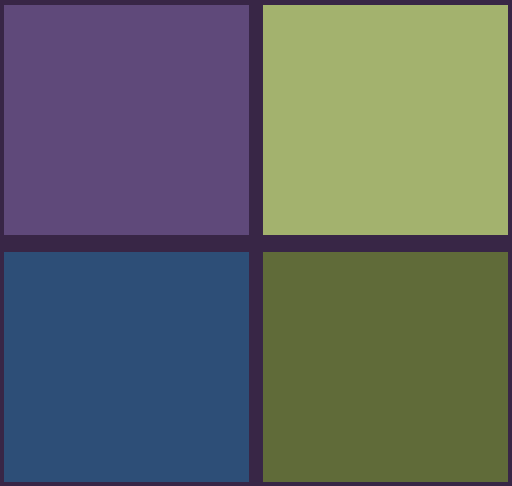
# PALLIATIVE AND END-OF-LIFE CARE: A FACULTY GUIDE FOR NURSING EDUCATION

*A teaching and learning resource based on a pedagogical model: Story-based learning*



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# ACKNOWLEDGEMENTS

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# INTRODUCTION TO STORY-BASED LEARNING

Story-based learning (SBL) is a pedagogical approach that is well suited for preparing students to provide palliative and end-of-life care. This model is an adaptation of case-method teaching and problem-based learning (Young, 2007). It was developed and evaluated by Dr. Young in collaboration with the University of Victoria School of Nursing students and faculty. Story based learning is designed to align with the tenets of health promoting nursing practice that falls within a humanistic-holistic-naturalistic paradigm. A key tenet of this perspective is that practice begins with an understanding of lived experience; hence the SBL model begins with storytelling, a strategy that illuminates experience. SBL is student-centered and thus, aligns with another key tenet: health promoting nursing practice is client/patient-centered. As a student-centered teaching/learning strategy, SBL requires instructors to 'teach' in a way that places the student at the center of the teaching/learning process. Rather than preparing a lecture and PowerPoint slides, the instructor uses carefully crafted stories to facilitate structured conversations that enable students to highlight key elements in the story, and also to develop awareness of personal knowledge gaps. By using stories rather than cases with clinical facts, students are able to view the patient as a 'person' rather than a 'case'. This approach leads learners to a deeper understanding of the lived experience of health and healing, while developing clinical knowledge to support practice. The SBL process of addressing knowledge gaps develops skills in searching, retrieving, and analyzing relevant literature, as well as the ability to work collaboratively with peers to acquire knowledge for practice. This process is consistent with current thinking about how to develop skills for life-long learning in higher education. In addition, the stories are developed to enable learners to grasp elements of the experience that they may not be aware of, including: social, economic, political, practical, and other influences on the health experience. Moreover, the stories are designed to have an emotional effect on students which fosters authentic engagement. The aim is for students to become interested in the events and the people in the story.

The process of working with SBL is non-linear and iterative. Although the end of one phase in the SBL process is the beginning of another, students can move through the phases multiple times even though the narrative itself moves forward as it does in a person's real life. In each of the six phases, students work with one another and their instructor to build on previous knowledge through identifying key questions, patterns, nursing support and then discussing, critiquing, and debating the identified knowledge issues. The instructor facilitates the learning process. For example, if students fail to note a particularly important element of the story, the instructor will guide students in this area, thus instructors require sophisticated facilitation skills. Throughout the discussions, students identify individual learning needs that are addressed as the SBL assignments progress. Each of the phases of SBL will be described further in this resource.

As a student-centered model, SBL requires students to take a lead role in their own learning. This approach promotes critical reflection and discussion among students, which aids in identifying gaps in their learning, and determining how they can enrich their knowledge, skills and attitudes. Two important aspects of the SBL model include 'participatory dialogue' and 'critical appraisal'. Both create a student-centered learning environment that fosters critical thinking. In participatory dialogue, the facilitator models the skills necessary for students to learn and how to authentically engage with each other, which includes attending to their own and other students' emotions, and listening to the details and meaning that the story illuminates. In modeling the skills, the facilitator asks 'good' questions that foster learning, and shares 'power' within the classroom. The role of the SBL facilitator is not to be a 'content' expert even though the subject matter may be within the instructor's expertise. This approach may be difficult for instructors used to a different teaching style; thus this resource includes suggestions for ways to develop skills required to be a successful SBL instructor.

Critical appraisal requires students to critically reflect, critique and discuss assumptions that emerge from the story. Facilitators can guide students in this area by probing them about claims made, the scientific merit of these claims, and the basis on which claims are made. Students search journals, books, media, expert opinion, and other resources to substantiate evidence of a claim. With this approach, students develop skills in information literacy, and apply their knowledge of research/ levels of evidence; they build their knowledge in areas where there are gaps.

## FACILITATION

Facilitation refers to “the process of enabling groups to work cooperatively and effectively” (Gaffney, 2000, para. 1). It is a learned skill that requires practice. The purposes of facilitation vary and may include enabling individuals and teams to analyze, reflect and change attitudes, behaviors and ways of working. The facilitator's role in SBL is to support students in thinking, critiquing and discussing within an atmosphere of authentic and mutual respect. While the facilitator is the leader, the role is also collegial and collaborative depending on the capability of students to be self-directed. The facilitator encourages full participation to promote thinking, creates a safe environment for students to speak and be heard, and cultivates a shared responsibility for gaining new perspectives, ideas, and challenging assumptions and biases. This process enables students to determine their present level of knowledge, and identify gaps, which can then be defined as learning needs and integrated into a learning plan.

As facilitators, SBL instructors do not provide students with the content to be learned. Their role is not to monopolize the discussion, determine the ‘right’ answers to pre-determined questions, or outline what is to be ‘learned’ through an agenda comprised of specific learning objectives. Instructors draw on students’ existing knowledge and facilitate the identification of gaps in knowledge. SBL embodies adult learning principles, which include stimulating motivation to learn by addressing individual needs and interests, centering learning on real-life situations, enabling self directed learning, and building on, learners’ previous experiences (Renner, 2005).

This resource is intended to be a guide to facilitate SBL in a palliative end-of-life story, and is not an in-depth resource on facilitation. Additional reading suggestions are included under ‘Faculty Resources’.

# HOW TO ASK GOOD QUESTIONS

In the SBL approach, formulating ‘good’ questions is the facilitator or instructors' primary tool to promote participatory dialogue and critical appraisal. The facilitator needs to know *what* to ask, *whom* to ask, and *how* to ask questions. In addition to questioning biases and assumptions, good questions will also emphasize critical points, assess understanding, and arouse interest.

Good questions are thought-provoking. Questions are not ‘yes/no’, ambiguous, lists or citations, leading, or multiple (two or more questions in one).

Some suggestions for asking ‘good’ questions include:

1. *Anne, that sounds like an interesting experience. What did you learn from that?*
2. *What do others think about what Jane had to say?*
3. *I am not sure I understand Sue’s response. What are some interpretations?*
4. *What are some other ways of looking at that particular issue?*
5. *How would that idea connect with our current line of discussion?*
6. *What are some ways in which you would approach that problem?*

Some suggestions to create a climate of inquiry in the classroom (Renner, 2005) include:

1. *Rarely tell students what you think they ought to know;*
2. *Use questioning as your main method of interacting;*
3. *To promote discussion, generally do not accept a single statement as an answer;*
4. *Encourage student-student interaction;*
5. *See learning as a ‘process’ rather than coming to an end or closure on a topic;*
6. *Measure the facilitator’s ‘success’ by the learner/student’s behavioral changes (asking more questions, changing positions, challenging other statements, and so on).*

**Student - Student Interaction**

# HOW THE RESOURCE IS ORGANIZED

This Faculty Guide accompanies the SBL PowerPoint Presentation. In both resources, *The Story of Mary*, a 48 year old Aboriginal woman with advanced metastatic colon cancer, is told (two part story). Each part of Mary's story presents different aspects of palliative end-of-life nursing care. For example, Mary moves from a surgical unit to her home, and as her disease progresses her care needs change. The purpose of the various aspects of the story is to foster the development of the *Palliative and End-of-Life Care Entry-to-Practice Competencies and Indicators for Registered Nurses* (CASN, 2011) through 'participatory dialogue' and 'critical appraisal'. The competencies and indicators can be found in Appendix D.

