Educational Design – Curriculum Project
An Introduction to Palliative care and the pediatric patient

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Context of teaching and learning

During my time on an adult medical surgical unit, I observed when a patient became palliative the floor staff appeared to struggle with the care and change of goals for this patient and family. I observed nurses being uncomfortable with the care of conversations that were necessary to appropriately care for the patient and family. I predict I will see similar behaviour on the pediatric unit that I am currently working on. To combine my passion of palliative care and current role in pediatrics I believe communicating with children about their death is of value. During the General Nursing orientation program at Alberta Children's Hospital, we cover a variety of topics however, nothing on death and dying and the pediatric patient.

Palliative and end of life care is often a challenge for health care professionals. Time spent in university is limited and there is competing priority of knowledge to be completed in a limited time frame. Binda et al. (2021) report some of the challenges between nursing and physician training noting that the difference and training between the groups is not cohesive and a lack of competencies is the largest barrier to end of life care. Health professionals' hesitation to end of life care discussions is a lack of knowledge, skills, and comfort with the topics (Binda et al, 2021). The authors further recognize that "healthcare professionals do not receive enough training or mentoring during their academic years to recognize that it is time to switch from cure to comfort" (p.15). Recognized within the literature is a common theme of a lack of confidence and knowledge. Death is a part of life and in health education we often focus on curative medicine and struggle with end-of-life care and conversations with clients, patients, and families. There are many ethical debates presented in the literature about hope and to discuss or not to discuss with children about their own death my belief is that we should be discussing death more across the life span. Faulkner (1997) states "children involved in open communication about their own or a family member's impending death are less likely to experience anxiety, withdrawal, and isolation than those who are "protected" from such knowledge-and that even very young children with terminal illnesses have demonstrated the desire and ability to participate (on a developmentally appropriate level) in decisions about their care" (p. 3).

Undergraduate education time is fully booked up with courses and programs to meet the objectives necessary for graduation as set by the university and guided by professional colleges which regulate nurses' practice. Introducing new courses during the undergraduate level is not a realistic goal. Adding programs that are accessible post-graduation are key and can add to professional development, continuing competencies or in an ideal world organizational required learning.

For the purposes of this assignment, I develop part of a larger program for nurses. Advanced goals would be to then adapt the information for other health care professionals to better care for palliative patients in the hospital setting.

Obstacles to learning could be both internal – within the individuals not believing that there is value in this information. I challenge that within bedside hospital nursing death can happen on any unit at any time. The organizations (employers) may not find value in having to pay for additional education time. To overcome this obstacle a well-designed program would meet the requirements set by the Alberta College of nurses (2019) competency 1.14 Provides nursing care to meet palliative care and end-of-life care needs.

Assessment of prior knowledge

I would like to start with a pre-course survey that asks the following questions:

1. In your own words describe for me what is palliative care or what do you believe palliative care is?
2. What is your biggest fear in caring for a child at the end of life?
3. What is your experience with end-of-life care? It is ok to have none.

I believe that the learners will have very minimal experience with the topic. They may have seen some care provided during a clinical school rotation. I believe that the definitions will be varied from those who google a definition, to those that may leave it blank, those who have a rough idea and a few that misinterpret the definition.

The start of class I would like to start with a story that relates to palliative care but in more relatable to the human experience i.e., a version of ideational anchor.

Story Thoughts – rough ideas

- Communication
- Difficult Communications in life; Leaving a relationship; Being stopped by the police; Public speaking?
  - Commonalities – nervous, not knowing what to say, is there a right answer something is looking for, what if I say the wrong thing, what

is the worst possible outcome from this conversation. How do you feel, engage with the emotions, the stress, the fear

- Relate this back to speaking and communicating with palliative/ end of life patients and families.

Learning Objectives

Knowledge

1. By the end of the presentation participants will have a shared definition of palliative care.
2. By the end of the presentation participants will be able to explain active listening.

Application and Skills

3. Participants will demonstrate active listening with a child experiencing end of life. (activity) [future development with AI simulation – capping project].
4. Participants will demonstrate the art of a difficult conversation: speaking with a child about their death. (activity) [future development with AI simulation– capping project]. Using the 3W's (wonders, worries, and wishes) in relation to speaking with children about end of life. (From Sick Kids, 2021, Toronto).

Synthesis – no presentation, activity only.

5. As a group, compose an appropriate working definition of palliative care specific to their work environment.

Student Activities and Tasks

Death is sensitive topic for some, but those that are participating are there to learn, creating a brave space for those to participate.

Communication Guidelines for a Brave Space (www.awarela.org)

1. **Welcome multiple viewpoints -** Speak from your own experience by using "I statements." Ask questions to understand the sources of disagreements.
2. **Own your intentions and your impacts -** Respect each other's experiences and feelings by taking responsibility for the effects of your words. On the other side, if you have a strong reaction to something, let the group know. Be open to dialogue.

