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

What is your age group?

• Choose one of the following answers Please choose **only one** 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 **only one** 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?

• Choose one of the following answers Please choose **only one** of the following:

CTU-central

CTU-West

CTU-North

Medical step-down

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	
Where did you receive your professional trainin Choose one of the following answers Please choose only one of the following: Canada Outside of Canada (please specify) Make a comment on your choice here:	ıg?
How long have you been practicing nursing? • Choose one of the following answers Please choose only one of the following:	

◯ <1 year

1-5 years

O 6-10 years

11-14 years

◯ >=15 years

How long have you been in your current position?
 Choose one of the following answers Please choose only one of the following:

\cup	<1 year
\bigcirc	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:
O Protestant
Other Christian
◯ Jewish
Hindu
◯ None
O Prefer not to say
Other

Have you received formal training in end-of-life care?

Please choose only one of the following:

◯ Yes

◯ No

How did this formal training occur?

(Please provide a brief description of the training, including type (e.g., e-learning, lectures, in-services, simulation-based, etc.) and duration (e.g., 4-hour session, 2-week course, etc.))

Only answer this question if the following conditions are met:

Answer was 'Yes' at question '10 [D11]' (Have you received formal training in end-of-life care?)

• Comment only when you choose an answer.

Please choose all that apply and provide a comment:

As part of my professional degree or diploma training	
Additional courses outside of degree or diploma training	
On-the-job training	
Other:	

Before starting the survey, we would like to understand your level of comfort with end-of-life care.

Please choose the appropriate response for each item:

	Completely uncomfortabl	Moderately euncomfortabl	Somewhat euncomfortabl	Neither comfortable nor euncomfortabl	Somewhat ecomfortable	Moderately comfortable	Completely comfortable
How comfortable are you with your role delivering end-of-life care to dying patients?	0	0	\bigcirc	0	\bigcirc	0	\bigcirc

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.	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
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	\bigcirc	0	0	\bigcirc	\bigcirc	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	\bigcirc	0	0	\bigcirc
Learning more about end-of-life care interests me.	0	\bigcirc	\bigcirc	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

Other:

After hours, I am hesitant to contact the on-call physician or resident because:

Check all that apply

Please choose all 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

Other:

	1 - Strongly disagree	2	3	4 - Neither agree nor disagree	5	6	7 - Strongly agree	N/A
am comfortable discussing issues related to end of life with patients.	\bigcirc	\bigcirc	0	0	\bigcirc	0	0	\bigcirc
am comfortable discussing issues related to end of life with families.	\bigcirc	\bigcirc	\bigcirc	0	\bigcirc	0	0	\bigcirc
l am comfortable discussing issues related to end of life with the healthcare team.	\bigcirc	\bigcirc	\bigcirc	0	\bigcirc	\bigcirc	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	\bigcirc	0	0	0
l am comfortable providing information to families on how the dying process might look for their loved one.	\bigcirc	\bigcirc	0	0	\bigcirc	0	0	0
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.	\bigcirc	\bigcirc	0	0	\bigcirc	0	0	\bigcirc
l find it challenging when family members have strong emotional reactions.	0	\bigcirc	0	0	\bigcirc	0	0	\bigcirc
am confident in my ability to engage with families who have strong emotional reactions.	0	\bigcirc	0	0	\bigcirc	0	\bigcirc	0

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

Please choose the appropriate response for each item:

			Frequency	Y			Comfort				
	Never	Rarely	Sometim	esOften				elŞomewh rtabbemfo	SomewhatCompletely comfortabtemfortabl		
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 only one of the following:

⊖ Yes

◯ No

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.	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
Resources for end-of-life care are easily accessible when needed.	\bigcirc	\bigcirc	0	0	\bigcirc	0	0	\bigcirc

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

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

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	

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

Communication

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	\bigcirc	\bigcirc	0	\bigcirc	0	\bigcirc	\bigcirc
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.	\bigcirc	\bigcirc	0	0	\bigcirc	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	\bigcirc	0	0	\bigcirc	0	0	\bigcirc
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	\bigcirc	0	0	\bigcirc	0	0	0