The SBL model involves six phases. There is no prescribed time frame for each phase. This is determined by the learners, and will vary from one classroom to another. For example, in the video component of this resource, students in the classroom spent the majority of the time in phase II: *What is going on here?* The amount of time spent can be pre-determined by the class, or can be decided along the way. An important factor to keep in mind is that not every aspect of palliative end-of-life nursing care can possibly be covered, nor should this be the goal. Instructors need to enable students to have enough time and engagement to determine *what* they know, what they *need* to know, and *how* they will seek the information required; assignments can be based on these factors.

The PowerPoint component of this teaching and learning resource includes classroom examples of the SBL model in action, using *The Story of Mary.* Although instructors may have different teaching styles, the intent of the video clips is to demonstrate the application of SBL in the context of palliative and end-of-life care to a group of 4th year nursing students. The class was two hours in length, and students focused on Part One of *The Story of Mary*. At the beginning of the class, the instructor explained the SBL model, and provided students with a diagram (see Appendix A) to illustrate how the model could be used. Following the explanation of the model and the reading of *The Story of Mary,* students broke up into small groups. They were given felt-tip markers and flip chart paper, and were asked to document their reflections, ideas, and thoughts; the 'BIG question' was positioned around the edges of the flipchart paper, and other ideas were positioned within the middle of the paper. The instructor facilitated students to use both 'participatory dialogue' and 'critical appraisal' as they moved through each phase. In addition, the instructor assigned one student in each group to be the facilitator as she circulated from group to group to ensure students were working together productively. With this approach, students also learned, and were coached on facilitation skills. At certain points, or after each phase, students came together to share and learn from each other's discussions.

Throughout this faculty resource there are '*Facilitation Tips'* that are meant to assist instructors in a particular area. Additionally, there are *'Examples'* that provide specific points of a phase that relate to *The Story of Mary*. For instructors who are not yet comfortable using SBL, there are suggestions within this resource called *'Try This'* that are meant to help individuals develop the skills required to teach using a student-centered pedagogical approach. Finally, *'Did You Know?'* bubbles are dispersed throughout the resource that provide related bits of information for instructors. In the appendix, there is a diagram of the SBL model (Appendix A) and additional palliative and end-of-life care resources (Appendix B & C).

**Student as facilitator of small group with instructor as main facilitator/mentor**

## Phase One: Attending to the Story

The first phase of the SBL model is the story. Stories written for SBL must have the following criteria:

- Be of adequate complexity
- Provide a wide range of issues
- Built on existing knowledge
- Elicit emotion
- Be Inviting
- Reflect reality

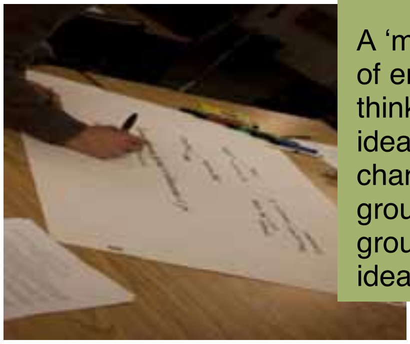
The story incorporates a variety of health experiences, some of which include physiological, social, ethical, political, ideological, and relational experiences. The story can be either a ‘one time’ situation or a series of two or more, illustrating multiple complexities in a person’s health experience. Students may write their own stories. This exercise not only develops an aesthetic side, but can also resolve a dilemma, or bring closure to a previous clinical situation. The instructor can be creative in how to introduce the story in the classroom. In this resource, the story is already written; one approach involves having the students read the story once or twice individually and/or aloud by a volunteer student. The intent is for students to engage in the story, and tap into the emotional aspect, while also thinking about the details within the story, and the meaning they make of it. Students can begin to formulate ideas, thoughts and questions that can be brought out in subsequent phases.

### *The Story of Mary: Part One*

*My patient today is Mary and she has just returned from the recovery room. She had an operation last night to release her bowel obstruction, which was caused by a malignant tumor. Mary came in just before I went off shift yesterday, so I was only able to spend a short time with her. Mary told me that she comes from a small, Aboriginal village far from here and that she required emergency surgery. Mary said that she was scared as she spent all of her life in the village, and now feels alone in this big city hospital. Her family only arrived this morning, so she was without their support all night; I think that was very hard for her. Mary said that the cancer in her bowel caused the obstruction. She said that the local doctor made arrangements to fly her out to our hospital for this ‘life-saving’ surgery. Last night when I was admitting her to the unit, she asked me if the cancer would be all gone when the surgery was over. Mary said that she had children and grandchildren who needed her and that she did not want to die. I did not know what to say; I did not want to take her hope away, so I just listened and held her hand. I have been thinking about that a lot and am worried about what I may say if she asks me this again. I don’t know her customs either. I want to be respectful, but I think she needs to know the truth…that her cancer is still there and that the surgery only bought her some time, and according to the chart, she only has a few short weeks. Oh dear…I need to care for her needs now… vital signs, the IV…*

## Phase Two: What Is Going On Here?

In this section, students are asked to think about the story they just read or heard, and begin the SBL process by responding to their individual thoughts as the story was read or told to them. They may be invited to listen to the story the first time and perhaps jot thoughts down during the second reading. The story can be told, posted on a wall, written on PowerPoint slides, or students can have printed copies on hand. To promote full participation, students are organized into small groups of usually no less than three and no more than six. The story can be told or presented to the whole group, or in each of the small groups. After initial thoughts about the story are shared by everyone within the group, the facilitator (instructor or student) encourages further discussion of the points raised, and also encourages students to continue to share more ideas or delve deeper into some of the ideas raised.



***Facilitator Tip:***

A 'mind map' is one method of encouraging students to think freely and broadly. The ideas can be written on flip chart paper, shared by a group, or individually. Each group can then share their ideas with the class.

A key pedagogical point in 'what is going on here?' is to work with students to identify what they know and what they do not know about the situation, and to then identify knowledge gaps and related learning issues that they can address during the SBL session. Students address their knowledge gaps by searching, reading, and analyzing the relevant literature and bringing this back to the group for discussion as in problem-based learning. Pedagogically, this is a critical step in the 'new' pedagogy as students develop a habit of mind as they begin to distinguish what they know from what they do not know, which ensures that they work from a position of knowing as they practice as a professional (as opposed to working from material that is memorized). In addition, students will also develop skills for information literacy in this process. This skill is essential for nurses and all health care professionals in this era of rapid knowledge development.

***Facilitator Tip…***

Provide students with resources in the classroom, such as relevant journals, books, articles, list of websites, etc. so that they are able to seek information related to their learning needs.

## *What are the Big Questions?*

The ‘Big Questions’ derive from case method teaching and are designed to bring out the learner’s awareness, and the overarching social, ethical, economic, cultural, and/or political influences relevant to the story. Stories in case method teaching are written to bring forward a specific overarching issue to excite discussion and guide learning in a particular direction. For example, the story can be used to foster reflection on ethical issues and to foster integration of ethical knowledge. The facilitator may provide some ‘good questions’ for each group if there are important aspects of theory that may not have been discussed. Although *The Story of Mary* takes place in an acute care hospital unit, and a lot of the care will be centered on recovery from surgery, there are other important aspects of this story that can promote students to think about the ‘experience’ and possible implications of this experience for Mary and her family. This process of facilitating a rich and meaningful discussion ensures students think about the wide array of aspects of a story, and enables students to begin the process of identifying what they know from what they do not know, which will expand during the SBL process.