3. **Work to recognize your privileges -** Use this space to recognize and investigate your privileges (for example: class, gender, sexual orientation, ability). Honor the different experiences we all bring to this space.
4. **Take risks: Lean into discomfort -** We are all in process. Challenge yourself to contribute even if it is not perfectly formulated.
5. **Step back -** Share speaking time and try to speak after others who have not spoken.
6. **Notice and name group dynamics in the moment -** We are all responsible for this space. Be aware of how others are responding or not responding. Ask for a "time out" or dialogue if needed.
7. **Actively listen -** Use your energy to listen to what is said before thinking about how to respond. Notice when defensiveness and denial arise.
8. **Challenging with care -** Find ways to respectfully challenge others and be open to challenges of your own views. Think about how w to question ideas without personal attacks.
9. **Confidentiality -** Share the message, not the messenger.
10. **Break it down -** Use simple language and background information when necessary. Ask for clarification if needed.

As with the preassessment, I will ask participants to write down their revised shared definition of palliative care and define active listening in the context of children. Work in small groups to create and then present a working definition of palliative care specific to their work area. Have a nominated person present the definition to the larger group. The definitions can they be added to their professional portfolios for proof of learning and educational continuing education. I encourage all participants to share the definition with their peers and colleagues.

Resources

Will use PowerPoint as an outline to the curriculum. With speaker notes and tips hidden to the viewer. Within the notes would be questions to engage active participation, access learning, and to show application of knowledge. Videos to demonstrate active listening both positive and negative interactions. PowerPoint can then easily be made into an online learning resource that is self-directed learning. This would add value to the program by making it more accessible and fit with organisational needs for self-directed learning.

Simulations and active participation to talking about death. Firstly, participants need to speak about their own views of death and their own death. What do you fear, your end-of-life plans, have you even thought about their own death. The goal of this would be to challenge some of our own fears and barriers to discussing death with our peers to better prepare our minds and body language for speaking with patients and families about death.

Sequencing

1. Introductions
2. Start PowerPoint – Title
    a. Contextualized Story – the Human experience, then relating the story to communicating with a dying child and providing the value for learning.
    b. Explaining my view on a brave space and why it is important for this lesson to be successful.

Engagement – Think Pair Share Activity. Working in pairs have students discuss together the following questions.

THINK– about the Questions

PAIR

    c. Definition of Palliative Care?
        i. Pair Students to discuss their definitions of palliative care. Allow time for students to discuss.
    d. What is your biggest fear of caring for a dying child?
        i. Walk between pairs and encourage. Share my personal fears, use of queuing words and phrases that might engage the learners for example too emotional, saying the wrong thing, complicated as it concerns the child; immediate family; extended family.
    e. What is your experience with end-of-life care? It is ok to have none.
        i. Has anyone cared for a dying patient adult or otherwise. Was it an expected death? Was it a traumatic death.

Allow ample time for the students to discuss and share their ideas, thought and fears. Then join pairs together to make fours for further discussion. In the fours instruct the students that they will need to nominate a spokesperson to present information to the larger group.

SHARE

Have the spokesperson present from each group.

Visually display the answers, if the presentation is well designed then hopefully all points will be addressed.

3. New PowerPoint Slide – Outline of the session including objectives.
4. New PowerPoint Slide – Objective One - By the end of the presentation participants will have a shared definition of palliative care.
    a. Define Palliative Care.
    b. Palliative care in the context of the pediatric patient.
    c. Palliative care in the context of family centred care and evaluation – does the family want us to discuss death with the child, are there boundaries.

Engagement – Would you want the medical staff discussing death with your own child? What would you want said or not said? Are there any ethical challenges for you?

5. New PowerPoint Slide – Objective Two - By the end of the presentation participants will be able to explain active listening.
    a. Define active listening – "Active listening is allowing children, and indeed adults, time to think, to take ownership of their learning, to explore and to problem-solve. It means allowing children not only to talk and converse, but also to listen and enabling them to decide and negotiate and to give them time to use their thought processes" (Gouldsboro, p. 72).
    b. Show Video of active listening https://youtu.be/WER63AY8zB8

Engagement – Active listening in the context of family centred care. How do families and children effectively communicate their needs and fears, relate this to your experiences or own family? Do parents listening to what their child is saying, how do they interpret what the child is saying.

6. New PowerPoint Slide – Objective Three - Participants will demonstrate active listening with a child experiencing end of life.

Engagement – Adapted from www.plan-international.org. Activity – Participants are to stand in a circle. Depending on class size this may need to be broken into smaller groups. A soft ball will be needed to pass around the circle. As the instructor I start with the statement – "I believe I would be comfortable with my own death, I have thought about it, there is a plan for my cremation and burial depending on where I die (Canada versus Bali), I fear dying before my parents as there will be no one to care for them as they age". The soft ball is then thrown to another individual who starts with a paraphrase for understanding of my statement and fear, validating the thoughts. The individual then does their own statement and then passes the ball, and the cycle continues.

