantation in Canada (Donation and Transplant Administrators Advisory Committee, 2020). Then, individual ODO managers from all provinces were contacted with information about this collaborative project and asked to appoint OTDCs representatives, and five ODOs responded positively. Finally, the OTDCs designated by the five ODOs were contacted and invited to participate in the discussion.

For the initial discussion, we arranged a conference call through Zoom® on a pre-determined date in accordance with the availability of participants. Prior to this initial meeting, OTDCs were provided with key literature about burnout and compassion fatigue specific to organ donation and transplantation to review and reflect on the topic. The meeting was recorded, was an hour in duration, and was facilitated by the national research lead (V.S.S.), the project manager (K.L.), and two research assistants (A.R. and A.R.S.). The discussion was guided through a semi-structured interview format using open-ended questions to allow the participants to share their opinions and experiences (Finlayson et al., 2019; Moll, 2014). Some examples of the questions from the interview guide were: Do you think burnout and compassion fatigue are problems faced by you and/or your OTDC colleagues (if so, please explain)? What, in your opinion, may be the triggers or causes of burnout or compassion fatigue, etc. During the video conference, there were a total of 11 participants that included OTDCs representing the Canadian provinces of British Columbia ( $n = 2$ ), Quebec ( $n = 1$ ), Manitoba ( $n = 1$ ), Ontario ( $n = 3$ ), and Nova Scotia ( $n = 1$ ), as well as international participants with expertise in burnout/compassion fatigue ( $n = 2$ ) and organ donation ( $n = 1$ ) to enhance the discussion. The aim of the discussion was for OTDCs to voice their views and experiences about burnout and compassion fatigue and the importance of this topic in the Canadian context, as well

as experts in the field to contribute with their academic experience and share evidence to further explore the perceptions of the OTDCs.

After the meeting was conducted, the core research team members reviewed their notes and recordings to identify themes that were highlighted during the discussion through an inductive approach (Graneheim et al., 2017). An inductive approach is useful to condense extensive and varied raw data into a concise summary format (Thomas, 2003). For this data analysis we followed five steps: initial read through data, identification of specific segments of information, labeling segments of information to create categories, reducing overlap and redundancy among categories, and incorporating the most important categories into themes (Thomas, 2003). We developed a narrative of the themes, and to ensure that the highlights in this collaborative work accurately reflected the discussions held, the narrative was reviewed and validated by all the attendants through a series of online meetings (Zoom®) and electronic communications (e-mail). The Research Ethics Board (REB) at the Children's Hospital of Eastern Ontario was consulted for ethical approval but, as this study is a narrative reflection, it was determined that it does not require research ethics board approval in accordance with the Tri-Council Policy Statement. Yet, verbal consent was obtained from those joining the conference calls and they are all included as authors of this paper.

## Results and Discussion

Since there is little empirical evidence in the literature around this topic of interest in the OTDC nursing population, we aimed to present a more comprehensive interpretation of our findings. Therefore, in this section we opted for presenting the results and discussion combined and presented in a narrative format. Exploring our findings while combining it with prior findings can help the reader to have access to a more comprehensive understanding. No quotations were used in an effort to avoid erroneous attribution of a quote to a participant.

The reflections and experiences that OTDCs shared during the focus group discussions were reported and concurrently discussed across four themes: (1) demands of the OTDC role; (2) burnout; (3) compassion fatigue; and (4) protective and coping strategies developed and needed.

### Demands of the Organ and Tissue Donation Coordinators' Role

All OTDCs agreed that they work in a high-pressure and demanding environment and, as a result, they need to work quickly and with a heavy workload. OTDCs are key individuals who participate in all phases of the organ donation process in collaboration with other members of the healthcare team such as critical care nurses and physicians. Therefore, the role can be challenging, as OTDCs need to deal with various multi-disciplinary professionals, engage in difficult interactions with families, work in complex environments (e.g., intensive care units and operating rooms) and face multiple demands involved in their role (e.g., family support, research, education and others) (Matesanz et al., 2011). Furthermore, the presence

of ethical conflict as it relates to moral distress can contribute to the burden of the role; for example, when the OTDC believes it may not be an ideal time to approach a family due to the emotional distress the family is facing, but they still go forward with the approach focusing on obtaining informed consent for organ donation due to organizational pressures as organ donation cases are time-sensitive. Ethical conflicts have been reported in the literature as a common source of stress among OTDCs as they constantly face situations where their attitudes are conflicting with their values, or there is a mismatch between their personal values and values of the others involved in the organ donation process (Danet et al., 2019; Fonseca, 2017; Tarabeih & Bokek-Cohen, 2020).

The size of the program and number of OTDCs can vary widely across Canadian ODOs. In smaller programs, OTDCs concurred that they are particularly affected by the multiple tasks of their role, as they may need to work extra hours to cover all shifts in the schedule. Even when they are not working, they may be in constant contact with colleagues to offer support for organ donation processes and difficult cases. For example, OTDCs reported using group chats or text messages to stay connected and offer support to ongoing donation cases, sometimes even during non-working hours. There were variations in the intensity of the issues reported by OTDCs depending on the province where they worked. Yet, testimonies were similar in their reports of the high pressure, challenges, and demands of the OTDC role, and the impact on their wellbeing.

### Burnout

Burnout is a psychological state that occurs in response to prolonged exposure to interpersonal and emotional job stressors and the accumulation of risk factors (Bury, 2019; Maslach et al., 2001; Sinclair et al., 2017). Burnout is considered a multidimensional syndrome that is characterized by three main dimensions: (1) exhaustion (overwhelming physical and mental depletion); (2) depersonalization (cynicism); and (3) reduced personal accomplishment (inefficacy) (Bury, 2019; Maslach et al., 2001). When HCPs are affected by burnout, they become more susceptible to errors in their work environment (e.g., adverse events) and less motivated to work, which can result in reduced quality of care (Chandler et al., 2017).

There was consensus among the OTDCs that burnout is an important issue in this population and that some of them may have experienced signs and symptoms of burnout throughout their career (e.g., sleep disturbance and diminished patience toward colleagues), which can also impact personal relationships and home life. They also discussed that some barriers they encounter within the system can leave them more vulnerable to burnout, such as complex scenarios involving donor stability, lack of resources, and availability of transplant teams or operating rooms that may prohibit optimal timing for approaching families. Some of the potential ways that OTDCs mentioned could help mitigate these aspects associated to burnout would be the availability of resources to meet their job demands (e.g., electronic platforms such

as iTransplant to help reduce the burden of documentation) and development of personal protective and coping strategies. Additionally, OTDCs can feel isolated and alone, especially in smaller programs with few staff and minimal coverage, as OTDCs are responsible for multiple roles (including management of organ retrieval and allocation) that can result in extra working hours, which negatively affects their personal lives. Also, in smaller programs, OTDCs felt a lack of control due to the perceived capacity in the scope of their actions. This perceived lack of control and/or professional autonomy and high psychological job demands can result in low job engagement (Blumenthal, 2007; Kress, 2009).