***AN EXAMPLE…***

STUDENTS MAY HAVE QUESTIONS RELATED TO ABORIGINAL PEOPLES, SUCH AS:

- WHAT ARE MY BIASES AND BELIEFS ABOUT FIRST NATIONS WOMEN?
- WHAT POLICIES ARE IN PLACE TO FUND TRAVEL FROM ISOLATED FIRST NATIONS VILLAGES?
- WILL FAMILY MEMBERS BE ABLE TO AFFORD TO STAY IN THE CITY FOR A PROLONGED PERIOD OF TIME?

***Facilitator Tip…***

By asking ‘good questions,’ the instructor can provide direction for students and expand their thinking. These can be ‘teachable’ moments where the facilitator can draw attention to using resources in the classroom to access information.

## Phase Three: Recognizing Patterns of Wholeness and Disruption

In this phase, students focus on patterns of wholeness and disruption, which brings together discussions from the first two phases. Wholeness characterizes patterns of how patients and families make meaning and order of life, and their relatedness with their environment (Hartrick Doane & Varcoe, 2005).

Disruption is encountered when the usual, organized, and predictable state of a person and his/her family moves through disorganization, broken-ness, uncertainty, unpredictability, and even chaos (Newman,1999). Such instances may include illness, divorce, birth, and death. In *The Story of Mary*, patterns may include how Mary is making sense of her illness within the context of her family, community, beliefs, values and relationships. Although an illness can initially cause disruption, the experience can also evolve into a new wholeness' and new meaning throughout the experience. "The 'brokenness' of the situation, however, is only a point in the process leading to a higher order. We need to join in partnership with clients… until order begins to emerge out of chaos" (Newman, 1999, p. 228). Identifying patterns of wholeness and disruption will lead students to determine nursing action or non-action.

***AN EXAMPLE…***

IN THIS PHASE, STUDENTS ADD TO THEIR LEARNING ISSUES WHICH MAY INCLUDE:

- BOWEL CANCER TRAJECTORY AND TREATMENT
- SURGICAL INTERVENTIONS FOR BOWEL OBSTRUCTION INCLUDING POST OPERATIVE NURSING CARE, PAIN MANAGEMENT, FLUID AND ELECTROLYTE BALANCE, ETC.
- CULTURAL PRACTICES RELATED TO ILLNESS

***Facilitator Tip…***

By having students discuss patterns, a holistic view of the patient's experience can be created.

## Phase Four: Nursing Support

Nursing support includes authenticity, and demonstrating care and compassion. Authenticity is demonstrated by empathy, presence, listening, becoming informed, and following the lead of the person/family in care. Nursing support enables nurses to develop a trusting relationship with those in care.

Many clinical areas implement tools and clinical pathways to improve patient care and support. Students can be encouraged to find tools and pathways appropriate to this story or in the area of palliative end-of-life care.

Students can be encouraged to think about appropriate standards of care in *The Story of Mary*. The 'Palliative and End-of-Life Care Entry to Practice Competencies and Indicators for Registered Nurses' (CASN, 2011) document can be made available to students to promote its application in different clinical situations.

***Try this…***

*Encourage students to think about support based on client and family strengths (Feeley & Gottlieb, 2000)*

***AN EXAMPLE…***

THE PALLIATIVE PERFORMANCE SCALE IS A BROADLY USED SCALE TO MEASURE FUNCTION. IT IS USEFUL AS A COMMUNICATION TOOL BETWEEN HEALTH CARE PROVIDERS. IF A NURSE TELLS THE PHYSICIAN THAT A PATIENT'S PPS IS 30%, THERE IS NO NEED FOR AN EXPLANATION OF THE 30%. THE SCALE IS GENERALLY NOT A USEFUL TOOL FOR COMMUNICATION WITH PATIENTS AND FAMILIES, ALTHOUGH IT CAN BE USED TO EXPLAIN PROGNOSIS (SEE APPENDIX B).

ANOTHER EXAMPLE OF A USEFUL TOOL IS THE LIVERPOOL CARE PATHWAY (FOUND AT: http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/). THIS TOOL IS USED WHEN THE PATIENT HAS A PPS OF 30% OR LESS. THIS SCORE PROMPTS THE INTRODUCTION OF CARE COMPONENTS TO SUPPORT THE LAST DAYS OF LIFE. THIS TOOL IS UTILIZED IN MANY COUNTRIES INCLUDING IN SOME CANADIAN HEALTH CARE PROGRAMS.

**Facilitator Tip...**

'Scaffolding' is a method in which the instructor can facilitate students to build a foundation of present knowledge and skills that they can add (or scaffold) as they gain new knowledge and understandings (de Grave, Dolmans, & van der Vleuten, 1999).

### Emotional

- Respectfully asking and observing how Mary, her family and their community support each other, and how a nurse can be supportive in their current situation

### Instrumental

- Identifying what may be needed to provide Mary and her family with practical and other assistance (promoting physical comfort, or advocating to meet required needs).

### Informational

- Asking and observing how Mary and her family seek, utilize and understand information at different times and in different situations, and providing the teaching and learning in an appropriate and timely manner.

### Spiritual

- Seeking to understand what gives Mary and her family meaning in their lives, such as religion, faith, beliefs and/or other sources, including nature, music, stories, ceremonies, artifacts, readings, and how to promote, support and advocate for these components.

### Aesthetic

- Identifying what is significant to Mary and her family within the environment, and from a cultural perspective (including mannerisms of the nurse), and in other ways.

***Try This…***

*Invite a skilled facilitator to share a class/portion of a class with you. First, observe an 'expert in action,' and then have the facilitator critique your performance after the session; use this feedback to improve your skills.*

## Phase Five: Reflection-Praxis

In this phase, students reflect on what they learned in the SBL process, think about how adequate the resources sought out were, ponder how they made sense of 'health' as wholeness in the story, and think about what biases and assumptions were operating in the previous phases. Developing students' abilities for reflection enables them to develop capacities for metacognition, including when and how to use particular learning strategies or to problem solve.

### *Examples of Guiding Questions:*

I. How did the story help you learn about palliative and end-of-life nursing care?

II. In what way(s) did the story identify gaps in your knowledge, skills and attitudes?

III. How did you the student identify learning opportunities that helped fill gaps in knowledge, skills and attitudes?

IV. Discuss how the class discussions aided the student to identify and articulate biases and assumptions?

V. How did the class discussions aid in forming new views, knowledge, skills, and attitudes in palliative and end-of-life nursing that were not apparent before?

VI. Did the discussion include potential implementation issues, and if so how?

## Phase Six and One: Attending to the Story

To close the circle in the SBL model, students are brought back to the story. Students may be asked to read the story aloud once or twice more. If time allows, students may continue to progress through the phases of SBL, or may go on to another part of the story (*The Story of Mary: Part Two* is included in this resource). The purpose of this phase is to demonstrate that caring is iterative and cyclical in nature, rather than a linear process.

