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# Learning needs and perceived barriers and facilitators to end-of-life care: a survey of front-line nurses on acute medical wards

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#### **ABSTRACT**

**Objectives** Caring for dying hospitalised patients is a healthcare priority. Our objective was to understand the learning needs of front-line nurses on the general internal medicine (GIM) hospital wards, and perceived barriers to, and facilitators of, optimal end-of-life care.

Methods We developed an 85-item survey informed by the Theoretical Domains Framework and Capability—Opportunity—Motivation—Behaviour system. We included demographics and two main domains (knowledge and practice; delivering end-of-life care) with seven subsections. Nurses from four GIM wards and the nursing resource team completed this survey. We analysed and compared results overall, by Capability, Opportunity, and Motivation, and by survey domain. We considered items with median scores <4/7 barriers. We conducted an a priori subgroup analysis based on duration of practice (≤5 and >5 years).

Results Our response rate was 60.5% (144/238). 51% had been practising for >5 years; most respondents were female (93.1%). Nurses had similar scores on the knowledge (mean 76.0%; SD 11.6%) and delivering care (mean 74.5% (8.6%)) domains. Scores for items associated with Capability were higher than those associated with Opportunity (median (first, third quartiles) 78.6% (67.9%, 87.5%) vs 73.9% (66.0%, 81.8%); p=0.04). Nurses practising >5 years had significantly higher scores on all analyses. Barriers included engaging with families having strong emotional reactions, managing goals of care conflicts between patients and families, and staffing challenges on the ward. Additional requested resources included formal training, information binders and more staff. Opportunities for consideration include formalised on-the-iob training, access to comprehensive information, including symptom management at the end of life, and debriefing sessions.

**Conclusions** Front-line nurses reported an interest in learning more about end-of-life care and identified important barriers that are feasible to address. These results will inform specific knowledge translation strategies to build capacity among bedside nurses to enhance end-of-life care practices for dying patients on GIM wards.

#### WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Adequate end-of-life care is a human right.
- ⇒ Globally, the majority of people die in an institution.
- ⇒ There are challenges to providing optimal end-oflife care in hospital environments.

#### WHAT THIS STUDY ADDS

⇒ Our study adds to the body of literature identifying important barriers and learning needs for providing personalised end-of-life care to dying patients in hospital (outside of the intensive care unit).

# HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

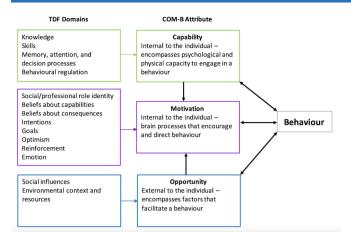
This study may help other healthcare organisations caring for dying patients to identify areas for improvement.

#### INTRODUCTION

In Canada, more than half of deaths annually occur in hospital, despite a preference by most Canadians to die at home. Globally, it is estimated that, among 36 nations representing every continent and more than 16 million deaths, 54% or more occurred in hospital. Therefore, compassionate endof-life care provided by interprofessional healthcare teams is important because of the emotional toll imparted by both the matter and manner of dying. However, given the historical biomedical model of care in many hospital settings, it can be challenging to provide person-centred care at the end of life that is grounded in comfort and dignity.

Some challenges to a 'good death' in hospital are the unfamiliar and sometimes austere institutional settings, limited professional education about end-of-life care, inadequate symptom control, communication barriers and the 'medicalisation of dying'.<sup>5</sup> A survey of 388 bereaved family members





**Figure 1** TDF domains linked to COM-B attribute and the interactions with behaviour. COM-B, Capability-Opportunity-Motivation-Behaviour; TDF, Theoretical Domains Framework.

reported significantly less satisfaction with end-of-life care in medical units than in extended care units, intensive care units (ICUs) or palliative care units.<sup>6</sup> The dissatisfaction was focused on physician and nurse care (eg, lack of compassionate and supportive providers, lack of trust and confidence in providers), illness management (eg, management of physical and emotional symptoms like pain and depression), health services (eg, calm environment, coordinated care), and communication and decision-making (eg, end-of-life discussions and treatment plan). Factors contributing to these findings are likely multifactorial and may include limited training in end-of-life care, competing care demands, high staff turnover and limited experience caring for dying patients. 7-10 Perceived barriers likely vary by level of training, discipline and institution. 11

The top three themes associated with a good death from patients, family and clinician perspectives distilled in a literature review were preferences for the dying process (eg, the how, who, where and when), a pain-free death and attending to the emotional well-being of patients. 12 One intervention that focuses on honouring and preserving the dignity of dying patients, and enhancing relationships among patients, families and the healthcare team is the 3 Wishes Programme (3WP). The 3WP was developed in the ICU at St. Joseph's Healthcare Hamilton (SJHH) to elicit and facilitate final wishes for dying patients and their loved ones. It has since transitioned from a study to an ongoing approach to practice. 13 Building on the recent expansion of the 3WP to the general internal medicine (GIM) wards, <sup>14</sup> our goal is to build the capacity of nursing staff to enhance end-of-life care practices in these settings through a multiphase approach; this survey to understand the current situation is the first phase. As front-line staff providing the day-to-day care of patients, the role of nurses in optimal end-of-life care is crucial and includes symptom management and support of patients and their loved ones. Our objective was to understand the learning needs of front-line nurses on the GIM wards, as

well as perceived barriers to, and facilitators of, optimal end-of-life care.

#### METHODS Survey development

We used two complementary knowledge translation (KT) frameworks, the Theoretical Domains Framework (TDF) 15 16 and the Capability-Opportunity-Motivation-Behaviour system (COM-B), <sup>17</sup> to develop our survey. These frameworks are inter-related—the TDF distills 33 theories of behaviour change into 14 domains focused on healthcare provider behaviour.<sup>18</sup> Each domain maps to one of Capability, Opportunity or Motivation in the COM-B system, which synthesises the critical interactions among Capability (eg, knowledge, skills), Opportunity (eg, social influences, resources) and Motivation (eg. beliefs about capabilities, intentions) for behaviour to occur. Figure 1 shows the TDF domains linked to COM-B attributes and the interactions of COM-B. In turn, the COM-B maps to the Behaviour Change Wheel<sup>17</sup> that helps to identify appropriate interventions to change behaviours.

We used rigorous survey development and testing methods<sup>19</sup> and followed the Checklist for Reporting Results of Internet E-Surveys to report this study.<sup>20</sup> See online supplemental appendix 1 for details on item generation and reduction, formatting, testing and administration. The survey instrument is in online supplemental appendix 2.

Our final survey instrument included 85 items across participant demographics, 2 domains (knowledge and practice, delivering end-of-life care), 7 subsections, a section on the 3WP and an open free-text section. We invited all nursing staff (registered nurse, registered practical nurse, clinical nursing externs) on the four GIM wards and from the nursing resource team (NRT) at SJHH to participate. Responses were anonymous. On completion, respondents received a CAD\$10 coffee gift card and entry into a draw for four larger prizes.

#### Patient and public involvement

The patients were not involved in the development of the research question, study design, recruitment or conduct of the study, however, patient and family partners have been included in the interpretation of results to ensure that the strategies we develop represent what is most important to them.