Although these OTDCs agreed that burnout is prevalent in this population, they also discussed that it can be difficult to recognize the signs and symptoms of burnout in themselves or colleagues until they are in an elevated stage. This difficulty in identifying signs of burnout at early stages has been documented in the literature, as burnout has a gradual onset with initial symptoms being subtle enough that they are not recognizable (Hawryluck & Brindley, 2018; Moss et al., 2016). OTDCs also agreed that work-related issues such as burnout and vicarious trauma within teams can perpetuate through social interactions among individuals and impact colleagues who may not otherwise be affected.

### **Compassion Fatigue**

Compassion fatigue is a result of prolonged exposure to human suffering and can manifest as physical, behavioural, psychological, or spiritual symptoms (Sinclair et al., 2017). With repeated exposure to myriad stressors, including ethical dilemmas and investment in outcomes, in addition to grieving and death, OTDCs are at risk of experiencing compassion fatigue. OTDCs mentioned that a source of compassion satisfaction during the organ donation process is to try to give some comfort to families by providing a positive experience. OTDCs work relentlessly to honor the wishes of donors and families and may experience emotional distress and a heavy burden while supporting families through cases with negative outcomes. For example, the level of exposure may also have an impact when an OTDC works on multiple cases with minimal time to recover/decompress in between. Additionally, OTDCs may be overwhelmed by a sensitive case when they do not have adequate time to reflect on their feelings about a situation prior to meeting with a family.

OTDCs discussed that all cases of organ donation are difficult, as they are dealing with families in their most vulnerable state following tragic events with their loved ones. However, the OTDCs emphasized two types of cases that can have remarkable personal impact: pediatric patients and organ donation following Medical Assistance in Dying (MAiD). Pediatric patients are impactful, as these children die at a young age without the opportunity to properly live their life. If the pediatric death involved non-accidental causes (e.g., domestic violence), this can be an extra burden to OTDCs, as these are vulnerable children who should have been protected and died due to unfortunate conditions that were not in their control. Also, if the case triggers a personal memory or connection,

the situation can be even more challenging (e.g., children that resemble someone from their family). Although there is no published literature on the impact of pediatric patients on OTDCs, there is evidence to suggest that for critical care nurses and other HCPs, pediatric patients are a source of moral distress and can potentially lead to the development of burnout and compassion fatigue jeopardizing HCPs' ability to care (Garros et al., 2015; Gribben et al., 2019; Kase et al., 2019; Mekechuk, 2006; Rourke, 2007).

The availability of MAiD in Canada following legalization in 2016 (Bill C-14), has allowed the possibility for eligible individuals to donate their organs by controlled organ donation after circulatory determination of death (Allard & Fortin, 2017). Organ donation following MAiD is an extremely complex process, charged with moral and ethical dilemmas including conscientious objection and respect for individual autonomy (Allard & Fortin, 2017). For that reason, OTDCs play a significant role in having crucial conversations with individuals about their request and decision to proceed with organ donation following MAiD. In addition, OTDCs provide patient and family support throughout the entire MAiD process that can last over six months, which is relatively long when compared to the management of organ donation cases in the ICU that usually last less than 48 hours (Danet & Cardoso, 2019). Following the patient through the entire journey of saying goodbye before the MAiD procedure, and during the organ retrieval surgery can be emotionally demanding. If the case is prolonged, it can be a cause of substantial stress and potential cause of compassion fatigue for OTDCs. This is not a problem faced only by OTDCs. Since the legalization of MAiD, Canadian RNs are facing conflicting feelings related to their participation in this process, and while for some RNs MAiD is an extension of their profession, for others this can be a source of emotional and moral distress (Beuthin et al., 2018).

### **Protective and Coping Strategies: Developed and Needed**

OTDCs recognized that various stressors can take a toll on them and they have identified a variety of defense mechanisms to help to support their wellbeing. For instance, some OTDCs take time off as a strategy to cope with difficult cases. Nurses and physicians working in demanding environments, such as intensive care units, report strong coping strategies and high levels of work engagement despite the high emotional burden of working in these areas (Mol et al., 2018). OTDCs are frequently reported in the literature to be developing coping and protective strategies to deal with the stressors experienced within their role, such as taking time off, debriefing with peers, focusing on the positive outcomes from their role, and others (Fonseca & Tavares, 2014, 2015; Fonseca et al., 2016; Lima et al., 2009; Ponzin, 2015). Although these OTDCs only mentioned positive coping strategies, there are studies showing a concerning pattern where HCPs frequently resort to negative coping mechanisms, such as alcohol and substance use, to cope with their emotions (Kunyk, 2015; Oreskovich et al., 2012). Additionally, OTDCs agreed that resilience, workplace dynamics, and support received from peers and management influence their workplace welfare.

OTDCs mentioned that years of experience in the OTDC role can directly affect the levels of resilience, thus it can be extremely difficult for novice coordinators to deal with the great number of stressors in their workplace. This perceived notion corroborates with findings from the literature that showed professionals with more years of experience working in organ donation are more resilient than novice OTDCs (Powell, 2020). While OTDCs recognize the importance of having protective and coping mechanisms for their wellbeing, some still have difficulty effectively developing these strategies. Therefore, some actions discussed that can be taken at institutional and system level to help support OTDCs workplace wellness include training about how to deal with difficult interactions; availability of more resources (e.g., iTransplant and increase in the size of teams); psychological support; and the development of specific education for OTDCs (e.g., specialty for organ donation).

### Limitations

This paper highlights the opinion of a group of OTDCs that may not reflect the perceptions of the entire community. The virtual platform, limited meeting opportunities, and the fact that the participants were also authors in this paper may have prohibited some individuals from sharing their views and opinions and may have prevented some minority perspectives from being expressed (e.g., negative coping strategies were not discussed). Also, the small sample size of this study may limit the transferability of our findings.

### Conclusions

This reflective narrative voiced the perceptions and experiences of a group of OTDCs related to burnout and compassion fatigue in the Canadian context, which presented aspects that have not been previously documented about this topic. Burnout and compassion fatigue are a result of the demanding and complex situations that these professionals encounter throughout the organ donation process. The high pressures and demands of the OTDC role are affecting their workplace wellbeing and mental health. Thus, understanding the experiences of OTDCs in Canada, as a first step toward addressing these negative outcomes, is imperative. Although OTDCs support each other and develop their own personal coping and protective strategies, there is a continued need for researchers and institutions to further investigate incidence and impact of moral distress, burnout, and compassion fatigue as a means of developing effective strategies to help mitigate these issues among these professionals in Canada.