### *The Story of Mary: Part Two*

*I love my job as a nurse in this rural community. Since moving here about six months ago, I have come to know the people and their way of life. In my case load, there is an Aboriginal village nearby comprised of about 150 people. Today I am going to see Mary, a 48 year old aboriginal lady who has breast cancer with metastatic spread to several other areas of her body. I have been caring for Mary since she returned from the City Hospital a few weeks ago, where she had emergency bowel surgery. Although she has recovered from the surgery fine, Mary is not really improving as she had hoped. She now finds eating difficult and has low energy. Mary told me that she still needs to care for her family; they rely on her, so this fatigue is really getting her down. Today Mary has more pain too, so I think her disease is progressing faster than the doctors expected.*

*The local physician here is great and I know I can depend on her to provide Mary with medications and/or support for Mary and her family. I know that the healer from the village has also been visiting regularly, and Mary says she feels better when he comes. I feel so honored to be caring for Mary, but I am scared and sad because I know she is dying and I will miss her. I just hope we can keep her here at home and not have to send her back to the city, as this would be so hard on Mary and her family. Well, I will do the best I can and hope I can support Mary and her family through this. Mary is not the first client that I have cared for who is dying, but I feel a special connection with her and I think about her a lot, even on my days off. Anyway…I must do an assessment and see how I can support her with the symptoms she is experiencing.*

This part of the story takes the students into the end stages of Mary’s illness. Because she is at home, there are other palliative end-of-life considerations that will be raised and therefore new questions asked, new learning needs identified, and new resources used. The phases are described in Part One and thus are not repeated here.

In closure, the following story and song is a reminder that all people will one day die and that they all are deserving of excellent palliative and end-of-life care.

The following song, written and performed by Lhasa de Sale was thought to be prophetic of her own death from breast cancer in 2010 at 37 years of age.

http://www.youtube.com/watch?v=ZDS4ZfZs2ko

**Anyone Everyone**

You walk out your front door front door
Out into sound and sun
And people say hello to you
And you say hello to everyone

The leaves are falling falling down
Down into sound and sun
And no one is afraid of you
And you're not afraid of anyone

Your sisters on the open sea
Your brothers here on land
There's not enough breath in a single day
To pray everyone will be ok

The leaves are falling falling down

Down into sound and sun
And no one is afraid of you
And you're not afraid of anyone

***Did you know?***

I hear, I forget
I see, I remember
I do, I understand
I think, I learn

(Ancient proverb)

## ALTERNATIVE WAYS OF USING SBL

1. Have students write their own story and use the SBL process. Criteria:
    - Adequate complexity
    - Wide range of problems, issues, and challenges
    - Build on existing knowledge
    - Elicit emotion
    - Inviting or dramatic
    - Reflective of current practice / realities
2. Use a story from a movie, documentary, book, or other media source
3. Seek opportunities in class or clinical areas to use components of SBL as a teaching strategy
4. Invite someone into the class to tell his or her story i.e. an individual with a chronic illness, a family member, a family caregiver, a health care provider. Have a students take notes of the story or ask the presenter if it can be recorded to enable further discussion in class following the presentation.
5. Co-teach with a faculty who is skilled at facilitation and may also be knowledgeable about palliative end-of-life care (although if a skilled facilitator does not have to have PEOL expert knowledge).

## SOME ADDITIONAL PEOLC RESOURCES FOR FACULTY

I. CASN PEOLC Environmental Scan

II. CASN Palliative and End-of-Life Care Toolkit – *An online teaching and learning resource to support undergraduate nursing education programs in Canada*

III. CASN and Canadian Virtual Hospice *"A Story About Care" video*

IV. Canadian Virtual Hospice www.virtualhospice.ca/

V. Canadian Hospice Palliative Care Association www.chpca.net/

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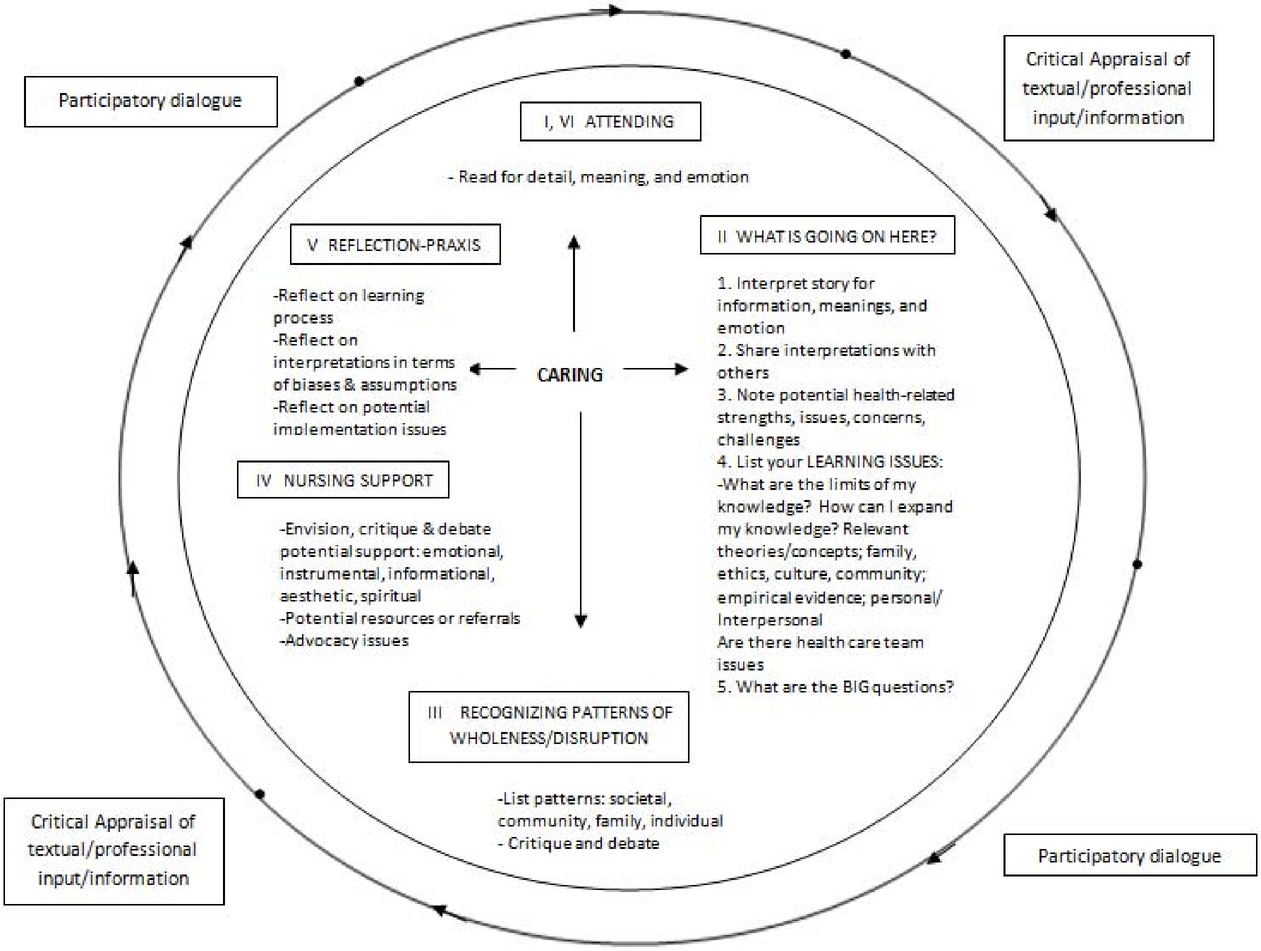
# APPENDIX A: STORY-BASED LEARNING MODEL- BLENDING CONTEXT AND PROCESS TO LEARN NURSING



SBL Model from *Story-based learning: blending context and process to learn nursing*, by L. E. Young, 2007, In L. Young & B. Paterson, *Teaching nursing: Developing a student-centered learning environment* (pp. 164-188). Philadelphia: Lipincott. Copyright 2007 by Young, L. E. Adapted with permission.