#### Statistical analysis

We conducted descriptive statistics using means and SD or medians and first, third quartiles (first, third) depending on data distribution. For categorical variables, we calculated counts and percentages. We conducted visual inspection and tests of normality using the Shapiro-Wilk test. We calculated response rate as the proportion of completed surveys divided by the number of eligible respondents. A survey was considered complete and suitable for analysis if the demographics and at least one other section was completed. We imputed missing data if

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Table 1 Demographics and characteristic  Characteristic	Value
Unit or team, n respondents/unit or team (% of u respondents)	ınıt, % total
1	29 (63.0, 20.1)
2	36 (56.3, 25.0)
3	27 (64.3, 18.8)
4	27 (62.8, 18.8)
5	25 (58.1, 17.4)
Sex, female, n (%)	134 (93.1)
Age, years, n (%)	
≤25	28 (19.4)
26–30	38 (26.4)
31–40	39 (27.1)
41–50	24 (16.7)
≥51	15 (10.4)
Religious/spiritual beliefs, n (%)*	
Christian†	88 (61.5)
Muslim	8 (5.6)
Hindu	1 (0.7)
None	36 (25.2)
Other‡	10 (7.0)
Professional background, n (%)	
Registered practical nurse	40 (27.8)
Registered nurse	103 (71.5)
Clinical extern	1 (0.7)
Duration of nursing practice, years, n (%)*	
<1	12 (8.3)
1–5	58 (40.3)
6–10	29 (20.1)
11–14	10 (6.9)
≥15	34 (23.6)
Formal training in end-of-life care, yes, n (%)	46 (31.9)
Type of end-of-life care training, n (%)§	
Within nursing degree/diploma training	19 (34.5)
Additional courses	12 (23.6)
Formal on-the-job training	22 (40.0)
Other¶	1 (1.8)
*Missing data (n=1)	

<sup>\*</sup>Missing data (n=1).

there was only one score missing per section. For overall scores, we included those respondents with no missing data (could include one imputation per section).

We aggregated Likert-type responses in three ways: (1) by individual domain, (2) overall and (3) by COM-B

attribute. By domain, we calculated sum scores, and summed items representing each of Capability, Opportunity and Motivation. For those questions with negative framing (eg, 'I feel overwhelmed when I must care for patients who are dying'), we reversed the scale during analysis to facilitate summing and item comparisons. We classified individual items with scores of <4/7 as barriers. To contextualise numeric results, we examined freetext responses. We descriptively analysed sum scores by domain and items contributing to each COM-B attribute, presenting these as proportions. Higher proportional scores indicate fewer learning needs and barriers. To compare Capability, Opportunity and Motivation scores, we used one-way analysis of variance or Kruskal-Wallis tests, depending on distribution. Using two-tailed t-tests or Wilcoxon rank sum tests (depending on distribution), we conducted subgroup analyses comparing survey scores, domain scores and COM-B scores by duration of nursing practice dichotomised as ≤5 years of practice and >5 years of practice. Alpha for all comparative analyses was 0.05. We applied Bonferroni corrections for multiple comparisons. We conducted all numeric analyses using Stata (V.14.2, StataCorp).

#### **RESULTS** Respondents

From November to December 2021, we invited 238 nurses to complete the survey; 147 surveys were returned, however, 3 were ineligible (unit manager n=1, nursing student n=1, care coordinator n=1). Therefore, 144 surveys were eligible for analysis. The final response rate was 60.5%.

Most respondents were female (93.1%), less than 40 years of age (72.9%) and had more than 5 years of nursing experience (51.0%). Each GIM ward and NRT was proportionally represented (table 1). Table 1 reports respondent characteristics.

We first asked respondents to rate their comfort level with end-of-life care. With a median (first, third) score of 6/7 (5,6) (higher scores indicate more comfort), respondents indicated that they were moderately comfortable with their role. At the end, we asked if they would be willing to be an end-of-life care champion on their ward; 61.7% of respondents indicated they would.

Many items and overall survey scores were high, therefore, we focused on optimising barriers. Table 2 summarises raw scores by COM-B attribute, domain and overall; sample items contributing to each attribute are also shown. Proportional scores are reported below.

#### End-of-life care knowledge and practice

There were 141 (98.0%) respondents who completed this domain. The mean (SD) proportional score was 76.0% (11.6%). Median scores (first, third) for items associated with capability and motivation were similar (76.5% (65.3%, 87.8%) and 78.1% (70.5%, 83.1%), respectively).

<sup>†</sup>Christian denominations include: Catholic (n=48), other Christian (n=23), Protestant (n=16), Anglican (n=1).

<sup>‡</sup>Other includes: Agnostic (n=2), Pagan (n=2), undecided (n=2), Punjabi (n=1), Seventh-day Adventist (n=1), spiritual (n=1), prefer not to say (n=1).

<sup>§</sup>Could be more than 100% if respondents participated in more than

<sup>¶</sup>Palliative care nursing lectures (simulation-based learning).

354

266/354

COM-B attrib	ute	Knowledge and practice domain	Delivering end-of-life (EOL) care domain	Overall
Capability	Number of items	7	1	8
	Max score	49	7	56
	Actual score	37/49	7/7	44/56*
	Sample item	'I am comfortable providing families with information on the processes that need to occur after a patient dies.'	'Palliative care is a needs-based concept aimed at optimising quality of life for patients with life-limiting illness.'	
Opportunity	Number items	0	17	17
	Max score	N/A	119	119
	Actual score	N/A	88/119	88/119
	Sample item	'There are adequate resources for EOL care available on the unit.'	'In general, our team's communication facilitates inclusive EOL care discussions and planning.'	
Motivation	Number of items	15	12	27
	Max score	105	74	179
	Actual score	82/105	56/74	136/179
	Sample item	'I am not comfortable giving PRN medications at EOL, as it may cause the end to come sooner.'	'I find that providing EOL care is challenging, often leading me to feel fatigue and burn-out.'	

\*Scores for Capability items across the survey were significantly higher than scores for Opportunity items across the survey (p=0.04). COM-B, Capability-Opportunity-Motivation-Behaviour; N/A, not available; PRN, As needed.

200

149/200

Nurses reported one barrier from the Likert-type questions in this section—challenges engaging with families who have strong emotional reactions (median score 3/7 (2,5)). In addition, free-text comments underscored a need for additional training in end-of-life care, including common medication practices, how frequently to complete assessments, role clarity (eg, who can 'declare a death') and what to do once a patient has died (ie, how to prepare the body).

Overall max score

Overall actual score

154

117/154

We also asked respondents to identify issues for which they would contact on-call physicians after-hours, and whether they hesitated to do so. The most frequently reported reason for after-hours contact of on-call physicians was for physical symptom management, followed by the need to address a change in goals of care, behavioural management and family concerns about patient status. Most respondents (62.2%) reported no hesitation in contacting on-call physicians after-hours. However, of those who did express hesitation (n=63, 44.1%), 73.0% (n=46) reported that it was because they were concerned that the physician would be annoyed and would have preferred to hear about it on rounds the next day. In addition, 61.2% (n=39) perceived that the on-call physician would not know the patient well enough and may not be able to assist over the phone.

Respondents reported feeling comfortable with managing symptoms, including using infusion pumps for continuous subcutaneous infusions (6/7 (4,7)). They also were comfortable knowing how to respond when

families or loved ones asked for more pain medications even when the patient was barely conscious but appeared comfortable (6/7 (4,7)), or conversely, knowing how to respond when families refused medications wanting the patient to be more awake, which would be inconsistent with effective symptom management (5/7 (3,6)). While these results suggest nursing comfort with symptom management, areas for improvement emerged in the free-text comments. For example, some nurses sought more training on identifying and managing symptoms in the last moments of life; others underscored the need for further training on common medication practices. Finally, when asked to rank six items that they would find most helpful to increase their comfort and confidence with end-of-life care, the #1 item was formalised on-the-job training for end-of-life care. The #2 ranked item was a symptom assessment and management tool.

#### **Delivering end-of-life care**

There were 119 (82.6%) respondents who completed this domain. The mean (SD) proportional score was 74.5% (8.6%). Within this domain, scores for items representing Capability, Opportunity and Motivation were similar (100% (85.7%, 100%), 73.5% (11.0%) and 74.8% (9.8%), respectively).