In summary, the discussion presented in this paper offers insight about the impact of the demanding role of OTDCs on mental health and wellbeing and provides direction for future research. In order to successfully address these concerns, we must develop interventions to identify and prevent work-related issues, such as moral distress, burnout, and compassion fatigue, improve team cohesiveness and the wellbeing of OTDCs, foster resilience, and maintain the quality and integrity of organ donation programs. Thus, the Burnout and Resilience in Organ and Tissue Donation Coordinators

(BRiC) study is currently being developed to examine the rate and experiences of work-related issues among OTDCs, to examine the extent of the problem and potential causative factors, and to develop an intervention to address the key issues identified in Canadian ODOs.

### Author Notes

*Vanessa Silva e Silva, PhD, RN, Children's Hospital of Eastern Ontario – Research Institute*

*Maryanne Bourret, RN, Quebec*

*Tricia Carta, RN, Manitoba*

*Shauna Matheson, RN, Nova Scotia*

*Hayley Rivett, RN, Trillium Gift of Life*

*Janet Taylor, RN, Trillium Gift of Life*

*Barb van Rassel, RN, Trillium Gift of Life*

*Heidi Butler, MScN, RN, BC Transplant*

*Jenna Baker, RN, BC Transplant*

*Andrea Rochon, MScN, RN, Children's Hospital of Eastern Ontario - Research Institute*

*Amina Regina Silva, MN, RN, Children's Hospital of Eastern Ontario - Research Institute*

*Bartira de Aguiar Roza, PhD, Federal University of Sao Paulo*

*Amber Appleby, MM, RN, Provincial Health Services Authority of British Columbia*

*Peggy John, Acting Director, Canadian Blood Services*

*Joyce Trompeta, PhD, International Transplant Nurses Society*

*Rachel Stoddard-Murden, MSc, RN, NHS Blood and Transplant*

*Ken Lotherington, Canadian Blood Services*

*Laura Hornby, MSc, Canadian Blood Services*

*Aimee Sarti, MD, The Ottawa Hospital*

*Sonny Dhanani, MD, Children's Hospital of Eastern Ontario - Research Institute*

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### Address for correspondence

*Dr. Vanessa Silva e Silva, PhD, RN, CHEO Research Institute, 401 Smyth Rd, Ottawa, ON K1H 5B2*

*Email: vsilvaesilva@brocku.ca*

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# Organ donation: A cross-Canada perspective of critical care nursing practice

BY ROSALIE STARZOMSKI, PhD, RN, ANITA E. MOLZAHN, CM, PhD, FCAHS, ROSELLA MCCARTHY, MSN, RN, (RETIRED), BERNICE BUDZ, MSN, RN, CNCC(C), AND SANDRA MATHESON, MN, MED, RN (RETIRED)

## Abstract

**Aim:** Our aim in this study was to describe the experiences of critical care nurses in the organ donation process in selected units across Canada. Interviews and focus groups were conducted to elicit perceptions of critical care nurses regarding their experiences with potential organ donors and their families.

**Methods:** Two adult critical care units (one with an active transplant program and one with no transplant program) in each of eight Canadian cities were studied. Purposive sampling was used to select three critical care nurses from each unit for individual interviews and six to eight nurses from the 16 critical care units for focus groups.

**Findings:** There were 112 participants who participated in an individual interview and/or a focus group. Following data analysis,

the themes identified were related to support, the process of organ donation (including preparing family and ourselves, lived experience of nurses, saying good-bye, death rituals, spiritual beliefs, and meaning of death), systemic considerations (culture and environment), and outcomes of the organ donation process.

**Conclusion:** While the benefits of organ donation and transplantation are clear, it appears that greater consideration can be given to policies, structures and processes, including education about systemic racism and unconscious bias that support nurses involved in the process.

**Keywords:** organ donation, critical care nurses, experiences, end of life care, moral distress, qualitative research, focus groups, interviews

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## Implications for Critical Care Nursing

- There are limited studies in Canada where researchers explored the perceptions and experiences of critical care nurses regarding organ donation.
- Lived experiences played a significant role in the interpretations of each individual critical care nurse about organ donation. The organ donation process often caused significant moral distress for the nurses and left moral residue.
- Collaborative practice models ought to be encouraged among healthcare leaders, health authorities and organ procurement organizations to improve communication and promote optimal teamwork that leads to effective change and enables critical care nurses to best care for organ donors and organ donor families.
- Support and education of nurses, as well as use of clinical protocols/guidelines are suggestions that could help improve the organ donation process for nurses.
- Because critical care nurses are often key personnel who are caring for organ donors and interacting with donor families, their views, knowledge and abilities about this process are extremely important. It is essential to support critical care nurses to improve their skills in relation to identifying, referring and maintaining organ donors, as well as improving interactions with donor families.

It is well known that organ transplantation dramatically improves the quality of life for individuals with end stage organ failure (Black et al., 2018). In addition, transplantation is the most cost-effective therapy for kidney failure (Yang et al., 2020). In Canada, the majority of organ transplants occur

through a process known as deceased donation, where organs are removed after death has been determined (Canadian Institute for Health Information [CIHI], 2020). Deceased organ donation occurs when a person has been declared dead because their heart, or brain, has permanently stopped working (Shemie et al., 2017). However, the shortage of organs for transplantation limits the availability of this treatment. A clearer understanding of the process and culture of deceased organ donation, as experienced by nurses working in critical care units who are involved in caring for organ donors, might facilitate best practices in organ donation.

The lack of organs available for transplantation is a complex problem with numerous related factors (Bea, 2020). It has been suggested that donation could be increased by focusing attention on the events that take place in the hospital around the time a family is offered the option to donate (Bea, 2020; Shemie et al., 2017), but there is limited Canadian research in this area. Alleviating the shortage of donor organs will depend, in large part, on the skills that critical care nurses bring to the organ donation process through identifying, referring, and maintaining organ donors and providing care to organ donor families (Canadian Association of Critical Care Nurses, 2019). Hence, our objective in this study was to describe the experiences of critical care nurses in the organ donation process while caring for potential organ donors and their families in selected intensive care units across Canada.

## Background and Literature Review

While the wait lists for organ transplantation grow, there remains a critical shortage of available organs. As of December

31, 2019, there were 4,352 Canadians actively waiting for organ transplants and, of those, approximately 75% were waiting for a kidney transplant (CIHI, 2020).