# APPENDIX B: PALLIATIVE PERFORMANCE SCALE (PPSv2) VERSION 2 ©

## *Palliative Performance Scale (PPSv2)*

***version 2*** ©

Victoria Hospice

| PPS Level | Ambulation | Activity & Evidence of Disease | Self-Care | Intake | Conscious Level |
|---|---|---|---|---|---|
| 100% | Full | Normal activity & work<br>No evidence of disease | Full | Normal | Full |
| 90% | Full | Normal activity & work<br>Some evidence of disease | Full | Normal | Full |
| 80% | Full | Normal activity *with* Effort<br>Some evidence of disease | Full | Normal or reduced | Full |
| 70% | Reduced | Unable Normal Job/Work<br>Significant disease | Full | Normal or reduced | Full |
| 60% | Reduced | Unable hobby/house work<br>Significant disease | Occasional assistance necessary | Normal or reduced | Full<br>or Confusion |
| 50% | Mainly Sit/Lie | Unable to do any work<br>Extensive disease | Considerable assistance required | Normal or reduced | Full<br>or Confusion |
| 40% | Mainly in Bed | Unable to do most activity<br>Extensive disease | Mainly assistance | Normal or reduced | Full or Drowsy<br>+/- Confusion |
| 30% | Totally Bed Bound | Unable to do any activity<br>Extensive disease | Total Care | Normal or reduced | Full or Drowsy<br>+/- Confusion |
| 20% | Totally Bed Bound | Unable to do any activity<br>Extensive disease | Total Care | Minimal to sips | Full or Drowsy<br>+/- Confusion |
| 10% | Totally Bed Bound | Unable to do any activity<br>Extensive disease | Total Care | Mouth care only | Drowsy or Coma<br>+/- Confusion |
| 0% | Death | - | - | - | - |

**Instructions for Use of PPS (see also definition of terms)**

1. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score.

2. Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

   Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

   Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

   Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'

3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.

4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

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## Definition of Terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall ‘best fit’ using all five columns.

### 1. Ambulation

The items ‘**mainly sit/lie**,’ ‘**mainly in bed**,’ and ‘**totally bed bound’** are clearly similar. The subtle differences are related to items in the self-care column. For example, ‘totally bed ‘bound’ at PPS 30% is due to either profound weakness or paralysis such that the patient not only can’t get out of bed but is also unable to do any self-care. The difference between ‘sit/lie’ and ‘bed’ is proportionate to the amount of time the patient is able to sit up vs need to lie down.

‘**Reduced ambulation’** is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer on their own but at PPS 60% needs occasional assistance.

### 2. Activity & Extent of disease

‘**Some**,’ ‘**significant**,’ and ‘**extensive’** disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply ‘some’ disease, one or two metastases in the lung or bone would imply ‘significant’ disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be ‘extensive’ disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, ‘some’ may mean the shift from HIV to AIDS, ‘significant’ implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. ‘Extensive’ refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc.

The above extent of disease is also judged in context with the ability to maintain one’s work and hobbies or activities. Decline in activity may mean the person still plays golf but reduces from playing 18 holes to 9 holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (eg. trying to walk the halls).

### 3. Self-Care

‘**Occasional assistance’** means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

‘**Considerable assistance’** means that regularly every day the patient needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat of his or her own accord.

‘**Mainly assistance’** is a further extension of ‘considerable.’ Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

‘**Total care’** means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

### 4. Intake

Changes in intake are quite obvious with ‘**normal intake**’ referring to the person’s usual eating habits while healthy. ‘**Reduced’** means any reduction from that and is highly variable according to the unique individual circumstances. ‘**Minimal**’ refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

### 5. Conscious Level

‘**Full consciousness**’ implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. ‘**Confusion**’ is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. ‘**Drowsiness**’ implies either fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. ‘**Coma**’ in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

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*Correspondence should be sent to Medical Director, Victoria Hospice Society, 1952 Bay Street, Victoria, BC, V8R 1J8, Canada*

4. *Intake:* Changes in intake are quite obvious with 'normal intake' referring to the person's usual eating habits while healthy. 'Reduced' means any reduction from that and is highly variable according to the unique individual circumstances. 'Minimal' refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

5. *Conscious Level:* 'Full consciousness' implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. 'Confusion' is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. 'Drowsiness' implies fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. 'Coma' in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

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# APPENDIX C: EXPLORING YOUR ‘OWN DEATH’

Many palliative care practitioners share the view that until one is comfortable with one’s own death, it is difficult to support others who are dying. Included here are several suggestions for nursing instructors and students to explore personal meanings of their own death (alone or with a class).

As a cautionary note, some of these exercises may cause a grief-loss reaction, especially if the person has recently experienced the death of a close friend or family member, has unresolved grief issues, or has a serious illness at the present time. Thus, when embarking on any of these exercises, it is imperative to have a plan for supporting those who may have an upsetting emotional reaction. If engaging in these activities with a class, one suggestion is to have a colleague in the room with you so that if a student requires support, your colleague can provide this outside of the room, if necessary.

*“The paradox is that although physical death will kill me… the idea of death will save me in the sense that it will prompt me to live my life more resourcefully and more fully.”*

*- Emmy van Deurzen & Martin Adams*

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## Exercise One: Write Your Own Eulogy

(From: http://wilderdom.com/games/descriptions/WriteYourOwnEulogy.html#About)

- You may like to have your class discuss what a eulogy is, you could share with them what you think a eulogy is, or you could read an example of a eulogy aloud to them.
- Ask students to imagine that they died today and ask them each to write the eulogy that they would like to have read at their own funeral.
- Give participants a chance to go and sit alone and write their eulogy.
- When the group comes back together, ask participants to discuss what it was like to think and write about their life and death.
- Invite each person to share his/her eulogy with the rest of the class (not compulsory).

## Exercise Two: Special Visits

In this exercise, students are asked to visit one of the following locations and sit quietly for 30-60 minutes (if possible).

1. A graveyard
2. A morgue
3. A hospice or palliative-care unit
4. A long-term care home
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5. A church or synagogue
6. An emergency department waiting room

At the next class, students can share their thoughts and experiences.

## Exercise Three: Drawing a Personal Timeline

(From: http://users.rider.edu/~suler/timeline.html)

Ask students to draw a timeline of their life, starting from their birth and including any significant events they choose. They must also include their future; what may happen, how they may die and when. This may be difficult and some students may not wish to participate, but it may be a useful exploration of fears, hopes, and wishes.

Provide students with colored paper and pens, pictures, and any other easily accessible material. After the exercise ask for volunteers to talk about their timeline.

## Exercise Four: Your "Bucket List"

Ask students to write down all the things they still want to do, places they wish to visit, and what they hope to accomplish in their life. Ask your students to share and discuss their "Bucket Lists" with a partner or the class.

## Exercise Five: Writing Your Own Death Notice

(From: http://users.rider.edu/~suler/mindwalk.html)

This exercise is similar to the eulogy exercise, but a little different; ask students to keep their death notices short and simple, just a few lines. Ask your students to share and discuss their death notice with the class.

## Exercise Six: Personal Death Awareness

(From: Lynn J, Schuster J, Kabcenell A. Improving Care for the End of Life: *A Sourcebook for Health Care Managers and Clinicians*. New York, NY: Oxford University Press, 2000.)

On a piece of paper, draw a straight line of any length. Consider this line to be your life span. Place a slash mark at any point along the line where you think you are today in your life's chronology. Complete the following fill-in-the-blank statements:

I expect to live until age _____ years.

I am now _______years old.

When you compare your present age to the age at which you expect to die, how much of your life do you find you have already lived? Half? Two-thirds? One-quarter? Now look at the line you drew. How does your estimate of the time you have left to live on the life-span line compare to your numerical estimate?