We identified four barriers—respondents reported being somewhat uncomfortable with managing requests for Medical Assistance in Dying (MAiD) from patients or families (mean (SD) 2.9 (1.1)). They also identified issues such as staffing pressures and high patient acuity that made it difficult to consistently offer high-quality endof-life care (6/7, (5,7)). Furthermore, staff reported that when they were caring for a patient at the end-of-life they tended to be given another busier patient assignment because the needs of the dying patient were perceived to be low (5/7 (3.5,6)). These barriers were also endorsed in the free-text comments.

Resources, including availability and accessibility of items such as online information and non-hospital blankets to assist in end-of-life care, were rated as neutral for both availability and accessibility (median score 4/7 (3,6)), however, the free-text comments highlighted a need for additional resources. The most helpful existing resources cited were the palliative care team, nursing colleagues, other experienced staff and the 3WP. The most requested additional resources were formal training, information binders accessible on the wards, and additional staff to care for dying patients and their families. Most respondents reported that they routinely suggested consulting palliative and spiritual care services for their dying patients (71.9% and 81.0%, respectively). Half of respondents (55.6%) reported barriers to consulting the palliative care team, including perceptions that families misunderstand the role (48.6%), the healthcare team members misunderstand the role (19.7%) and the role of the team was unclear to the respondent (4.9%). Other reported barriers were nurses hesitating to suggest a palliative care consultation, believing it was either not their role or perceptions that the GIM team thought they could manage the end-of-life care of the patient, or when families and patients appeared to fear the introduction of palliative care. Barriers to consulting the spiritual care team were indicated by 20.4% of respondents, including perceptions that the role of the team was unclear to the respondent (12.0%), followed by the ward's general practice to not consult spiritual care (4.9%). Other reported barriers included often not thinking about it, uncertainty about a patient or family receptivity to the idea and being unaware of patients' spiritual identity or preferences.

Respondents agreed that all stakeholder groups, including nursing colleagues, charge nurses, interdisciplinary colleagues, physicians, medical learners, educators, managers and hospital administrators, are supportive of end-of-life care that surpasses symptom management (eg, to include transfer to a private room if available, allowing pet visitation). When asked about the emotional impact of caring for dying patients, with a median score of 5/7 (4,6), respondents often found comfort that patients and families were well cared for.

Most respondents (83.5%) reported that having the opportunity to debrief would increase their comfort and confidence with end-of-life care (ie, score >4/7), however, only 27.0% reported participating in formal or informal debriefings within the previous year. Of those who did participate, 92.1% indicated it was informal and 23.7% indicated that formal debriefing opportunities were not offered on their wards.

#### **Overall scores and comparisons**

The maximum possible survey score from all Likert-type questions was 354. The mean (SD) proportional score for the survey was 75.2% (8.7%). Respondents had similar scores in the knowledge and delivering care domains, however, scores for items representing Capability across the survey were significantly higher than scores for Opportunity (p=0.04) indicating that knowledge and skills may be less of a challenge to providing optimal end-of-life care than issues such as resources, social influences and environmental stressors (table 2). The mean (SD) or median (first, third) proportional scores for items contributing to Capability, Opportunity and Motivation across the survey were 78.6% (67.9%, 87.5%), 73.5% (11.0%) and 75.6% (9.2%), respectively.

#### Subgroup analysis

A priori subgroup analyses revealed significant differences according to duration of practice. All scores were significantly higher for nurses with >5 years of practice experience, indicating fewer learning needs and perceived barriers compared with those nurses with ≤5 years experience.

Table 3 summarises raw scores, proportional scores and p values for each domain and COM-B attribute by duration of practice group. Figure 2 shows the distribution of scores for items contributing to capability, opportunity and motivation.

#### 3 Wishes Project

Most respondents were aware of the 3WP (87.4%) from KT sessions including ward in-services. Most staff (71.3%) reported having been involved with this end-oflife intervention previously, either directly or indirectly (ie, witnessing their colleague's involvement). Finally, although initiating the 3WP does not require a specific consult or physician order, only 43.6% of respondents knew this; 41.4% were unsure and 15.0% indicated that a consult to the 3WP team was required.

#### DISCUSSION

We conducted a self-administered survey of front-line nursing staff on four GIM wards and the NRT at our hospital to understand the learning needs, perceived barriers and facilitators to providing optimal end-of-life care. We achieved a high response rate, especially in the context of the COVID-19 pandemic and staffing shortages. We identified a keen interest in end-of-life care practices. Using the theoretically driven COM-B KT framework, several areas for future consideration included discomfort with challenging situations, the need for more training and education (including clarifying team roles), practice resources and debriefing opportunities. Table 4 outlines selected barriers and our suggested optimisation strategies.

Our results indicated that, compared with self-reported Capability, Opportunity to provide optimal end-of-life care was a significant challenge. Opportunity encompasses

	≤5 years practice	>5 years practice	P value
Overall survey			
Capability	40/56; 71.4% (59.8, 83.3)	48/56; 84.8% (74.1, 93.8)	< 0.001
Opportunity	87/119; 73.1% (64.7, 77.3)	93/119; 78.2% (68.9, 84.0)	0.008
Motivation	131/179; 73.3% (9.7)	139/179; 77.8% (8.2)	0.005
Total	256/354; 72.2% (8.5)	276/354; 78.0% (8.0)	< 0.001
Knowledge and practice	e domain		
Capability	35/49; 70.4 (55.1, 83.7)	41/49; 83.7 (73.5, 93.9)	< 0.001
Motivation	78/105; 73.9 (10.3)	83/105; 78.7 (10.0)	0.006
Total	111/154; 72.3 (11.6)	122/154; 79.6 (10.5)	< 0.001
Delivering end-of-life ca	are domain		
Capability	6/7; 85.7 (71.4, 100)	7/7; 100 (85.7, 100)	0.039
Opportunity	87/119; 73.1 (64.7, 77.3)	93/119; 78.2 (68.9, 84.0)	0.008
Motivation	54/74; 72.6 (10.7)	57/74; 76.9 (8.6)	0.012
Total	144/200; 72.1 (8.0)	153/200; 76.6 (8.6)	0.004

the behavioural domains, social influences and environmental context and resources, eliciting constructs such as social and group norms, role-modelling, power dynamics, environmental stressors, resources, organisational culture and a person's interaction with their environment.<sup>17</sup> The reasons behind lower Opportunity scores are likely multifactorial and may include high rates of staff turnover and absenteeism (particularly during the COVID-19 pandemic), new staff physicians using new approaches such as different medications or routes of administration, and rotating medical staff and trainees. The free-text comments provided some insights into barriers related to environmental context including staffing pressures and high patient acuity. Resource barriers included lack of dedicated end-of-life care rooms on some units, and the need for more informational documents (eg, comprehensive nursing-focused end-of-life binders, informational resources to offer families, and a symptom assessment and management tool). Social influences cited included professional approaches (eg, concern that contacting the on-call attending physician after-hours would not be well received), and the observation that some physician practices do not involve consulting the palliative care team.

A recent study by Harasym *et al* similarly used the COM-B system to understand barriers to optimal end-of-life care in long-term care facilities through qualitative interviews with 23 physicians who visit LTC facilities in Canada.<sup>21</sup> They reported barriers in each of the three attributes—Capability (lack of a standardised symptom assessment and management tool), Opportunity (lack of dedicated spaces and inadequate staff for patients nearing the end of life and limited awareness of the unique spiritual and mental health needs of residents) and Motivation (managing grief emotions).<sup>21</sup> A 2017 scoping review endorsed these and other barriers from a macrolevel, mesolevel and

microlevel perspective. For example, spending time with dying patients was not prioritised in some busy clinical settings where limited resources exist, lack of education and experience were common, and clinicians were reluctant to prescribe high dose analgesia.<sup>22</sup> Indeed, lack of time and education are supported by studies evaluating healthcare provider perceptions of end-of-life care from Hong Kong,<sup>7</sup> Malaysia,<sup>8</sup> Australia<sup>23</sup> and the USA.<sup>24</sup> Nearly all studies identified lack of formal education or training on end-of-life care, particularly for nursing staff, as a substantial barrier. Additional barriers we identified also align with other studies, including perceptions that the treating teams are self-sufficient and can provide satisfactory palliative care independently, and that patients and families may resist involvement of the palliative care team.<sup>25</sup> Despite palliative care improving outcomes for

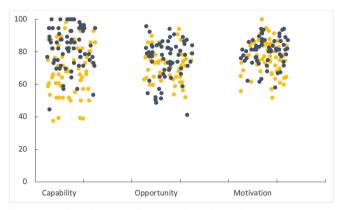


Figure 2 Distribution of respondents' median proportional scores for items contributing to Capability, Opportunity and Motivation. Yellow=scores for nurses with duration of practice ≤5 years; blue=scores for nurses with duration of practice >5 years.

