Development of a Learning Resource for Pediatric Palliative Care

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Abstract

Background: There is currently no pediatric palliative care unit in the province of Newfoundland and Labrador, therefore most children with life-threatening illnesses are admitted to the medicine unit at the Janeway Children's Health and Rehabilitation Center (Janeway) for palliative and end-of-life (EOL) care. Many of the nurses working on this unit have never had any formal training in pediatric palliative care. **Purpose:** The purpose of the practicum project was to develop a learning resource for nurses on the medicine unit at the Janeway to educate and support them when providing palliative care to children. **Methods:** (1) literature review related to the need for education and specific education interventions; (2) consultations with nurses on the unit and key informants; (3) environmental scan to find resources available in Eastern Canada; and (4) development of a resource. **Results**: Multiple topics were identified through the various sources. Based on these findings a learning resource was developed. The resource consists of four self-learning modules that cover a variety of topics associated with pediatric palliative care, such as communication, pain, symptom management, and the EOL stage. Each module includes self-evaluation components such as reflection exercises, case studies, and "test your knowledge" questions. **Conclusion:** This learning resource can be used by any healthcare professional who cares for palliative care children or is interested in learning more on this topic. The next step is to pilot test this learning resource.

Key words: palliative care; pediatrics; children's hospital; and end-of-life

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Palliative care has been defined as a way of improving the quality of life of patients diagnosed with life-threatening illnesses (World Health Organization, 2018). The majority of pediatric deaths occur in hospitals (Widger et al., 2016) therefore, it is crucial that pediatric nurses in hospital settings are prepared to provide patients and their families with exceptional palliative and end-of-life (EOL) care.

There is currently no pediatric palliative care unit in the province of Newfoundland and Labrador, therefore most palliative care children end up spending their last few months of life on the general medicine unit at the Janeway Children's Health and Rehabilitation Centre (Janeway). The nurses caring for these children at EOL have had little to no training on palliative care, and orientation to the unit currently does not include any education at all on palliative care. A formal needs assessment was conducted in 2015-2016 which revealed that nurses in the area self-identified palliative care as a learning need (S. Eason, personal communication, March 26, 2018). Thus, the purpose of this practicum project was to provide nurses on the Medicine unit at the Janeway with information and education to support them when providing palliative care to children.

Objectives

The overall goal of this practicum project was to develop a learning resource for nurses on the topic of pediatric palliative care. The specific objectives of this practicum project were:

1. Identify learning needs and key issues related to pediatric palliative care.

2. Develop an evidence-based learning resource on the topic of pediatric palliative care.
3. Demonstrate advanced nursing practice competencies.

Overview

There were three methods used to meet the practicum objectives: a literature review, consultations, and an environmental scan. Results from the literature review, the consultations, and the environmental scan supported the need for education on the topic of pediatric palliative care, identified specific palliative care topics to include in the resource, and helped to determine which type of learning resource would be most effective for educating nurses on this topic. Further details of these methods and their results will be discussed below.

Literature Review

A brief summary of the literature review is discussed below. The full literature review report including the literature summary tables can be found in Appendix I.

Search Methods

The CINAHL database was searched for literature using the key words "nurs*," "palliative," "end-of-life," and "pediatric." The key question that guided the search was "What does the current literature tell us about pediatric nursing and palliative care in the hospital setting?" Multiple combinations of the key words produced over 700 results. The search was confined by limiting the results to articles published in the last ten years, academic journals, and the English language. Both analytic and descriptive articles were included. The abstracts of all articles were scanned for relevance to the search question.

A total of 28 articles were selected and critically analyzed for inclusion in this integrative literature review. The Critical Appraisal Toolkit of the Public Health Agency of Canada (2014) was used to critically analyze quantitative studies, while the Critical Appraisal Skills Programme (2017) qualitative research checklist was used to critically analyze qualitative studies. The articles will be discussed in this paper according to purposes: support for the need of a learning resource, key issues and content to be addressed in the learning resource, and education delivery methods and preferences. Literature summary tables for the articles can be found in Appendix A of the full report which is found in Appendix I.