How did it feel to commit yourself to a definite life span? Some people worry that they may "jinx" themselves by doing this. Does this concern you? Were you uncomfortable? If not, why do you think you felt comfortable doing this? Take a minute and answer these questions.

## Exercise Seven: First Death Experience

(From: Lynn J, Schuster J, Kabcenell A. *Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians*. New York, NY: Oxford University Press, 2000.)

The first death that I experienced was the death of: ________________________________________

I was _______ years old.

At that time, I felt: ____________________________________________________________

I was most curious about: ____________________________________________________________

The things that frightened me most were: ______________________________________________

The feelings that I have now as I remember that death are: _________________________________

The most intriguing thing about the funeral was: ___________________________________________

I was most scared at the funeral by: ___________________________________________________

The first personal acquaintance of my own age who died was: _______________________________

I remember thinking: _______________________________________________________________

The death of _________________________ has been the most significant for me. It was significant because: __________________________________________________________________________

The most recent death I experienced was ____________________ when _________________ died _______ years ago.

The most traumatic death I ever experienced was: ________________________________________

## Exercise Eight: The Story of Your Own Death

This exercise takes at least 1-1 ½ hours to do, so be sure to allot enough time.

Generally, the facilitator reads a story and students imagine they are the person in the story. A series of questions and activities are interspersed throughout the story. At completion, a facilitated discussion takes place. You can write the story yourself, or use one that is already written. In this example, the story is provided. Below are preparatory activities:

1) *Prepare 4 different colored strips of paper (large enough to write a sentence on); for this example use red, yellow, green, and blue. Distribute 5 of each of the colored papers to each student. They will each have 20 pieces of paper, 5 of each of the 4 colors.*
2) *Next, ask students to write valued relationships on each of the red pieces of paper; one relationship per red piece of paper.*
3) *Next, ask students to take the yellow paper slips and on each piece write what possessions they most value (one valued possession on each piece of yellow paper).*
4) *Next, on the green paper ask them to write what they love most in nature (one per piece of paper).*
5) *Finally, on the blue paper, ask them to write what activities they enjoy most (one activity per piece of paper).*
6) *Students will each have 20 pieces of paper with something written on each one. Tell students to place these face down in front of them on a table, lap or floor.*
7) *Next, read the story aloud and pause for a couple minutes at the breaks:*

   **You are in the shower and feel a lump in your left breast. Immediately you know this is new as you do self-examinations regularly. You tell yourself not to panic as you know most lumps are not cancer.**

   - *Ask students to do this reflection: write down your first thoughts and feelings.*

   **As soon as you are out of the shower, you call your physician and make an appointment for the next day. When the family gathers for dinner that evening you don't say anything as you don't want to alarm them.**

   **The next day you go to the doctor whom you know well as you have been his patient for a few years. You feel comfortable and confident in his opinion. After examination, he recommends that you have a few more tests done to diagnose the lump; you sense no alarm and try to calm yourself.**

   - *Ask students to do this reflection: write down what are you thinking and feeling now.*

   **The following week you go for your tests. They are not painful, but there is some discomfort in your left breast. At your appointment with the doctor you share this and he gives you a prescription for Tylenol with codeine. He also shares the results of the**

**test and tells you that the lump is cancerous. He tells you that he is booking an appointment with the surgeon for a lumpectomy.**

- *Ask students to do this reflection: write down what you will tell your family and how you want them to support you during this time.*

**A few months go by since you've had the surgery, radiation treatment and chemotherapy. You are feeling stronger and have more energy now. Your family is very supportive and you are deeply appreciative to have them with you now.**

- *Ask students to do this reflection: write down what you want to do now; who you want supporting you and what you need from them.*

**After several more months you start to feel some discomfort again and begin to take some mild pain relievers. These only help for a short time and you realize that you may need something stronger; you make an appointment with your physician. You also notice that you are a little short of breath lately and you are not sure why.**

- *Ask students to do this exercise: turn to your left and take away 3 papers of any color randomly; the person on your right will do the same with you. Share what you've had taken away from you and write down how you feel about this. Take these 3 papers and put them under your chair.* (NOTE: This symbolizes what some patients have 'taken away' from them as they experience phases of an illness).

**You feel your energy draining from you as your pain and shortness of breath become more bothersome. You are also feeling fatigued and can barely cook or do any chores. You rely more heavily on others for meals and cleaning.**

- *Ask students to do this reflection: write down what you want to do now; who you want supporting you and what you need from them. Also, turn to your left and take away 5 papers of any color randomly; the person on your right will do the same with you. Share what you've had taken away from you and write down how you feel about this.*

**You have so much pain that you are admitted to hospital. Finally, after a week you are feeling better but still have very limited energy. The nurses want you to have help at home now.**

- *Ask students to do this reflection: write down what are you thinking and feeling now.*

**When you get home, you are happy that family and friends are helping out with meals and chores but you wish you could do more. You feel like you are slowly fading away.**

- *Ask students to do this exercise: turn to your left and take away 4 papers of any color randomly; the person on your right will do the same with you. Share what you've had taken away from you and write down how you feel about this.*

**Days later you cannot get out of bed and know that death is near.**

- *Ask students to do this reflection: write down what is important to you now and how you want people to remember you.*

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*Following the exercise allow a few minutes of silence so that students can quietly reflect and write if they wish.*

*You may then ask the following questions:*

1. At first, what did you hope for? Did this change as time went on?
2. What were the hardest ‘pieces of paper’ taken from you and why?
3. As time went on what was most important to you? Least important to you?
4. What were your initial fears? What were they in the middle of the story? At the end?
5. How did you feel about the loss of control over what was taken from you?
6. How may this exercise influence/inform your role as a nurse?

There are many questions and probes the instructor/facilitator can use in this discussion that will bring an awareness of what a journey from being ‘healthy’ to dying is possibly like. Factors will include time, skill and experience of the facilitator and the students, but it is recommended that at least 1 hour be dedicated to ensure a rich discussion and learning is supported.
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# APPENDIX D: CASN PALLIATIVE AND END-OF-LIFE CARE ENTRY-TO-PRACTICE COMPETENCIES AND INDICATORS FOR REGISTERED NURSES

## 1. Uses requisite relational skills to support decision making and negotiate modes of palliative and end-of-life care on an ongoing basis.

1.1. Discusses the benefits and burdens of the usual palliative and end-of-life (PEOL) treatment options to assist the patient and family members in meeting their goals of care, and documents the information provided.
1.2. Provides information and assurance to the patient and family members regarding comfort measures during the last days/hours of living, and documents the information provided.
1.3. Communicates respectfully, empathetically and compassionately with the PEOL patient and family members.
1.4. Conserves patient and family dignity by facilitating expression of their feelings, needs, hopes, joys, and concerns in planning for palliative and end-of life care.
1.5. Invites, facilitates, negotiates and respects the involvement of the patient and family members and other team members in discussions about the plan of palliative and end-of-life care.
1.6. Provides the opportunity for the patient approaching end-of-life to conduct a life review.
1.7. Reviews, and clarifies the patient and family members' understanding of palliative and end-of-life care information presented by other care providers, and documents this.
1.8. Facilitates conversations that support end-of-life decision making such as health care directives, living wills and tending to personal affairs.
1.9. Communicates and documents decisions made by the patient and family members regarding their goals for palliative and end-of-life care.
1.10. Identifies and documents the need for referral to support palliative and end-of-life decision making and provides necessary follow-up to ensure timely referral.
1.11. Creates a safe environment to build patient and family members' trust and facilitate palliative and end-of-life decision making.