Barrier	TDF domain(s)	COM-B attribute	Change concept	Change idea
Organised debriefings are not offered, and informal debriefings rarely occur	Environmental context and resources; Social influences	Opportunity	Enhance opportunity	In collaboration with ward managers and educators, develop sessions that will combine education and open discussion opportunities on end-of-life care topics that are important to nursing staff (eg, palliative sedation, ethics at the end-of-life).
Lack of information resources for family	Environmental context and resources	Opportunity	Remove constraints; enhance opportunity	Work with key stakeholder groups (eg, palliative and spiritual care teams, physician group, social work, family partners) to develop a comprehensive information resource that can be tailored for families. Information could include medical team members (eg, nursing, physician, therapy staff), medications that might be used, resources for support, what to do after death, etc.
Need more education on common medication practices	Knowledge; Beliefs about consequences	Capability; Motivation	Remove constraints	Develop an accessible, easy-to-read medication resource for specific medications and how they are used in end-of-life care in collaboration with pharmacists and physicians.
Lack of understanding of team and programme roles (ie, palliative care, spiritual care, 3WP)	Knowledge; Social influences	Capability; Opportunity	Remove constraints; use visual cues	Develop an infographic highlighting services available at the end of life, including palliative and spiritual care and the 3WP. Have one version tailored towards families/loved ones and another specific for staff. Place these visual reminders in the hallways, nursing station, conference room, etc to encourage engagement from staff and patients' loved ones.
Staffing challenges	Environmental context and resources	Opportunity	Enhance opportunity; have contingency plans	Introduce a volunteer role on the wards to assist with certain activities (eg, offering the patient ice water or a comfortable blanket, help direct family to various like cafeteria, parking services) for dying patients and their loved ones.

COM-B, Capability-Opportunity-Motivation-Behaviour; TDF, Theoretical Domains Framework; 3WP, 3 Wishes Project.

individuals at the end of life, many patients who could benefit from palliative services (eg, those with complex communication needs, spiritual and cultural needs, and high stress needs<sup>26</sup>), do not receive timely consultations. <sup>27–29</sup> A survey of 133 healthcare professionals from a private hospital in Australia reported that nearly 40% of dving patients received palliative care 'sometimes, rarely or never'. 23

Nurses with more experience (ie, >5 years) demonstrated higher scores across both domains and all COM-B attributes as compared with those nurses with ≤5 years of experience. The relationship between experience and views on end-of-life care has been endorsed by other studies, including by Omar Daw Hussin et al who surveyed 553 nurses from hospital wards in Malaysia and found that nurses with 11-20 years of experience reported more facilitators to end-of-life care than those with less experience.<sup>8</sup> In contrast, a survey of 175 nurses from Hong Kong reported that years working alone was not significantly associated with perceived barriers; instead the amount of experience caring for dying patients was significantly associated with perceived barriers (ie, those with less experience perceived more barriers). Thterestingly, we found that nurses with ≤5 years of experience

had the lowest Capability scores, which may be expected, but their Motivation and Opportunity scores were higher compared with nurses with >5 years of experience. Finally, among nurses with more experience, Motivation scores, while relatively lower than Capability and Opportunity, were still quite high, indicating important positive attitudes towards ensuring optimal end-of-life care.

Despite a large proportion of patients dying in hospital, end-of-life care is sometimes not a priority for providers or institutions.<sup>30</sup> However, when death is an expected outcome for seriously ill individuals and a curative approach is either not available or not desired, the focus of care needs to shift.<sup>31</sup> Consensus statements from India and Australia outlined common themes that encompass a 'good death'. They highlight the importance of communication being open, honest and patient-centred, the need to address individual preferences during the dying process, adequate symptom management and support for loved ones in the perideath period.<sup>32 33</sup> The location of death within the hospital also plays an important role. For example, family ratings of care, emotional support, communication and pain control were less favourable for decedents who received ward-only care compared with ICU-only or mixed-ward and ICU care in a survey of 28 062

family members.<sup>34</sup> Higher nurse to patient ratios, higher mortality and more staff experience with end-of-life care in the ICU may help to explain these findings. Research indicates that there is still much work to be done to optimise end-of-life care practices on acute medical wards.

Our study has limitations. Quantitative studies can elicit important information; however, they often provide limited contextual information to help understand the root causes of barriers and facilitators. Another limitation of any survey is potential for response bias; we could not ascertain whether differences existed between responders and non-responders. This was a single-centre study, but our study design and results may provide useful insights for other healthcare organisations that care for dying patients to identify areas for improvement.

There are also important strengths including the focus on bedside nurses who provide crucial care for hospitalised patients. We developed our survey using established KT theories that provide a framework for to identify both barriers and potential strategies to overcome them. We engaged diverse stakeholder groups in rigorous survey instrument testing (pretesting, pilot testing and clinical sensibility testing). Despite the COVID-19 pandemic, we achieved a 61% response rate, which enhances the external validity of our results. Finally, the survey results allowed us to identify actionable targets for intervention.

Given the large number of patients who die in hospital, it is imperative to ensure that end-of-life care practices are optimised and prioritised to facilitate a good death for them and their surviving loved ones. Our survey sought to determine front-line nurses' learning needs regarding end-of-life care, as well as barriers to and facilitators of, optimal end-of-life care. Overall, nurses reported an interest in learning more, indicating that providing good end-of-life care to patients and families was important to them. By identifying barriers and using rigorous KT theory to develop and implement strategies, we can work to enhance end-of-life practices on our GIM wards. Future research will include prioritising interventions to implement in practice, evaluating their impact on processes of care, and patient and family units, and understanding the needs of hospital leadership to sustain effective change strategies. Our work may serve as a template or steppingstone for other institutions caring for dying patients to identify and introduce strategies to inform clinical practice and hospital policy.

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Ethics approval This study was exempt from formal review by the Hamilton Integrated Research Ethics Board as it was considered within the scope of a quality improvement initiative. Participation was voluntary, which was clearly stated on both electronic and paper forms of the survey. A letter of information was made available to all participants describing confidentiality, any associated risks or harms, and withdrawal procedures. Informed consent was implied by survey completion.

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**Data availability statement** Data are available on reasonable request. Data are available from the corresponding author on reasonable request.

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#### **REFERENCES**

- 1 Canada S. Table 13-10-071501 deaths, by place of death (hospital or non-hospital). Data table; 2022.
- 2 Association CHPC. What canadians say: the way forward survey report. Ottawa, ON Harris/Decima; 2013.
- 3 Broad JB, Gott M, Kim H, et al. Where do people die? an international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. Int J Public Health 2013;58:257–67.