Numerous hypotheses regarding the shortage of donor organs exist. While there is a need for public education regarding organ donation, there is also widespread public commitment to organ donation. In an Ipsos Reid poll (2010), it was found that 95% of Canadians either strongly, or somewhat, approved of organ and tissue donation. Half the respondents reported a decision to donate their organs, 7% had decided not to, and 42% had not yet decided (Ipsos Reid, 2010). In a systematic review of research, it was found that individuals who were younger, female, had higher education levels and socioeconomic status, held fewer religious beliefs, had high knowledge levels, knew others with positive attitudes, were more altruistic, and had fewer concerns about manipulation of the body of the deceased donor were more likely to have positive attitudes toward donation and were more willing to donate their organs (Wakefield et al., 2010).

Researchers for more than 20 years have suggested that, for the most part, health professionals also have positive attitudes regarding organ donation (Butler, 2017; Molzahn, 1996, 1997a; Radunz et al., 2010; Starzomski, 1997; Zambudio et al., 2009). In a scoping review, Butler (2017) found that nurses mostly had positive attitudes toward organ donation, but they had a perceived lack of knowledge regarding brain death and the donor process. Nurses also lacked confidence and skills in initiating conversations with family members regarding organ donation and they recognized a need for further continuing education about organ donation (Butler, 2017).

They recognized a need for further continuing education regarding organ donation. Cantwell and Clifford (2000) studied medical and nursing students and found that although both groups held positive attitudes toward organ donation, nursing students were significantly more likely to have already signed their donor cards than were medical students (74% versus 43%). They also reported that nurses in practice were far less likely to have signed a donor card than were student nurses (57% versus 74%). These authors suggest further study to explore the nature of these differences in perceptions. It may be that there are concerns that brain death is not truly death, as Floden and Forsberg (2009) found.

In some cases, negative attitudes and a lack of knowledge about organ donation and transplantation have a negative impact on the process. For example, in the only Canadian study, found including both health professionals and lay people, Starzomski (1997) found that support for organ donation among consumer groups (93%) was higher than in groups of healthcare providers (76%). The main reason given by healthcare providers for not supporting organ donation was 'negative personal experiences.' This was particularly true of critical care nurses in a hospital where multi-organ transplantation was occurring. Nurses in critical care units in non-transplanting hospitals had a much more positive attitude about organ donation and indicated they all had signed their organ donor cards.

In studies of nurses' and physicians' knowledge and attitudes regarding organ donation, Molzahn (1996, 1997b) found that critical care nurses scored significantly higher on the knowledge sub-scale than nurses practising in other areas. Knowledge, attitude, age, and number of hospital beds were significant predictors of nurses' involvement in organ donation (Molzahn, 1996, 1997b). Further, Molzahn (1997b) found that 85% of critical care and emergency nurses participating in her study were reluctant to approach families about organ donation. While 35.6% of the critical care nurses reported that nurses were the first to recognize a potential donor, only 13.6% reported that nurses were the first to approach the family.

Weiland et al. (2013) found that cultural and religious influences might be barriers to facilitating organ donation and transplantation. In emergency departments in Australia, they found that physicians and nurses of Arabic, Jewish, North African and Middle Eastern background reported low competence in referring and caring for potential donors and comforting distressed families. Professionals of Islamic faith reported lower competence in identifying potential organs and low support for organ donation; those of Buddhist and Hindu faiths reported low competence in identifying potential donors.

Obtaining consent for deceased organ donation can be an issue; Siminoff et al. (2013) noted that at least 25% of families decline organ donation. Factors associated with consent for organ donation include characteristics of the patients, the donor families' beliefs and attitudes about organ donation, the families' satisfaction with the hospital care their relatives received, specific aspects of the donation-request process, and the families' understanding of brain death. They argued that detailed explanations of brain death were not necessary and, indeed, might be confusing to families. They suggested that a simple message that a loved one died was more appropriate.

Effective communication during organ donation requests has been found to be key to obtaining family consent (Shemie et al., 2017; Siminoff et al., 2009). This includes initiating the request with empathy, acknowledging the loss, soliciting family's perspectives and beliefs about organ donation and the patient's donation wishes, developing and maintaining a supportive relationship with the donor family, providing closure by summarizing the family's position, and outlining next steps and expressing gratitude (Shemie et al., 2017; Siminoff et al., 2009). In Europe, an evaluation of effectiveness of international recommendations of the European Donor Hospital Education Program (EDHEP) were measured using a Donor Family Questionnaire (Poppe et al., 2019). Of the 64 families that participated, 89% considered the communication to be tactful. Only 24.1% had a separate conversation about death and donation (which is the recommendation). The physician was seen to be the most active care provider offering emotional support during the entire procedure. It seems that nurses and other health professionals could be more involved in the process.

Rodrigue et al. (2008) examined the instability of organ donation decisions made by next of kin and factors that predict whether non-donors wish they had consented to donation. Using semi-structured telephone interviews, they found that

94% of families and 64% of non-family non-donors would make the same decision again. Regret among non-donors was more likely when the next of kin had more favourable transplant attitudes, had the first donation discussion with a non-organ procurement organization (non-OPO) professional, was not told their loved one was dead before this discussion, did not believe they were given enough time to make the decision, had not discussed donation with family members, and had not heard a public service announcement about organ donation.

Simpkin et al. (2009) conducted a systematic review of 20 observational studies of modifiable factors in the process of requesting organ donation. Reduced rates of refusal were associated with: provision of adequate information on the process of organ donation and its benefits; high quality of care of potential organ donors; ensuring relatives had a clear understanding of brain stem death; separating the request for organ donation from notification that the patient had died; making the request in a private setting; and using trained and experienced individuals to make the request. These investigators suggested that critical care nurses have an important role to play in enhancing organ donation.

A variety of strategies have been employed in attempts to increase organ donation rates. Required request legislation and policies for routine notification of OPO programs of donor-eligible patients failed to have a significant impact on consent rates (Siminoff et al., 2013).

In Spain, high organ donation rates have been achieved through the development of a national organ donation program that includes the employment of specially trained healthcare professionals (mostly physicians) responsible for identifying potential organ donors and requesting donation inside and outside the intensive care setting, using expanded criteria for donors and developing a framework for donation after circulatory death (Matesanz et al., 2017). In the United States, from the evaluation of the Organ Donation Collaborative (Howard et al., 2007) where best practices in donor requests were emphasized, it was noted that there were higher conversion rates in participating hospitals than control hospitals (from 51% to more than 60%) (Siminoff et al., 2013). Upon examination of data from Ohio, researchers showed that first person authorization of organ donation through electronic registries accounted for an increasing proportion of recovered donors (Donate Life America, 2011), but further evaluation of registries is needed.