## 2. Demonstrates knowledge of grief and bereavement to support others from a cross-cultural perspective.

2.1. Accurately assesses and documents the patient's and family members' needs related to loss, grief and bereavement.
2.2. Identifies individuals experiencing, or at high risk for experiencing, a complicated and/or disenfranchised grief reaction, and discusses, documents and makes appropriate referrals.
2.3. Uses insights gained from personal experiences of loss, bereavement and grief to provide supportive care to others.
2.4. Identifies situations when personal beliefs, attitudes and values result in limitations in the ability to be present for the patient and family members experiencing loss, grief, and/or bereavement.
2.5. Demonstrates understanding of grief theories and their application to PEOLC.
2.6. Demonstrates understanding of the common, normal manifestations of grief (emotional, physical, cognitive, behavioural).
2.7. Demonstrates understanding of individual, social, cultural, and spiritual variables that affect grief.
2.8. Provides guidance, support, and referrals to bereaved family members and documents such practice actions.

2.9. Listens, affirms, and responds empathetically and compassionately to the patient and family members working through the tasks of grief and bereavement.
2.10. Develops the capacity to be in the presence of patient and family members’ suffering.

**3. Demonstrates knowledge and skill in holistic, family-centered nursing care of persons at end-of-life who are experiencing pain and other symptoms.**

3.1. Identifies gaps in knowledge, skills, and abilities as a first step in acquiring new knowledge, skills, and abilities for PEOLC.
3.2. Demonstrates understanding of the concept of ‘total pain’ when caring for PEOL patients and their family members, total pain being inclusive of physical, emotional, spiritual, practical, psychological, and social elements.
3.3. Applies principles of pain and other symptom management when caring for PEOL patients.
3.4. Utilizes best practice assessment tools for baseline and ongoing assessment of pain, including word descriptors, body maps, precipitating and alleviating factors, and documents pain assessments.
3.5. Utilizes and documents evidence-informed pharmacological approaches to alleviate pain, including intended effects, doses and routes of medication, and common side-effects.
3.6. Utilizes and documents evidence-informed non-pharmacological approaches to pain, including any potential adverse effects.
3.7. Assesses and documents common non-pain symptoms at end-of-life.
3.8. Understands causes of common non-pain symptoms at end-of-life.
3.9. Implements and documents evidence-informed pharmacological and non-pharmacological approaches for non-pain symptoms at end-of-life.
3.10. Discusses, teaches, assists PEOL patient and family members in managing pain and other symptoms including the recognition of areas requiring further assessment, and documents this.
3.11. Evaluates and documents all outcomes of pain and symptom management interventions throughout the course of the patient’s illness experience against a baseline assessment using comparative evaluations.
3.12. Practices person-centered PEOLC that incorporates the unique contributions of the particular family and community members in routine care giving while also demonstrating general knowledge of pain and symptom management in the PEOL population.
3.13. Demonstrates the capacity to be present with pain and suffering.
3.14. Effectively collaborates with the inter-professional team in the management of pain and other PEOL symptoms.

**4. Recognizes and responds to the unique end-of-life needs of various populations, such as elders, children, multicultural populations, those with cognitive impairment, language barriers, those in rural and remote areas, those with chronic diseases, mental illness and addictions, and marginalized populations.**

4.1. Recognizes and responds to the unique needs or backgrounds of patients of varying ethnicities, nationalities, cultures, genders, ages and abilities that may affect their experience of palliative and end-of-life care.
4.2. Identifies who the family is for the PEOL patient, and responds to family members’ unique needs and experiences.

4.3. Adapts communication, assessment and information sharing to the unique needs of the PEOL patient and family members to facilitate informed decision-making, and consults with/refers to appropriate supports such as translated documents and interpreters.
4.4. Considers and incorporates the determinants of health when formulating a plan of care for PEOL patients and families with unique needs.

**5. Applies ethical knowledge skillfully when caring for persons at end-of-life and their families while attending to one's own responses such as moral distress and dilemmas, and successes with end-of life decision making.**

5.1. Identifies and addresses ethical issues in palliative and end-of-life care using ethical principles, and documents this.
5.2. Provides the patient and family members with accurate and complete information to make informed decisions about treatment choices, and documents this.
5.3. Inquires about the patient's and family members' preferences regarding the extent to which they wish to be informed about the patient's condition and the treatment options, respects their wishes for information where ethically appropriate, and documents this.
5.4. Understands the distinctions among the following concepts: principle of double effect, palliative sedation, euthanasia, and physician assisted suicide.
5.5. Identifies situations in which personal beliefs, attitudes and values result in limitations in the ability to be present and care for the patient and family members, and then collaborates with colleagues to develop strategies to ensure optimal care is provided.
5.6. Recognizes and addresses indicators of moral distress in self and in other team members and seeks appropriate support.

**6. Demonstrates the ability to attend to psychosocial and practical issues such as planning for death at home and after death care relevant to the person and the family members.**

6.1. Identifies and provides verbal and written information about dying at home and after death care that the patient and family members' request, and documents the information provided.
6.2. Conducts and documents an assessment which includes emotional, psychological, social, spiritual and practical strengths and needs of the PEOL patient and family members.
6.3. Identifies and documents the PEOL patient's and family members' values, beliefs, and preferences regarding the various components of palliative and end-of-life care provision.
6.4. Demonstrates openness and sensitivity to social, spiritual and cultural values and practices that may influence palliative and end-of-life care preferences of the PEOL patient and family.

**7. Identifies the full range and continuum of palliative and end-of-life care services, resources and the settings in which they are available, such as home care.**

7.1. Demonstrates knowledge of the full range of PEOLC services, resources, and settings.
7.2. With compassionate empathy, initiates regular conversations with patient and family members about their goals of care.
7.3. Identifies and accesses services and resources specific to the PEOL patient and family members' goals of care, and documents this.
7.4. Initiates and documents referrals/requests for access to resources, services, and settings for the PEOL patient and family members.

7.5. Provides available relevant information and resources to the PEOL patient and family members, and documents this.
7.6. Advocates for the PEOL patient and family members' access to relevant resources, and documents this.
7.7. Facilitates the PEOL patient and family members in navigating the system, and documents this.

8. **Educates and mentors patients and family members on care needs, identifying the need for respite for family members, and safely and appropriately delegating care to other caregivers and care providers.**

8.1. Facilitates the PEOL patient and family members' participation in care planning.
8.2. Identifies, documents, and integrates the strengths of the PEOL patient and family members in the plan of care.
8.3. Assists PEOL family members in the performance of caregiving roles.
8.4. Provides family members with opportunities and information to participate in research about family caregiving at the end-of-life.
8.5. Identifies, verifies, and advocates for perceived and real needs of the PEOL patient and family members, and documents this.
8.6. Engages in family and team conferences regarding the PEOL patient.
8.7. Develops a separate plan of care for the PEOL family members.
8.8. Assists the family members in acquiring respite care as needed, and documents this.

9. **Demonstrates the ability to collaborate effectively to address the patient and family members' priorities within an integrated inter-professional team, including non-professional health care providers, and the patient himself or herself.**

9.1. Demonstrates knowledge of the role of the nurse and other team members in PEOLC.
9.2. Communicates respectfully with the interprofessional team using effective communication skills including conflict management.
9.3. Builds on collaborative relationships with patient and family members, and members of the inter-professional palliative care team in determining patient's goals and plans of care.
9.4. Reflects on the need for different inter-professional team approaches in different situations.
9.5. Respects and considers the opinion, knowledge, and skills of others in a shared decision-making process regarding the priorities of care for the PEOL patient.