- 4 Cook D, Rocker G. Dying with dignity in the intensive care unit. N Engl J Med 2014;370:2506–14.
- 5 Al-Qurainy R, Collis E, Feuer D. Dying in an acute hospital setting: the challenges and solutions. *Int J Clin Pract* 2009;63:508–15.
- 6 Stajduhar K, Sawatzky R, Robin Cohen S, et al. Bereaved family members' perceptions of the quality of end-of-life care across four types of inpatient care settings. BMC Palliat Care 2017;16:59.
- 7 Chan CWH, Chow MCM, Chan S, et al. Nurses' perceptions of and barriers to the optimal end-of-life care in hospitals: a cross-sectional study. J Clin Nurs 2020;29:1209–19.
- 8 Omar Daw Hussin E, Wong LP, Chong MC, et al. Nurses' perceptions of barriers and facilitators and their associations with the quality of end-of-life care. J Clin Nurs 2018;27:e688–702.
- 9 Zheng R, Lee SF, Bloomer MJ. How new graduate nurses experience patient death: a systematic review and qualitative meta-synthesis. *Int* J Nurs Stud 2016;53:320–30.
- 10 Thompson G, McClement S, Daeninck P. Nurses' perceptions of quality end-of-life care on an acute medical ward. J Adv Nurs 2006;53:169–77
- 11 Friedenberg AS, Levy MM, Ross S, et al. Barriers to end-of-life care in the intensive care unit: perceptions vary by level of training, discipline, and institution. J Palliat Med 2012;15:404–11.
- Meier EA, Gallegos JV, Thomas LPM, et al. Defining a good death (successful dying): literature review and a call for research and public dialogue. Am J Geriatr Psychiatry 2016;24:261–71.
- 13 Cook D, Swinton M, Toledo F, et al. Personalizing death in the intensive care unit: the 3 wishes project: a mixed-methods study. Ann Intern Med 2015:163:271–9.
- 14 Reid J, Clarke F, Hoad N, et al. 3 wishes without borders: enhancing end of life care for hospitalized patients. Canadian Journal of General Internal Medicine 2021;16:93–102.
- Michie S, Johnston M, Abraham C, et al. Making psychological theory useful for implementing evidence based practice: a consensus approach. Qual Saf Health Care 2005;14:26–33.
- 16 Cane J, O'Connor D, Michie S. Validation of the theoretical domains framework for use in behaviour change and implementation research. *Implement Sci* 2012;7:37.
- 17 Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implement Sci* 2011;6:42.
- 18 Francis JJ, O'Connor D, Curran J. Theories of behaviour change synthesised into a set of theoretical groupings: introducing a thematic series on the theoretical domains framework. *Implement Sci* 2012;7:35.
- 19 Burns KEA, Duffett M, Kho ME, et al. A guide for the design and conduct of self-administered surveys of clinicians. CMAJ 2008;179:245–52.

- 20 Eysenbach G. Improving the quality of web surveys: the checklist for reporting results of Internet E-surveys (cherries). J Med Internet Res 2004;6:e34.
- 21 Harasym P, Brisbin S, Afzaal M, et al. Barriers and facilitators to optimal supportive end-of-life palliative care in long-term care facilities: a qualitative descriptive study of community-based and specialist palliative care physicians' experiences, perceptions and perspectives. BMJ Open 2020;10:e037466.
- Threapleton DE, Chung RY, Wong SYS, et al. Care toward the end of life in older populations and its implementation facilitators and barriers: a scoping review. J Am Med Dir Assoc 2017;18:1000–9.
- 23 Saunders R, Glass C, Seaman K, et al. Clinical staff perceptions on the quality of end-of-life care in an Australian acute private Hospital: a cross-sectional survey. Aust Health Rev 2021;45:771–7.
- 24 Price DM, Strodtman LK, Montagnini M, et al. Health professionals perceived concerns and challenges in providing palliative and end-of-life care: a qualitative analysis. Am J Hosp Palliat Care 2019;36;308–15.
- 25 McDarby M, Carpenter BD. Barriers and facilitators to effective inpatient palliative care consultations: a qualitative analysis of interviews with palliative care and nonpalliative care providers. Am J Hosp Palliat Care 2019;36:191–9.
- 26 Cox CE, Olsen MK, Parish A, et al. Palliative care phenotypes among critically ill patients and family members: intensive care unit prospective cohort study. BMJ Support Palliat Care 2022.
- 27 Hsu AT, Garner RE. Associations between the receipt of inpatient palliative care and acute care outcomes: a retrospective study. Health Rep 2020;31:3–13.
- 28 Tanuseputro P, Budhwani S, Bai YQ, et al. Palliative care delivery across health sectors: a population-level observational study. Palliat Med 2017:31:247–57.
- 29 CIHI. Access to palliative care in canada. In: Canadian Institute for Health Information. 2018.
- 30 Pincombe J, Brown M, McCutcheon H. No time for dying: a study of the care of dying patients in two acute care Australian hospitals. J Palliat Care 2003;19:77–86.
- 31 Robertson SB, Hjörleifsdóttir E, Sigurðardóttir P. Family caregivers' experiences of end-of-life care in the acute hospital setting. A qualitative study. Scand J Caring Sci 2022;36:686–98.
- 32 Macaden SC, Salins N, Muckaden M, et al. End of life care policy for the dying: consensus position statement of Indian association of palliative care. Indian J Palliat Care 2014;20:171–81.
- 33 ACo Safety. Care qih: national consensus statement: essential elements for safe and high-quality end-of-life care. Sydney, NSW, Australia: ACSQHC, 2015.
- 34 Rolnick JA, Ersek M, Wachterman MW, et al. The quality of end-oflife care among ICU versus ward decedents. *Am J Respir Crit Care Med* 2020;201:832–9.

**Title:** Learning needs and perceived barriers and facilitators to end-of-life care: A survey of frontline nurses on acute medical wards

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#### Appendix 1.

#### **SURVEY METHODS**

#### Item generation and reduction

We conducted a literature review and consulted with content experts to identify potential survey items to explore frontline nursing experience with, and attitudes towards end-of-life care. We ensured that each TDF domain, and thus each COM-B attribute, was represented at least once in the survey. To reduce items, we identified questions that were redundant, of limited relevance, and those that exceeded the scope of the project. Most questions were answered using a 7-point Likert-type scale (e.g., 1 = strongly disagree, 7 = strongly agree).

#### **Formatting**

Our survey instrument included participant demographics, 2 domains (Knowledge and practice, Delivering end-of-life care), 7 subsections (your role in end-of-life care, symptom management, ethical issues, resources, palliative and spiritual care, interprofessional roles in end-of-life care, and emotional impact of end-of-life care), a section on the 3WP, and an open free text section to capture any ideas not addressed in the survey that respondents wanted to share. There were 85 questions with four possible additional questions depending on responses to the preceding question (i.e., branching logic questions). In the electronic survey, respondents encountered 10 screens after the consent page with variable number of items per page (range 1 to 21 items). In the paper survey, there were 8 pages with a variable number of items per page range 6 to 21 items).

#### **Testing**

We engaged 24 individuals from frontline nurses, educators, managers, physicians, and researchers in pre-testing, pilot testing, and clinical sensibility testing to evaluate instrument feasibility, face validity, and ease of administration. We revised the survey at each stage based on feedback. Pilot testing suggested a 20-minute survey completion time.

#### Administration

Prior to administering the survey, we sent all nurses an electronic notification letter outlining the purpose of the survey, that all responses were anonymous, and that completion was voluntary. In addition, we posted advertising flyers in high-traffic nursing areas, such as ward conference rooms, staff washrooms, and the nursing stations of each ward.

We used two administration methods to maximize response rates: 1) electronic via LimeSurvey (5.1.14, Hamburg, Germany: LimeSurvey GmbH), a web-based, secure, ethics-compliant platform, which assigns participants a unique identifier to prevent duplicate survey completion; 2) manual completion with paper surveys.

Items appeared in the same order for the electronic and manual survey, and for all participants. All questions were voluntary. Questions had either a "not applicable (N/A)", "other (specify)", or "prefer not to say" option.

Electronic completion

All potential respondents received an electronic survey invitation with a unique token to access the survey. Respondents were not required to log in and once a token was used, it could not be used again. However, respondents did have the option to save responses and resume later, in which case an email was sent with access to their partially completed survey. Survey responses and participant email addresses were stored separately within the LimeSurvey platform. Respondents could navigate backward and forward in the electronic survey. There were 137 visitors to the LimeSurvey website with 31 (22.6%) starting but not completing the survey and 106 (77.4%) who completed the survey. Only completed surveys were included for analysis.