Presumed consent (i.e., donation unless people opt out) legislation has been used in a number of countries with mixed results (Rithalia et al., 2009). It has recently been implemented in the United Kingdom (Walton et al., 2020). In a recent Canadian survey, 7 in 10 respondents reported support for a new system of organ donation that enables presumed consent and some provinces, such as Nova Scotia, have moved in this direction (Canseco, 2020).

It has been recognized that the Canadian organ and tissue donation and transplantation system is complex (Zavalkoff et al., 2019) and the optimal solution involves collaboration, consensus and coordination. Some of the most limiting factors in relation to organ donation include failure to determine which patients are potential organ donors, failure to refer potential

donors to the organ procurement organization, and refusal of patients' families to consent to donation. Shemie et al. (2017) highlight research-based guidelines relating to effective end-of-life communications with family members.

Regardless of the enabling legislation, critical care nurses play an important role in organ donation (CACCN, 2019). In Sweden, where presumed consent legislation is in place, critical care nurses have varying views of the process and, in a phenomenological study, critical care nurse participants emphasized that nothing should go wrong with the organ donation process (Floden & Forsberg, 2009). They perceived a heavy burden and did not want to further traumatize the donor family. We suggest that a better understanding of critical care nurses' experiences in caring for potential organ donors and their families, and a better understanding of the attitudes, values, and practices in relation to those experiences might facilitate improvements in practice relating to organ donation.

## Methods

The approach used for this study was naturalistic inquiry informed by a social constructivist perspective, that is, human perceptions are shaped by individuals' interactions with society and culture (Denzin & Lincoln, 2018). Hence, a situation cannot be considered in isolation from the context (Patton, 2015). The research process consisted of successive iterations of purposive sampling, inductive analysis of the data, the development of themes and categories, and planning for subsequent steps based on the analysis (Denzin & Lincoln, 2018).

### Participants and Settings

Two adult critical care units (one in a hospital with an active transplant program and one in a hospital with no transplant program) in each of eight cities across Canada (Vancouver, Edmonton, Winnipeg, Toronto, Ottawa, London, Montreal [English speaking] and Halifax) were studied. Purposive sampling, where participants who met the selection criteria of being English speaking and willing to be involved in the study, were invited to participate. Three critical care nurses from each of the study units were invited to participate in individual interviews. In addition, six to eight nurses from each of the 16 critical care units were recruited to participate in focus groups.

### Data Collection

Data were collected through individual interviews and focus groups over a two-and-a-half year period. Onsite coordinators at each location assisted in recruitment of participants. Guiding individual interview and focus group questions were developed by the study research team. Questions included asking participants to tell us about their involvement and experiences caring for organ donor patients and families and asking them probing questions following their responses.

Individual interviews were conducted to elicit perceptions of the critical care nurses regarding their experiences with potential organ donors and their families. The interviews were conducted by one person, the study research coordinator, and held in a room close to where the nurses worked. All interviews lasted from one to two hours, were audio-recorded and transcribed verbatim by the study research coordinator.

Focus groups were held in order to uncover understandings and insights about critical care nurses' experiences with the organ donation process that were not accessible through individual interviews. Each focus group was conducted by the study research coordinator with assistance from the onsite local coordinator and was held in the hospital to facilitate easy access for participants. Some participants were given time off work to attend and others participated on their own time.

### Data Analysis

Our aim in the analysis was to identify, interpret, and reconstruct understandings of individuals' reality. Data collection and data analysis occurred simultaneously throughout the study period. Analysis was inductive and thematic as described by Denzin and Lincoln (2018). Analysis began by having members of the team read transcripts. During team analysis meetings, investigators shared initial perceptions and understandings of the data and emerging categories. Through a process of refinement and review, and constant comparison, patterns and relationships were developed into themes.

Denzin and Lincoln (2018) propose that researchers in the naturalistic paradigm pursue rigour by establishing the "trustworthiness of the interpretations." In our study, given that the narratives were co-constructed through dialogue, the requirements for rigour rested on the establishment of good rapport with participants, clear articulation of all sources of data, the establishment of a detailed audit trail whereby another researcher could critically examine the process and decision-making of the researcher(s), as well as the construction of the interpretative account/findings. These factors were attended to in this project by writing field notes following each interview and transcribing data verbatim. In addition, members of the research team ensured that interpretations were founded within the data by analyzing and critically evaluating findings and interpretations.

### Ethical Considerations

Approval for the study was obtained from the Human Research Ethics Board of the university where the investigators were employed, as well as from each participating hospital. Informed consent was obtained from all participants in verbal and written form, and confidentiality was assured by storing the consent forms, separate from the data, in two locked filing cabinets in the project coordinator's private office.

## Findings

There were 112 people (95 women and 17 men) who participated in either an individual interview and/or a focus group. They ranged from novice practitioners to highly experienced nurses. Thirty-one participants had up to five years' experience working as critical care nurses, 17 between six to 10 years, 29 between 11 to 15 years, 20 between 16 to 20 years, eight between 21 to 25 years, four between 26 to 30 years and three participants had more than 30 years' experience. All of the nurses had considered organ donation, with 50 indicating they would be organ donors. Of the remainder, 14 would not be organ donors and the others were undecided or did not respond to this question.

The themes that emerged from the data related to support, the process of organ donation, the systemic considerations (culture and environment), and the outcomes. The sub-themes that related to process included preparing family and ourselves, lived experience of nurses, saying good-bye: death rituals, spiritual beliefs, and meaning of death (See Table 1).

**Table 1**

*Themes Emerging Related to Organ Donation Among Nurses Working in Critical Care*

Support	Process, time, and timing	Systemic factors and structure	Outcome
Family	Preparing the family and ourselves	Ethnocultural factors	Successful transplantation
Nurse	Lived experience of nurses	Environment for organ donation (e.g., country, unit)	Moral distress
Program	Saying goodbye Spiritual beliefs Meaning of death		

### Support

Participants identified support surrounding their experiences of organ donation from a variety of perspectives. Support for organ donation was discussed in relation to the family, nurse, and transplant program.