7. New PowerPoint Slide – Objective Four - Participants will demonstrate the art of a difficult conversation: speaking with a child about their death - Using the 3W's (wonders, worries, and wishes).

Engagement – working in groups of 3 or 4. Have one person be the child and one person be the healthcare professional. The additional persons can be family or can add additional points of view. As the child speak of your own fears, as the healthcare professional respond. Discuss and provide feedback to each other. List what you feel would be a 1. Wonder about end of life, what would you as a child ask or want to know? 2. Worries – what would you worry about? What would your own child worry about; 3. List some wishes. If you were dying what would be your wish?

8. New Slide – compose an appropriate working definition of palliative care specific to their work environment.

Engagement – Work as a group to define.

9. New Slide – Review objectives
10. Final Slide – Questions and Thank you for participating.

Potential Roadblocks to Learning

Death is a common life experience, but not an experience that is often discussed or addressed. Participants maybe hesitant to share their views on death with peers or with the larger group. Providing my own experiences and views on death, some humours some serious would help to set the tone of the experience. Working first in small groups and then presenting to the larger group would encourage open, honest, and safe discussions.

Other roadblocks could include no one attends the program, organisational roadblocks in finding value in a program that is very specific for a small population (pediatric palliative care), for a small number of staff that will encounter this scenario. Palliative care in adults is more expected with children it is often over a longer period or a tragic death.

It would be my hope that my tone and classroom management style will foster an environment in which people want to share and become passionate about the subject matter.

Horizontal and vertical links

This curriculum would meet the needs of those working with children who have life limiting conditions. The palliative curriculum would meet the entry to practice requirements for registered nurses or act as an appropriate course for those looking to add to their professional learning as required by the College of Registered Nurses of Alberta for continuing competencies. I invasion this as a learning module that could be added to the General Nursing Orientation for those starting a new position at Alberta Children's Hospital. There is a gap in the research and information shared by Child Life and Social Workers of Alberta children's – the research and knowledge gaps presented are.

1. Limited research of speaking with children about their own death. Most research focus' on the family and grief post death.
2. Most information available is for the religious – unable to find any information for those who do not use faith as a coping mechanism. (*Future research*)

Links to previous learning may be limited depending on the participants exposure during university clinical rotations, and if any end-of-life experiences took place it is likely that this took place with adult patients as most clinical rotations focus on adults – with only a single unit focused on children and families.

Developing the learner's adaptive metacognition and self-regulation

To help guide learning and thinking, via the post program reflection can use questions to guide the reflective journal entries. Journals can be added to professional portfolios for proof of continuing competencies.

1. Explain how you would actively listen to a child? Can you provide a step by step summarized interaction? Can you provide two – three rationalizations for your decisions?
2. Explain some of your non-verbal communication and how that has affected interactions with your patients and those around you? What do you think the other person was thinking about your non-verbal communication, and why do you think that?

Potential assessment

Assessment is of learning and personal development through reflective journaling that are then kept as proof of continuing education for professional colleges. If used as a workplace learning would need to create a small 10 question quiz for the end of learning. If the program was used as required learning for Alberta Health Services or for the Alberta Children's General

Nursing orientation the use of multiple-choice questions with feedback would be required as this would be self-directed learning. If I developed this to an online self-directed learning activity the engagement and interactive portions on in person training would need to change to learning videos and personal reflective questions or "food for thought" stimulating questions.

Reflection

During the course I was able to see some of the teaching that I already do reflect in the theories that were presented during the first class. This style of curriculum development has motivated me to model the development of a course from what I already know. The structure is familiar and allows for a style of teaching that I am comfortable with. This allows the introduction of material, teaching, and application through discussions and interactive activities. I need to learn more about asking open ended questions to encourage engagement and interaction of participants. This would be best achieved with participant feedback and listening to specific feedback of those involved to improve the course and adapt for the learners needs and clarity. I enjoyed having an introduction to metacognition however, still need to develop ways to have students engaged and actively thinking about their own thought processes. This is something I have never consciously thought about – so need to develop my own skills before I can teach or expect others to reflect in this manner.

Spoke with child life and social they were very enthusiastic about my topic and are interested in having my share. It was agreed that some information was missing i.e. speaking to children about their own death, resources that were shared where about talking with children about grief and supporting families. It was also agreed that there was a non-religious part missing, resources for coping in the context of religion but for the non-religious or non-spiritual there was limit or no data.

Future Thought

I would like to explore with families the idea of end of life being related to the following concept for the finality of death in a non-religious/ non-spiritual context, "If you could go to one place and always be happy, healthy and safe, where would that place be?".

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