#### Manual completion

In this method, respondents entered their names on a detachable form that was collected separately. We matched the total number of completed paper surveys with the total number of detachable forms and these were equal (i.e., we did not identify duplicate entries).

**Title:** Learning needs and perceived barriers and facilitators to end-of-life care: A survey of frontline nurses on acute medical wards

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#### Appendix 2.

# Helping patients die well: Enhancing end-of-life care practices on the medical units

Thank you for taking the first step and opening our survey! Your participation is entirely voluntary, and your responses are anonymous.

On behalf of the 3 Wishes Project team, we're interested in learning about your experiences with end-of-life care. Research shows there are important challenges in providing end-of-life care, including complex symptoms, grieving families, and varying perspectives about goals of care among family members. We'd like to understand the challenges you encounter so we can build capacity and enhance practices to help patients have a good death. As a nurse caring for patients on these units, your insights are critical.

We anticipate the survey will take approximately 20-minutes. But don't worry, if you start and run out of time, you can always close and resume later (just don't forget to write down your password!). There are also paper copies available in your staff lounge if you'd prefer.

We know you're very busy, so as a token of our appreciation, on completion, you'll receive a \$10 Tim Hortons gift card, and be entered to win one of two pairs of Apple AirPods, or one of two \$75 Amazon gift cards! Also, the unit with the highest completion rate will enjoy lunch for the whole team!

Thanks again for your participation. For further information on confidentiality, any associated risks or harms, or withdrawal procedures, please see the accompanying <u>letter of information</u> (/limesurvey/upload/surveys/539762/files/EOL%20survey%20LOI-(final)FINAL.pdf).

There are 50 questions in this survey.

### **Demographics**

Legend: CTU - clinical teaching unit; NP - nurse practitioner; NRT - nursing resource team; RN - registered nurse; RPN - registered practical nurse

one. Or o dimindal leadining drint, for market practitioner, for market practical narrow, for the registered practical narrow	
What is your age group?	
Choose one of the following answers	
Please choose <b>only one</b> of the following:	
<=25 years	
26 to 30 years	
31 to 40 years	
41 to 50 years	
>=51 years	
With which gender do you self-identify?	
Choose one of the following answers	
Please choose <b>only one</b> of the following:	
Female	
Male	
Trans, transgender, two-spirit, gender non-conforming, gender variant, or analogous term	
Prefer not to say	
What is your current unit affiliation?	
D Choose one of the following answers Please choose only one of the following:	
CTU-central	
CTU-West	
CTU-North	
Medical step-down	
○ NRT	

What is your highest level of education?
● Choose one of the following answers Please choose only one of the following:
Diploma
Bachelors
○ Masters
Doctorate
Other
What is your professional background?
Choose one of the following answers
Please choose only one of the following:
○ RPN
○ RN
○ NP
Other
Who are did you are a incorporate a circumstance and the initial of
Where did you receive your professional training?  • Choose one of the following answers
Please choose <b>only one</b> of the following:
Canada
Outside of Canada (please specify)
Make a comment on your choice here:
Here have you been presticing proving?
How long have you been practicing nursing?
Choose one of the following answers
• Choose one of the following answers Please choose only one of the following:
• Choose one of the following answers Please choose only one of the following:  <1 year
• Choose one of the following answers Please choose only one of the following:
• Choose one of the following answers Please choose only one of the following:  <1 year 1-5 years
<ul> <li>♣ Choose one of the following answers</li> <li>Please choose only one of the following:</li> <li>&lt;1 year</li> <li>1-5 years</li> <li>6-10 years</li> </ul>

How long have you been in your current position?  ● Choose one of the following answers Please choose only one of the following:  <1 year 1-5 years 6-10 years 11-14 years >=15 years
With which religious/spiritual beliefs do you identify?
Choose one of the following answers  Please choose only one of the following:
Catholic
Protestant
Other Christian Use Sewish
○ Muslim
Hindu
None
Prefer not to say
Other
Have you received formal training in end-of-life care?  Please choose only one of the following:  Yes  No

Before starting the survey, we release choose the appropriate response for e	ach item:	Moderately	Somewhat	Neither comfortable nor leuncomfortable	Somewhat ecomfortable	Moderately comfortable	Complete
		o understa	ria your iev			<u> </u>	re.
			nd vour lov	vel of comfo	ort with en	d-of-life ca	
ther:							
On-the-job training							
Additional courses outside of degree or iploma training							
As part of my professional degree or diploration	ma						
Comment only when you choose an answe lease choose all that apply and provide a co							
only answer this question if the following conc nswer was 'Yes' at question '10 [D11]' (Have		mal training in e	nd-of-life care?)	1			
imulation-based, etc.) and du	ration (e.g.,					iuics, iii-s	ei vices,
Please provide a brief descrip		rainina inc	dudina tun	0/000010	arnina la	sturac in c	oniooc

## Your role in end-of-life care

	1 - Strongly disagree	2	3	4 - Neither agree nor disagree	5	6	7 - Strongly agree	N/A
My role in end-of-life care is clear and I understand what is expected of me.	0	$\circ$	0	0	$\bigcirc$	0	0	0
When I sense a patient is deteriorating and dying, I have a responsibility to help facilitate end-of-life care planning with the medical team.	0	0	0	0	0	0	0	0
It is important for me to be actively engaged in end-of-life care discussions and planning for my patients.	0	0	0	0	0	0	0	0
Learning more about end-of-life care interests me.	0	$\circ$	0	0	$\bigcirc$	0	0	$\bigcirc$

# End-of-life care knowledge and practice

End-of-life care is the practice of helping to prepare patients and their loved ones for the last stages of life.

After hours, I would contact the on-call physician or resident for the following:
Check all that apply
Please choose all that apply:
Physical symptom management
Behavioural management
Family concerns about patient status
Change in goals of care
Palliative care consult
None of the above
Thome of the above
Other:
After hours, I am hesitant to contact the on-call physician or resident because:
● Check all that apply
Please choose <b>all</b> that apply:
I am not sure what information they will need
I feel they do not know my patient as well and may not be able to assist over the phone
I perceive they will be annoyed and would prefer that I wait for rounds the next day
I have no concerns about contacting the on-call physician or resident after hours
Thave no concerns about contacting the on-call physician of resident after hours
Other:

Please	choose	the	approp	oriate	response	e for	each	item:

	1 - Strongly disagree	2	3	4 - Neither agree nor disagree	5	6	7 - Strongly agree	N/A
I am comfortable discussing issues related to end of life with patients.	0	0	0	0	0	0	0	0
I am comfortable discussing issues related to end of life with families.	0	0	0	0	0	0	0	0
I am comfortable discussing issues related to end of life with the healthcare team.	0	$\circ$	0	0	$\bigcirc$	0	0	0
I am comfortable engaging in discussions about end-of-life care with families even when the patient is unable to make their own goals of care or end- of-life decisions (e.g., due to decreased level of consciousness).	0	0	0	0	0	0	0	0
I am comfortable providing information to families on how the dying process might look for their loved one.	0	$\circ$	0	0	$\bigcirc$	0	0	$\bigcirc$
I am comfortable providing families with information on the processes that need to occur after a patient dies (e.g., contacting the physician, morgue, directing family to contact funeral home, etc.).	0	0	0	0	0	0	0	0
I am confident in my ability to support family members in their grief.	0	$\circ$	0	0	$\circ$	0	0	0
I find it challenging when family members have strong emotional reactions.	0	0	0	0	0	0	0	0
I am confident in my ability to engage with families who have strong emotional reactions.	0	0	0	0	0	0	0	0