Support for family members was focused on the initial conversation concerning organ donation, the need for education about the diagnosis of brain death, and the need to work with family members to discuss and support them throughout the entire organ donation process. One participant shared the following:

*...If it's in the middle of the day, it's great, you have your educators there, you have your organ team, you have your transplant team, you have everybody there. But if it's in the middle of the night, there's the nurse and the resident to approach the family on, you know, would you like to donate and there is no support for them.*

Support for the individual nurse at the bedside included a need for protocols for evidence-based donor management, and the need for teaching and support on brain death criteria. Nurses also identified a need for personal emotional support. Many participants described organ donation as a very traumatic, emotionally draining experience. They also identified examples of effective support, particularly from their co-workers. For example:

*I know recently we had a young fellow that was an organ donor, and the family had all said goodbye...I knew the nurse in there had never experienced anything like that*

*before and she was alone, you know with the patient and she was just sobbing like just from her toes sobbing, and she had said she'd never had that before. And we've all been there and we knew what she was feeling.*

Transplant programs with 24-hour support resources available to the family and staff were highlighted as making a positive difference in the experience of organ donation for nurses. One participant shared the following:

*Well, she is one person who is focused on organ donation and donors whereas we're a big staff of like 150 people... the last time I did organ donation, you know, we did it this way and now it's been a couple of months, now we're doing it this way.*

### **Process, Time and Timing**

#### *Preparing the family and ourselves for organ donation*

Nurses wanted to know how to ask families about organ donation and how to support family during the request period. There was also a high need for education about determining brain death, knowing how to explain that concept to families and a need for an updated check list for preparing donors for donation. There was support for a core group of people to be trained in requesting organ donation and preparing donors due to the infrequency of the process. Many nurses said they learned on the job and believed that more formal training was needed for the entire interdisciplinary team. In one unit, the nurses said: "nurses were hungry for education on organ donation." If the first donor experience was positive, or negative, for the critical care nurse, this set the tone for how supportive the nurse would be to participate and support future donors and the process. Suggestions that nurses cited to help support them in the organ donation process included a training program on how to ask for organs, an introduction to organ donation in the unit orientation, reading packages and videos for staff, resource binders, and a biannual panel presentation of donor families and transplant recipients about their experiences.

Nurses wanted to be sure the families were well supported and suggested inclusion of pastoral care workers and social workers to augment nursing support. Some nurses said that the donor process at the bedside was so labour intensive that they often did not have as much time to spend with the family as they wished because of the challenge of providing care to the donor. Nurses believed strongly that more public education on organ donation was needed in schools, media and in the home, for example, over the dinner table, and that this would facilitate the process.

### **Lived experience of nurses**

Many participants shared stories about memorable situations, particularly while caring for their first organ donor. These stories were often vivid and emotional, and influenced the critical care nurse's future practice either positively or negatively. For instance, one nurse said,

*The first time I saw brain death criteria...this patient eventually did become a donor on a different shift...just seeing all of the criteria and the care and, all the procedures, as*

*we go through it, makes me feel much more confident that, yes, they, you know, they are brain dead. They're not really, they're not alive...*

Some indicated frustration with the organ donation process and the work and energy expended.

*I think that sometimes we, as nurses, are all ready to either assume the responsibility or are asked to assume the responsibility... and, all of a sudden, we are faced with managing an unstable donor patient with an R1 who is reading his Marino ICU book...I become frustrated and I've got a family that's at the end of the bed crying at the same time, but watching me try to lead the doctor through managing their loved one.*

Several stories were shared by participants describing the frustration and anger caused by receiving patients identified inaccurately as potential donors from outlying centres. These emotions related both to the associated heavy workload, as well as the stress and loss to families unnecessarily separated from their injured loved ones.

Examination of the lived experiences of the participants indicated that their beliefs regarding the outcomes for patients and families had a significant influence on them. One nurse stated: "I've seen the families who have seen the joy of hearing that they're getting a transplant and I've seen the other side of the family who has made the decision to donate." Many participants revealed that in their experiences with the donation side of the process, almost all of the families who went on to donate were comforted by the decision to donate their loved ones' organs. Some reported angst about times when the family was not able to be with their loved one in a meaningful way at the end of life. Sometimes, the process just did not proceed as well as it did other times. Past experiences with unsuccessful transplants resulted in negative attitudes.

*We aren't doing a service to a lot of people...they're already "sipping tea with Jesus" and you're going to put an organ in there that was previously healthy, you're going to pummel the living [heck] out of it trying to make it work, and then if they die two months down the road, oh yeah, you did them a lot of favour. They laid in the bed and they were tortured, and an organ ended up that could have gone to somebody else who was maybe sitting at home.*

Some participants related conversations with transplant patients who stated they would never repeat the process. These patients described the trauma and the side-effects to be unworthy of the risks. Interestingly, a few of these patients indicated that their families would "do it all again."

Many participants identified that because each experience affected their subsequent experiences, more opportunities to share and discuss these experiences with team members would be of benefit. One nurse described a poignant experience where her emotional response was noticed by a colleague, who then arranged for a break and critical incident debriefing. This participant believed that this support enabled her, at the time and in the future, to be "relatively intact mentally" and influenced

her belief that the climate of working with staff shortages would greatly affect the lived experiences of future critical care nurses who would not “have time to heal.”

### **Saying goodbye: Death rituals**

Many of the nurses talked about facilitating the process of saying goodbye by enabling family members to have time with their loved ones. They were very open and flexible about visiting hours, recognizing that families needed the time. The rituals took a number of forms, from talking with the family members to providing privacy and final meaningful opportunities to spend time. This was often a very difficult process for the nurses, as well as the family members, as evidenced by the emotion in their voices and the words they used.

*Be alone, you know, and so you try, or sometimes you say, ‘Look, I’m just here. You take them to the other side’, and you touch his hand...be alone with him or we just close the door, so they can just, you know. But, these are things too for the family you know. Because for me, too, the families are very important because they’re going through this big loss.*

Another nurse said:

*I recently had a case where the girlfriend said, ‘I just want to sleep with him one more night’. He wasn’t quite pronounced, but that was going to happen the next day... I managed to get her into bed with him and she said, ‘this is where I put my head right here’ and she put her head on his chest and then she said, ‘Could you just bring his arm, just bring it right around me’.*

One nurse talked about listening to the families’ stories about their loved ones: “They always really start to open up about the patient. It’s very, very rewarding. And when that patient rolls out, it’s a person you’re looking after, you’ve never known before, so stories, it’s like stories...” A few of the nurses talked about cutting locks of hair for relatives and offered other supports.

*We asked the two daughters if they wanted a piece of their mother’s hair. And we cut a lock of her hair. We tied it with a little ribbon and gave them each and...and I remember I came into this room where they were, you know, having this little quiet time and we gave them each a teddy bear. And, I remember when I said good bye to them, hugging the two daughters, the two teenagers and I remember the teddy bears were soaked with tears, I think it made a difference.*

### **Spiritual beliefs**

The nurses discussed spiritual beliefs in relation to organ donation. One nurse said: “We have actually had some people in the past who have absolutely refused to care for transplant patients because it was against their religion, that this sort of thing was playing God and interfering with the natural process in a person’s life.” A few nurses talked about how their religious beliefs were not consistent with organ donation. For example, one nurse said: “... I have to get there complete. ... You go to heaven when you pass away and they have to get complete. My heart, it will be hard to get there without my heart. So, it’s just beliefs, too.”