Logistics

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.	\bigcirc	\bigcirc	0	0	\bigcirc	0	0	\bigcirc
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	\bigcirc	0	0	\bigcirc
Logistics on the unit (e.g., staffing, acuity of patients, etc.) make it difficult to implement consistent, high-quality end-of-life care.	\bigcirc	\bigcirc	0	0	\bigcirc	0	0	\bigcirc
I am comfortable engaging family in the care of their loved one at the end of life (e.g., repositioning, bathing, etc.).	0	\bigcirc	0	0	\bigcirc	0	0	0

I have participated in a debriefing (either organized or informal) after the death of a patient in the last year. Please choose only one of the following:
⊖ Yes
() No
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.)
Check all that apply Please choose all that apply:
I have participated in an organized debriefing after the death of a patient in the last year
I have participated in informal debriefings with my colleagues
Organized debriefings are generally not offered on my unit
Informal debriefings with colleagues rarely occur
I do not have time to participate in debriefings
Other:
Please select the response(s) regarding debriefing that best align with your practice and 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 'No' at question '28 [SS4]' (I have participated in a debriefing (either organized or informal) after the death of a patient in the last year.)

• Check all that apply Please choose **all** that apply:

Organized debriefings are not offered on my unit

Informal debriefings with colleagues rarely occur

I do not have time to participate in debriefings

Other:

Debriefing

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
Having the opportunity to debrief after a death would be helpful to increase my knowledge, skills, confidence, and comfort with end-of-life care.	\bigcirc	\bigcirc	0	0	\bigcirc	0	0	\bigcirc

Organizational Support

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	\bigcirc	0	\bigcirc	0	0	\bigcirc
My charge nurse is supportive	0	\bigcirc	\bigcirc	0	\bigcirc	0	0	\bigcirc
My interdisciplinary colleagues are supportive	\bigcirc	\bigcirc	\bigcirc	0	\bigcirc	0	\bigcirc	\bigcirc
Physicians are supportive	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
Medical learners (e.g., residents) are supportive	0	\bigcirc	0	0	\bigcirc	0	0	\bigcirc
The educators are supportive	0	\bigcirc	\bigcirc	0	\bigcirc	0	0	\bigcirc
My manager is supportive	0	\bigcirc	\bigcirc	0	\bigcirc	\bigcirc	0	\bigcirc
Hospital administration is supportive	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	0	\bigcirc	\bigcirc

Palliative and spiritual care

	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.	\bigcirc	\bigcirc	0	0	\bigcirc	0	0	\bigcirc

I routinely suggest palliative care consultations for dying patients.

Please choose **only one** of the following:

YesNo

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.)
O Check 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: 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'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
Ccupational therapist
Pharmacist
Physiotherapist
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
The healthcare team perceives patients dying as a failure or giving up hope.	0	\bigcirc	0	0	\bigcirc	\bigcirc	0	\bigcirc
I perceive decisions to transition patients to comfort care and not offering active medical interventions as a failure or giving up hope.	0	\bigcirc	0	0	\bigcirc	0	0	\bigcirc
I feel overwhelmed when I must care for patients who are dying.	\bigcirc	\bigcirc	0	0	\bigcirc	\bigcirc	0	\bigcirc
I find that providing end-of-life care is challenging, often leading me to feel fatigue and burnout.	0	0	0	0	\bigcirc	0	0	\bigcirc
I find that providing end-of-life care is uplifting, often leading me to feel joy and comfort knowing that patients and families are well cared for.	0	0	0	0	\bigcirc	0	0	\bigcirc

What would be most helpful to you to increase your confidence and comfort with end-of-life care? *The choice you would find the most helpful should be at the top right

• All your answers must be different and you must rank in order.

• Please select at most 5 answers

Please number each box in order of preference from 1 to 7

Formalized on-the-job training
Simulated learning for end-of-life care discussions
Electronic resources for staff (e.g., education modules, medication information sheets, etc.)
Information resources for patients/families (e.g., on the dying process, what happens after, etc.)
End-of-life care champions on your unit
Symptom assessment and management tool
I do not feel I need anything further to increase my comfort or confidence currently (*if yes, please rank only this option)

Т

What else, not listed above, would be helpful to increase your confidence and comfort with end-of-life care? Please write your answer here:
The 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:
 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

O 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:

\bigcirc	Yes
\bigcirc	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:

You 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 jureid@stjosham.on.ca.

Thank 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.