How often do you encounter	the following ethical issues	and how comfortable a	are you dealing with them
if encountered?	_		

Please choose the appropriate response for each item:

			Frequency	/				Comfort		
	Never	Rarely	Sometim	esOften	Always	-	el§omewh ortanbemfo			atCompletely abbemfortable
Conflicts between patient and family regarding goals of care	0	0	0	0	0	0	0	0	0	0
Conflicts among family members regarding goals of care	0	0	0	0	0	0	0	0	0	0
Differing views among clinical team members about treatment plans	0	0	0	0	0	0	0	0	0	0
Decisions about which interventions to continue at the end of life	0	0	0	0	0	0	0	0	0	0
Requests for MAID (Medical Assistance in Dying) from patients or families	0	0	0	0	0	0	0	0	0	0

Prior to this survey, did you know that patients can request MAID (Medical Assistanace in Dying) at St. Joe's? While MAID is not performed on site, MAID assessments and referrals are available at patients' request.
Please choose <b>only one</b> of the following:

#### Resources

These may include informational resources (e.g., online learning, pamphlets, etc. for staff and/or for patients/families), stock of non-hospital blankets or other items for person-centered care, personnel, etc. Please use the free text boxes to provide any additional information you feel is important for us to know.

Please choose the appropriate response for each item:

	1 - Strongly disagree	2	3	4 - Neither agree nor disagree	5	6	7 - Strongly agree	N/A
There are adequate resources for end- of-life care available on the unit.	0	$\bigcirc$	0	0	$\bigcirc$	0	0	$\bigcirc$
Resources for end-of-life care are easily accessible when needed.	0	$\circ$	0	0	$\circ$	0	0	0

What existing resources (e.g., physical, electronic, personnel) are most helpful for you to provide end-of-life care?
Please write your answer here:
What additional resources (e.g., physical, electronic, personnel) would you find most helpful to provide end-of-life care?
Please write your answer here:

End-of-life symptom management

consistent with effective symptom

management.

	1 - Strongly disagree	2	3	4 - Neither agree nor disagree	5	6	7 - Strongly agree	N/A
In general, I am uncomfortable approaching physicians if I feel that a patient needs more of, or a change in medications to manage symptoms.	0	0	0	0	0	0	0	0
Orders received from residents are generally not adequate or appropriate to manage symptoms of dying patients.	0	0	0	0	$\circ$	0	0	0
I do not know how to manage symptoms when patients can no longer speak or tell me what symptoms they are experiencing.	0	0	0		0	0		0
When medications are ordered as a range of doses, I am uncertain about which dose to use.	0	0	0	0	0	0	0	$\circ$
I am uncomfortable giving 'PRN' medications at the end of life, as it may cause the end to come sooner.	0	0	0	0	0	0	0	0
I am uncomfortable giving scheduled medications (e.g., dilaudid or versed) at the end of life when the patient is drowsy or sleeping.	0	0	0	0	0	0	0	0
I am uncomfortable using IV pumps for continuous subcutaneous infusion of medications (e.g., versed).	0	0	0	0	$\bigcirc$	0	0	$\bigcirc$
I am unsure of what to do when families are asking for more pain medications for their loved one, but the patient is barely conscious.	0	0	0	0	0	0	0	0
I am unsure of what to do when families want their loved one to be more awake,	0	0	0	0	$\bigcirc$	0	0	0

Hydromorphone (dilaudid) and other opioids can be useful in palliative care or at the end of life for several reasons. My practice is to administer these medications at the end of life for (please select all that apply):
Check all that apply Please choose all that apply:
Pain Shortness of breath or respiratory distress Cough Anxiety Restlessness Agitation Bedside procedures (e.g., dressing changes) Other:
Midazolam (versed) and other benzodiazepines can be useful in palliative care or at the end of life for several reasons. My practice is to administer these medications at the end of life for (please select all that apply):
• Check all that apply Please choose all that apply:
Pain Shortness of breath or respiratory distress Cough Anxiety Restlessness Agitation Bedside procedures (e.g., dressing changes)  Other:
When I notice that a patient is agitated or restless, I check the following issues for potential causes:  • Check all that apply
Please choose all that apply:  Respiratory distress Pain Positioning Bladder Bowel Sleep If patient is receiving home pain or anti-anxiety medications (or equivalent in hospital)  Other:

Delivering end-of-life care

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Please choose the appropriate response for each item:

	1 - Strongly disagree	2	3	4 - Neither agree nor disagree	5	6	7 - Strongly agree	N/A
In general, our healthcare team's communication facilitates inclusive end-of-life care discussions and planning.	$\bigcirc$	0	0	0	$\bigcirc$	0	0	$\circ$
With few exceptions, end-of-life care discussions that have taken place between the medical team and patients/families are well documented and communicated to all other team members.	0	0		0	0	0	0	0
Most physicians trust my judgment when it comes to delivering end-of-life care (e.g., utilizing appropriate PRN doses of medications, etc.).	$\bigcirc$	0	0	0	$\bigcirc$	0	0	0
When I call the physicians or residents to notify them that a patient has acutely changed and is likely nearing the end of their life, I feel they are responsive and that I have been heard.	0	0	0	0	0	0	0	0

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Please choose the appropriate response for each item:

	1 - Strongly disagree	2	3	4 - Neither agree nor disagree	5	6	7 - Strongly agree	N/A
Usually, if I need another nursing colleague's assistance to provide end- of-life care to a patient, I will not have trouble getting it.	0	0	0	0	0	0	0	0
In general, when I am caring for a patient at the end of life, I tend to be given another busier patient assignment because the needs of the dying patient are perceived to be low.	0		0	0	0	0	0	0
Logistics on the unit (e.g., staffing, acuity of patients, etc.) make it difficult to implement consistent, high-quality end-of-life care.	0	0	0	0	0	0	0	0
I am comfortable engaging family in the care of their loved one at the end of life (e.g., repositioning, bathing, etc.).	0	0	0	0	0	0	0	0

I have participated in a debriefi year.	ng (either	organize	ed or info	rmal) after	the deat	h of a pa	tient in the	last
Please choose <b>only one</b> of the following:								
Yes								
○ No								
Please select the response(s)	regarding	dehriefin	a that he	et alian wit	h vour n	ractice a	nd views:	
Please select the response(s) regarding debriefing that best align with your practice and views:  Only answer this question if the following conditions are met:  Answer was 'Yes' at question '28 [SS4]' (I have participated in a debriefing (either organized or informal) after the death of a patient in the last year.)								ar \
• Check all that apply Please choose all that apply:	e participated in	a debileling	(either organ	nzed of informal	aller the de	atii oi a patie	in the last ye	ai. <i>)</i>
I have participated in an <b>organized</b> debrie	efing after the d	eath of a nati	ent in the lee	t vear				
I have participated in <b>informal</b> debriefings	-	•	one in the las	. ,				
Organized debriefings are generally not of	•	-						
Informal debriefings with colleagues rarely	occur /							
I do not have time to participate in debriefi	ings							
Other:								
Please select the response(s) I Only answer this question if the following cond Answer was 'No' at question '28 [SS4]' (I have  Check all that apply Please choose all that apply:  Organized debriefings are not offered on Informal debriefings with colleagues rarel I do not have time to participate in debriefing Other:	ditions are met: participated in my unit y occur							ır. )
Debriefing  Please choose the appropriate response for each	ach item:							
	1 - Strongly disagree	2	3	4 - Neither agree nor disagree	5	6	7 - Strongly agree	N/A
Having the opportunity to debrief after a death would be helpful to increase my knowledge, skills, confidence, and comfort with end-of-life care.		0	0	0	0	0	0	

Organ	izational	Suppor	t

In general, St. Joe's culture is supportive of end-of-life care that extends beyond solely symptom management (that may include personalized care such as transferring to a private room if available, allowing pet visitation, allowing patients to wear their own clothes, etc.):