Even when they did not speak explicitly about religion, spiritual beliefs came through. One nurse said:

*We don’t have a problem with death and dying in our family; we feel very comfortable with it. You know like you’re going on to a better place and to donate our organs we’ve all agreed, except my brother. He believes in miracles (laughs).*

Another nurse commented that her beliefs changed through education.

*There was a time when I said, don’t you dare donate my eyes. Eyes are the windows to the soul. I now know better, now that I’ve had that education...the eyes are the windows to the spirit, not the window to the soul. You know what, your spirit, it’s more of my own philosophy about where are you going, what you do. This is merely a shell and if I can make a difference.*

### **Meaning of death**

Most of the participants in the study talked about their observation that organ donation gave families meaning to the death of their loved ones. Also, organ and tissue donation helped some nurses make sense of the situation of young people who experienced untimely deaths.

*I had a mother begging me on the phone to make something good come out of this...I mean, there with her son. We’re asking for organ donation over the phone...but I mean she’s in tears and she’s begging me on the phone to make sure that I keep him alive. Alive in, quotes, “until something good came of this.”*

Another nurse said:

*[They] are at the breaking point of something that’s happened to their loved one, but get peace and comfort from knowing that they’ve helped someone else...but it’s been a good experience for 99% when you know they embrace it wholeheartedly...it brings peace to the whole, whole thing.*

The majority of families who consented to organ donation felt comforted by the fact that they decided to allow the loved ones to donate. Similarly, for some of the nurses, the donation gave meaning to the tragedy of death.

*And then, I think if you’ve looked after somebody who’s received a heart, these people like they’ve just seen another view of life. And a transplant patient in the CCU and his kids were like literally swinging from the rafters and he’s just sitting there watching them. He says, ‘I’m just happy to see ‘em do it ‘cause I didn’t think I was going to have this opportunity.’*

Another nurse talked about organ donation as the “ultimate sacrifice.” They said that “if you focus on that, that’s kind of a helpful feeling.”

### **Systemic Factors and Structure**

There was awareness on the part of many of the nurses that ethnocultural factors played a role in family decisions regarding organ donation. The nurses identified specific ethnocultural

communities (for example, Indo-Canadians, Muslims) and Indigenous communities where they had experienced reluctance to donate on the part of some individuals. One nurse said: "It is a very difficult one with Aboriginal people because [some] will receive organs, but they won't donate them. So that's a bit of an oxymoron to me." Another noted,

*Aboriginal people, in my experience anyway, don't tend to donate organs. They receive donations and once they die, they actually have all of the organs and artificial things removed so their body is maintained back whole and returned to the earth.*

Some nurses talked about hypothetical cases, and others gave examples from their experience. One nurse, talking hypothetically, discussed a Muslim man refusing to accept an organ for his daughter if the donor had eaten pork. It seemed from each of these situations that the nurses may not have understood, or respected the cultural values of either the Indigenous or Muslim people they discussed.

At least one of the nurses acknowledged that they needed to be careful about making assumptions based on ethnocultural beliefs.

*We ask despite, even the most religious Orthodox Jewish person you could meet, we're still going to ask...we've had surprises and there's even some Rabbis who will tell you, you know, there's nothing written in the Torah that says you can't donate organs...so we ask everyone.*

The nurse participants in this study discussed the significance of the environment for organ donation in a number of ways, including geography and the environment/culture of the unit. From a geographic perspective, nurses were able to identify provinces/regions where there was considerable support for organ donation and other regions where there were few donations. For example, one nurse's perspective was: "Atlantic Canada has a better donor rate than the rest of Canada...and the biggest supply of organs from Atlantic Canada comes from Newfoundland. Newfoundland has a tremendous organ donation program where they have a lot of "buy-in."

They also attributed many of the values that they (and other Canadians) held about organ donation to "a different perspective in Canada where we really want people to volunteer, give their blood, give this, give something else." These Canadian values were used to explain why financial incentives should not be considered for donor families to help families make the decision to donate a loved one's organs. They were also used to explain why there was a reluctance to request organ donation.

*Our numbers are so down in Canada. Is it because we are too nice a people to be asking? But is it because we're so complacent that we don't want to put anybody out by asking? There's lots of donors out there who should be donors that aren't being asked and why is that?*

They also discussed their observations that organ donation was more likely to take place in major urban settings. Some nurses raised the topic of the variety of ethnic backgrounds in their province that made it more challenging to request organ donation.

Nurses in the study described the environment of specific intensive care units as important. They talked about the important role of the physician in creating an environment conducive to organ donation. They knew the opinions of various physicians about organ donation, whether or not those opinions were spoken.

*Some of them aren't comfortable with it. They aren't comfortable with approaching the families and so, you know, lots of times I'm sure that the organs go by. Because they'll wait and they'll wait and wait before...I guess it is so uncomfortable they don't want to approach the family and sometimes it's lost.*

Another nurse noted, "There's a very bad rapport between the transplant surgeons and the ICU team. So, I think that there's really bad communication there and I think that contributes to a negative attitude in terms of transplantation."

The nurses also discussed the frustrations of working in environments with inexperienced residents and physicians who were not knowledgeable about neurological determination of death, or unwilling to come in to declare someone neurologically dead. On the other hand, in some centres, the critical care nurses identified specific clinicians who "put organ donation in a more positive light." Some talked about social workers, or pastoral care professionals, who facilitated their work in relation to organ donation. The support of nurse managers in the organ donation process helped to create an environment where organ donation was considered to be a positive action. One group of nurses discussed the systems in their unit where the entire team worked towards improving organ donation.