# APPENDIX D CON'T: LINKING POTENTIAL LEARNING ELEMENTS FROM '*THE STORY OF MARY'* WITH THE PEOLC COMPETENCIES AND INDICATORS

| **POTENTIAL LEARNING ELEMENTS FROM *THE STORY OF MARY: PART ONE*** | **PEOLC COMPETENCY. INDICATOR** |
|---|---|
| Care in hospital for terminal patients | 1.7; 3.2; 3.3; 3.4; 3.5; 3.6; 3.7; 3.8; 3.9; 3.10; 3.12; 3.13; 3.14; 4.1; 4.3; 5.1; 5.2; 5.3; 5.5; 6.1; 6.2; 6.3; 6.4; 7.1; 7.2; 7.3; 7.4; 7.5; 7.6; 7.7; 8.1; 8.2; 8.4; 8.5; 8.6; 9.1; 9.2; 9.3; 9.4; 9.5 |
| Culture | 2.7; 3.12; 4.1; 4.2; 4.3; 4.4; 6.3; 6.4 |
| Self-care | 2.4; 5.5; 5.6 |
| Communication | 1.1; 1.2; 1.3; 1.4; 1.7; 1.8; 1.9;1.10;2.1; 2.2; 2.4; 2.9; 3.10; 3.14; 4.3; 5.2; 5.3; 5.5; 5.6; 6.1; 6.2; 6.3; 7.2; 7.4; 7.5; 7.6; 7.7; 8.1; 8.2; 8.4; 8.5; 8.6; 9.2; 9.5 |
| Team | 1.5; 1.7; 1.10; 2.2; 2.4; 3.14; 4.3; 5.5; 5.6; 7.4; 8.6; 9.1; 9.2; 9.3; 9.4; 9.5 |
| Symptom management | 3.2; 3.3; 3.4; 3.5; 3.6; 3.7; 3.8; 3.9; 3.10; 3.11; 3.12; 3.13; 3.14; 5.4 |
| Family /patient support | 1.3; 1.4; 1.5; 1.7; 1.8; 1.9; 1.10; 1.11; 2.1; 2.2; 2.3; 2.4; 2.9; 3.10; 3.12; 3.13; 4.1; 4.2; 4.3; 4.4; 5.2; 5.3; 6.1; 6.3; 6.4; 7.2; 7.3; 7.4; 7.5; 7.6; 7.7; 8.1; 8.2; 8.5; 8.6; 9.3 |
| Plan/goals of care | 1.1; 1.4; 1.5; 1.9; 1.10; 4.4; 6.1; 7.2; 7.3; 8.1; 8.2; 9.3; 9.5 |
| Suffering (client, family, nurse) | 2.2; 2.4; 2.5; 2.6; 2.9; 2.10; 3.13; 5.5; 5.6 |
| Psychosocial/emotional/spiritual support | 1.3; 1.4; 1.5; 1.7; 1.11; 2.1; 2.2; 2.3; 2.4; 2.5; 2.6; 2.7; 2.9; 2.10; 3.2; 3.3; 3.13; 6.2; 6.3; 6.4 |
| Knowledge of disease and treatment options | 1.1; 3.1; 3.5; 3.6; 3.7; 3.8; 3.12; 5.2; 5.4 |
| Knowledge of grief, loss and bereavement | 2.1; 2.2; 2.3; 2.4; 2.5; 2.6; 2.7; 2.8; 2.9; 2.10; 3.1 |
| Advance care planning | 1.8; 4.3; 4.4; 6.1; 7.2; 8.1 |
| Legal issues (e.g. health care representation) | 1.8; 5.4 |
| Ethics | 2.4; 5.1; 5.2; 5.3; 5.4; 5.5; 5.6 |
| Decision making | 1.5; 1.8; 1.9; 1.10; 1.11; 4.3; 4.4; 5.2; 5.3; 5.4; 5.5; 5.6; 6.1; 6.4; 8.1; 8.6; 9.5 |
| Advocacy | 1.9; 1.10; 2.2; 2.4; 4.1; 4.3; 5.5; 5.6; 7.6; 7.7; 8.1; 8.2; 8.5 |

| **POTENTIAL LEARNING ELEMENTS FROM *THE STORY OF MARY: PART TWO*** | **PEOLC COMPETENCY. INDICATOR** |
|---|---|
| Dying at home | 1.1; 3.2; 3.3; 3.4; 3.5; 3.6; 3.7; 3.8; 3.9; 3.10; 3.12; 3.13; 3.14; 4.1; 4.2; 4.3; 4.4; 5.2; 5.3; 5.5; 6.1; 6.2; 6.3; 6.4; 7.1; 7.2; 7.3; 7.4; 7.5; 7.6; 7.7; 8.1; 8.2; 8.3; 8.4; 8.5; 8.6; 8.7; 8.8; 9.1; 9.2; 9.3; 9.4; 9.5 |
| Resources | 7.1; 7.3; 7.4; 7.5; 7.6; 8.3; 8.8 |
| Self-care | 2.4; 5.5; 5.6 |
| Culture | 1.4; 2.7; 3.12; 4.1; 4.2; 4.3; 4.4; 6.3; 6.4 |
| Communication | 1.3; 1.4; 1.5; 1.7; 1.8; 1.9; 1.10; 2.1; 2.2; 2.4; 2.9; 3.10; 3.12; 3.14; 4.3; 5.2; 5.3; 5.5; 5.6; 6.1; 6.2; 6.3; 7.2; 7.4; 7.5; 7.6; 7.7; 8.1; 8.2; 8.4; 8.5; 8.6; 8.7; 9.2; 9.3 |
| Team | 1.5; 1.7; 1.10; 2.2; 2.4; 3.14; 4.3; 5.5; 5.6; 7.4; 8.6; 9.1; 9.2; 9.3; 9.4; 9.5 |
| Symptom management | 1.2; 3.2; 3.3; 3.4; 3.5; 3.6; 3.7; 3.8; 3.9; 3.10; 3.11; 3.12; 3.13; 3.14; 5.4 |
| Family /patient support | 1.2; 1.4; 1.5; 1.6; 1.7; 1.8; 1.9; 1.10; 1.11; 2.1; 2.2; 2.3; 2.4; 2.9; 3.12; 3.13; 4.1; 4.2; 4.3; 4.4; 5.2; 5.3; 6.1; 6.2; 6.3; 6.4; 7.2; 7.3; 7.4; 7.5; 7.6; 7.7; 8.1; 8.2; 8.3; 8.5; 8.6; 8.7; 8.8;9.3; 9.5 |
| Plan/goals of care | 1.1; 1.4; 1.5; 1.9; 1.10; 4.4; 6.1; 7.2; 7.3; 8.1; 8.2; 8.6; 8.7; 9.3; 9.5 |
| Suffering (client, family, nurse) | 2.2; 2.5; 2.6; 2.9; 2.10; 3.2; 3.13; 5.5; 5.6 |
| Psychosocial/emotional/spiritual support | 1.2; 1.3; 1.4; 1.5; 1.6; 1.7; 1.11; 2.1; 2.2; 2.3; 2.4; 2.5; 2.6; 2.7; 2.9; 2.10; 3.2; 3.3; 3.13; 6.3; 6.4; 8.3 |
| Knowledge of disease trajectory | 1.1; 3.1 |
| Knowledge of grief, loss and bereavement | 2.1; 2.2; 2.3; 2.4; 2.5; 2.6; 2.7; 2.8; 2.9; 2.10; 3.1 |
| Legal issues: health care representation | 1.8; 5.4 |
| Ethics | 2.4; 5.1; 5.2; 5.3; 5.4; 5.5; 5.6 |
| Decision making | 1.5; 1.8; 1.9; 1.10; 1.11; 4.3; 4.4; 5.2; 5.3; 5. 8.2; 4; 5.5; 5.6; 6.1; 6.4; 8.1; 8.2; 8.3; 8.6; 8.8; 9.5 |
| Advocacy | 1.9; 1.10; 2.2; 2.4; 4.1; 4.3; 5.5; 5.6; 7.6; 7.7; 8.1; 8.3; 8.5; 8.8 |

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