Please choose the appropriate response for each item:

	1 - Strongly disagree	2	3	4 - Neither agree nor disagree	5	6	7 - Strongly agree	N/A
My nursing colleagues are supportive	0	$\bigcirc$	0	0	$\bigcirc$	0	0	$\bigcirc$
My charge nurse is supportive	0	$\bigcirc$	0	0	$\bigcirc$	0	0	$\circ$
My interdisciplinary colleagues are supportive	0	0	0	0	$\circ$	0	0	0
Physicians are supportive	0	$\bigcirc$	$\circ$		$\bigcirc$	0	0	$\bigcirc$
Medical learners (e.g., residents) are supportive	0	0	0	0	$\circ$	0	0	0
The educators are supportive	0	$\bigcirc$	$\circ$		$\bigcirc$	0	0	$\bigcirc$
My manager is supportive	0	$\circ$	0	0	$\circ$	0	0	$\circ$
Hospital administration is supportive	0	$\circ$	0	0	0	0	0	$\circ$

## Palliative and spiritual care

Please choose the appropriate response for e	ach item:							
	1 - Strongly disagree	2	3	4 - Neither agree nor disagree	5	6	7 - Strongly agree	N/A
Palliative care is a needs-based concept aimed at optimizing quality of life for patients with life-limiting illness.	0	0	0	0	0	0	0	0

I routinely suggest palliative care consultations for dying patients.  Please choose only one of the following:	

I routinely suggest palliative care consultations for management of the following:  Only answer this question if the following conditions are met:  Answer was 'Yes' at question '34 [SS7]' (I routinely suggest palliative care consultations for dying patients.)  Otheck all that apply Please choose all that apply:  Pain  Dyspnea  Delirium  Goals of care discussions  Family dynamics  Place of care or disposition (e.g., palliative care suite, home, hospice)  Other:
Please identify any barriers that prevent you from suggesting palliative care consults:  ① Check all that apply Please choose all that apply:  ☐ I do not perceive any barriers  ☐ The role of palliative care is unclear to me  ☐ The healthcare team misunderstands what palliative care means  ☐ Families misunderstand what palliative care means  ☐ I am reluctant to involve another service  ☐ The palliative care team is very busy  ☐ Other:
I routinely suggest or offer spiritual care consultations for dying patients.  Please choose only one of the following:  Yes  No
I routinely suggest or offer spiritual care consultations for the following:  Only answer this question if the following conditions are met:  Answer was 'Yes' at question '37 [SS8]' (I routinely suggest or offer spiritual care consultations for dying patients.)  ◆ Check all that apply  Please choose all that apply:  Only if the patient and/or family has requested spiritual care  Only if I know the patient and/or family or loved ones have specific religious beliefs  Psychological support for the patient  Psychological support for the patient's loved ones  Other:

Please identify any barriers that prevent you from suggesting or offering spiritual care consultations:
• Check all that apply
Please choose all that apply:
I do not perceive any barriers
The role of spiritual care is unclear to me
General practice on my unit is not to engage spiritual care very often
Spiritual care clinicians are very busy
Other:
Interprofessional roles in end-of-life care
•
The following professions or people are routinely involved in caring for patients at the end of life:
Check all that apply Please choose all that apply:
Dietician
Occupational therapist
Pharmacist
Physiotherapist  Description of the agents to the second of the second o
Recreational therapist
Respiratory therapist Social work
Speech language pathologist
Volunteers
Wound care specialist
Other:

Emotional impact of end-of-life care

	1 - Strongly disagree	2	3	4 - Neither agree nor disagree	5	6	7 - Strongly agree	N/A
he healthcare team perceives patients lying as a failure or giving up hope.	0	$\circ$	0	0	$\circ$	0	0	$\circ$
perceive decisions to transition atients to comfort care and not ffering active medical interventions as failure or giving up hope.	0	0	0	0	0	0	0	0
feel overwhelmed when I must care for attents who are dying.	0	$\circ$	0	0	$\circ$	0	0	$\circ$
find that providing end-of-life care is challenging, often leading me to feel atigue and burnout.	0	0	0	0	0	0	0	0
find that providing end-of-life care is plifting, often leading me to feel joy nd comfort knowing that patients and amilies are well cared for.	0	$\circ$	0	0	0	0	0	0
Vhat would be most helpful to	you to inc	rease yo	ur confid	ence and o	comfort v	vith end-	of-life care	?
The choice you would find the All your answers must be different and you Please select at most 5 answers	most help	oful shou				vith end-	of-life care	?
The choice you would find the All your answers must be different and you Please select at most 5 answers	most help must rank in or e from 1 to 7	oful shou				vith end-	of-life care	?
The choice you would find the All your answers must be different and you Please select at most 5 answers lease number each box in order of preference	most helpmust rank in or	oful shou der.				vith end-	of-life care	?
The choice you would find the All your answers must be different and you Please select at most 5 answers lease number each box in order of preference Formalized on-the-job training	most help must rank in or e from 1 to 7	oful shou rder.	ld be at t	he top righ	t	vith end-	of-life care	?
All your answers must be different and you Please select at most 5 answers ease number each box in order of preference.  Formalized on-the-job training Simulated learning for end-of	most help must rank in or e from 1 to 7  G  -life care discu (e.g., educatio	oful shou rder. ssions n modules, m	ld be at t	he top righ	t etc.)	vith end-	of-life care	?
The choice you would find the All your answers must be different and you Please select at most 5 answers ease number each box in order of preference Formalized on-the-job training Simulated learning for end-of Electronic resources for staff	most help must rank in or e from 1 to 7  G  -life care discu (e.g., education dents/families (contents/families)	oful shou rder. ssions n modules, m	ld be at t	he top righ	t etc.)	vith end-	of-life care	?
Simulated learning for end-of  Electronic resources for staff  Information resources for pat	most help must rank in or e from 1 to 7  G  life care discu (e.g., education ients/families (control of the control of the con	oful shou rder. ssions n modules, m	ld be at t	he top righ	t etc.)	vith end-	of-life care	?

What else, not listed above, would be helpful to increase your confidence and comfort with end-of-life care?
Please write your answer here:
Γhe 3 Wishes Project
I am aware of the 3 Wishes Project from:
♠ Check all that apply Please choose all that apply:
From the ICU From patients who have been enrolled on my unit, cared for by others From knowledge translation, such as information sessions, in-services on the units, or publications
I am not aware of the 3 Wishes Project  Other:
I have been involved with patients enrolled in the 3 Wishes Project:  ① Check all that apply Please choose all that apply:  ☐ In ICU ☐ On the unit ☐ I have not been directly involved with any patients enrolled in 3 Wishes, but indirectly witnessed this ☐ I have not been directly or indirectly involved with any patients enrolled in 3 Wishes ☐ Other:
I am able to initiate the 3 Wishes Project on my own and do not require a specific consult.  Choose one of the following answers Please choose only one of the following:  Yes  No
I don't know
With training, would you be willing to be an end-of-life care champion on your unit?  Please choose only one of the following:  Yes
○ No

Would you be willing to participate in a follow-up focus group to gather more information on learning needs, barriers, and facilitators?  Please choose only one of the following:  Yes  No
Thank you for your willingness to participate in a follow-up focus group. So that we may contact you, please provide your name and email address: *
Only answer this question if the following conditions are met:  Answer was 'Yes' at question '48 [Q01]' (Would you be willing to participate in a follow-up focus group to gather more information on learning needs, barriers, and facilitators?)
Perceptions of end-of-life care
Is there anything else you would like to tell us about caring for patients at the end of life that has not been captured in this survey?  Please write your answer here:
ou will receive your electronic Tim Hortons gift card within 1 week of completion. If you have not received your card in this time, please email ureid@stjosham.on.ca.
hank you for taking the time to complete this survey. Your answers are vital to enhancing end-of-life care practices.
Submit your survey. Thank you for completing this survey.