### **Outcome**

While successful transplantation was the desired and usual outcome, a number of participants conveyed unresolved feelings of moral distress when recounting their experiences about caring for organ donors. Even though some experiences described by participants took place years ago, for some, unresolved moral distress and moral residue remained. For example, one participant related the following experience:

*I almost cried with them, it was very, very emotional for me; it was very difficult for me. And then he went to the OR for harvesting, and in the same 12-hour (shift), I got the recipient. It was the hardest thing for me. I had to physically put on armor. It was too much for me. Now it was turning into the most beautiful thing, the same event had such different meaning for me. It was so sad in the morning, and in the afternoon, it was the best thing that ever happened to that family, because he got his heart. Both occasion(s) the family was there, that was so really hard for me. You know, the family was saying, "Isn't this wonderful!" And in the morning, it was a young donor, and it was so hard. And I'm sure if the family were not there in the morning when I got that person as a donor, I probably would not have felt it that bad. I would have detached myself. Like I was just taking care of a patient, a sleeping patient. I have to, ah; it's never been easy for me. And it's not getting easier for me with experience.*

Another participant conveyed a sense of unresolved moral distress by saying:

*Well, I mean I always find it hard, you know, working with somebody who's dying especially if they're young or, there's a really tragic circumstance...but, you get a sense of satisfaction after it's all over. Often the families will come up and give us a hug and thank us for all that we've done for them and, so you feel really good afterwards. But I know sometimes, I'm over at the desk in tears while they're behind the curtain in tears. So, it's, it's hard. And I'd just as soon not have to do it. I know it's part of the job, but if I never had to that again, that would suit me fine."*

## Discussion

Organ donation is a complex process that involves caring for, and identifying, potential donors, obtaining consent from families, and procuring the organs around the time of death. There is limited research in Canada exploring the perceptions and experiences of critical care nurses regarding organ donation. The data we obtained in our study elucidated for us that lived experiences played a significant role in the interpretations of each individual critical care nurse about organ donation. The organ donation process often caused significant moral distress for the nurses and left moral residue. Nurses recounted painful experiences, which they had never forgotten. These experiences often happened many years before their interviews for this study. Nurses required considerable support when caring for organ donors and engaging in the organ donation process. The findings of this study are consistent with Elpern et al. (2005) and Floden and Forsberg (2009) who also noted that there were times when nurses experienced moral distress regarding organ donation.

Although participants in the study identified the need and desire for information about organ donation, in Canada, most healthcare professionals do not receive specific education about identifying, caring for and recruiting organ donors (Norris, 2020). However, discussion has occurred in Canada in the last number of years about ways to improve critical care environments to help support critical care staff, including nurses, to more effectively be involved in the OD process. Much of this work was initiated and coordinated by national groups, such as organ procurement organizations (for example, Trillium Gift of Life, British Columbia Transplant) and national groups (for example, Health Canada, the Canadian Council for Donation and Transplantation [CCDT] and the Canadian Blood Services [CBS]). The CCDT launched an organ donation collaborative bringing together healthcare professionals from Western and Atlantic Canada who were committed to making changes in their organ donation programs. The focus of the collaborative was for critical care teams to identify and share practices, as well as develop best practices for the future. More education for critical care staff about organ donation and adding organ donation coordinators to critical care units in hospitals were two of the interventions emerging from these discussions (Canadian Council for Donation and Transplantation, 2007).

The participants in this study also talked about the system issues that interfered with the organ donation process. There is evidence demonstrating that collaboration with healthcare leaders produces positive outcomes (Shafer et al., 2008). Collaborative

practice models ought to be encouraged among healthcare leaders, health authorities and organ procurement organizations to improve communication and promote optimal teamwork that leads to effective change and enables critical care nurses to best care for organ donors and organ donor families. Issues relating to support of nurses, education of nurses, and use of clinical protocols/guidelines were suggestions offered that could help improve the organ donation process for nurses. Further education about systemic racism and unconscious bias also seems to be warranted based on a few of the responses of nurses in the individual interviews and focus groups.

There are a number of implications for practice, as a result of this study. Because critical care nurses are often key personnel who are caring for organ donors and interacting with donor families, their views, knowledge and abilities about this process are extremely important. It is essential to support critical care nurses to improve their skills in relation to identifying, referring and maintaining organ donors, as well as improving interactions with donor families. Researchers have concluded that enhancing the quality of hospital care and ensuring that the request for organ donation is handled in a way that meets the families' needs could increase organ donation rates (Shemie et al., 2017). As critical care nurses are key personnel who interact with donor families, it is vital that they understand both the transplant and organ donation process and their role in these processes (CACCN, 2019). Further, they must be involved in discussions about ways to influence change in the system.

There is an urgent need to work towards the development of national evidence-informed best practices and to disseminate these findings to critical care nurses. There are a number of initiatives in this area that show promise (CBS, 2021; Health Canada, 2021). For example, since 2018, Health Canada has been leading an initiative that involves the collaboration of a number of stakeholders, such as the CBS, critical care practitioners, healthcare administrators, OPOs, and patients and families across Canada, to continue to improve the organ donation and transplantation system. Further evaluation of these initiatives is required to determine the overall effect of these interventions on the experience of critical care nurses and to establish whether these practices continue to increase organ donation in Canadian critical care units.

The development and sharing of national standards and best practices can provide critical care nurses with a significant resource, so that they can practice in a more effective, consistent and collaborative manner.

## Limitations

Participants volunteered for this study from a number of adult critical care centres in Canada. Qualitative research is typically not generalizable and it is difficult to know if participants' views and perspectives are representative of Canadian critical care nurses' experiences with organ donation. The inclusion of nurses from multiple centres, both in individual and focus group interviews, helped mitigate this limitation. Future research should include evaluation of interventions to examine the outcomes of education of nurses, support programs for family members and critical care nurses, and/or new targeted collaborative approaches to enhance organ donation.

## Conclusion

In conclusion, the themes that emerged from this study of critical care nurses involved in organ donation included the need for support, more attention to the process of organ donation (including preparing family and ourselves, lived experience of nurses, saying good-bye: death rituals, spiritual beliefs, and meaning of death) the systemic considerations (culture and environment), and the outcome of the process (including moral distress). The benefits of organ donation and transplantation are well documented in the research literature and it appears that greater consideration should be given to policies, structures and processes that support the health care professionals who are involved. In addition, evaluation of the interventions that are currently in use should be carried out in order to ensure that critical care nurses are supported when caring for organ donors and employ evidence-informed best practices as they carry out their work in regard to organ donation. Critical care nurses are key stakeholders in the organ donation process and should be involved in initiatives to influence change in this area.

## Author Notes

Rosalie Starzomski, PhD, RN, Professor, School of Nursing, University of Victoria

Anita E. Molzahn, CM, PhD, FCAHS, Professor Emerita, Faculty of Nursing, University of Alberta

Rosella McCarthy, MSN, RN, Retired, Clinical Nurse Specialist, Cardiology, British Columbia Children's Hospital

Bernice Budz, MSN, RN, CNCC, Consultant, Healthcare Concepts to Solutions, Vancouver, BC

Sandra Matheson, MN, MEd, RN, Retired, Clinical Nurse Specialist, Cardiovascular, Nova Scotia Health Authority

## Corresponding Author

Rosalie Starzomski, University of Victoria School of Nursing, PO Box 1700, Victoria, BC V8W 2Y2

Phone (250-721-7204); Email: rosestar@uvic.ca

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