Of the 28 articles included in this literature review, 19 were intervention studies, eight were surveys, and one was a qualitative study. The qualitative study explored the experiences of novice pediatric oncology nurses providing palliative and EOL care. The study was deemed credible, according to the criteria of the Critical Appraisal Skills Programme (2017).

Eleven intervention studies evaluated the effect of education interventions on nurses’ and nursing assistants’ knowledge, confidence, skills, and attitudes. Three intervention studies evaluated the effect of education interventions on mixed healthcare workers’ (HCWs) confidence, understanding, knowledge, and competence. Five intervention studies evaluated the effect of education interventions on medical residents’, medical students’ and nursing students’ comfort, knowledge, and attitudes.

Seven of the intervention studies assessed the effectiveness of face-to-face workshops while five assessed the effectiveness of online learning modules. One of the studies examining face-to-face workshops was a randomized controlled trial (RCT) while one of the studies examining the online learning modules was an uncontrolled post-test. All the other studies were uncontrolled before-after (UCBA) designs. Ten were of medium quality and two were of low quality (Jacobs, Ferrell, Virani, & Malloy, 2009; Wittenberg-Lyles, Goldsmith, Ferrell, & Burchett, 2014). Two other intervention studies assessed both face-to-face workshops and online modules combined, one of which was a non-randomized controlled trial (NRCT) of medium quality, while the other was an UCBA of low quality. Five other studies, all medium quality, evaluated four different interventions: paper-based learning modules (one UCBA), both paper and multimedia education combined (one cluster-randomized controlled trial), simulation activities (two UCBA), and reference cards (one UCBA).

Two surveys assessed self-identified palliative care education needs of health care providers, two surveys assessed health care providers' perceived confidence providing palliative care to children, one survey examined health care providers' attitudes towards providing EOL care to children, one survey explored barriers to palliative care experienced by health care providers, while another survey explored supportive behaviors, and one survey determined nurses' knowledge of palliative care. Two of the surveys were high quality, five were medium quality and one was low quality.

Key Findings

Support for the resource. Findings from the literature revealed that nurses lack education and training on pediatric palliative and EOL care. For example, in a cross-sectional survey conducted by Knapp et al. (2009) 86% of 279 participating nurses reported never having received palliative care training ever, while in a cross-sectional survey conducted by Price et al. (2017) 100% of nurses in acute care had never received any formal education on palliative or EOL care.

Findings also revealed that nurses lack confidence in providing palliative and EOL care to children. Results from three cross-sectional surveys revealed that nurses had low self-confidence when providing palliative care to children (Akpinar, Senses, & Er, 2009; Amery, 2012; Price et al., 2017). Similar findings were reported in a qualitative study that used focus groups with 14 novice oncology nurses (Hendricks-Ferguson et al., 2015); participants identified feeling that they lacked the necessary skills to act independently when providing palliative and EOL care to children.

It was also found that education was effective in increasing nurses' knowledge and skills. For example, O'Shea, Lavallee, Doyle, and Moss (2017) found that nurses who had received education on palliative care in the past five years had significantly higher mean scores on the End-Of-Life Professional Caregiver Survey which indicated greater palliative care knowledge and skills.

Effectiveness of different types of education interventions. Many different types of education interventions were examined amongst the literature: workshops, online education, paper and pencil learning packages, simulation, and pocket cards.

Workshops. Six studies examined the effects of face-to-face facilitated workshops on palliative and EOL care (Ersek et al., 2010; Jacobs et al., 2009; Machira, Kariuki, & Martindale, 2013; Milic et al., 2015; Paneduro et al., 2014; Pesut et al., 2015). The workshop interventions varied in terms of length, content, and delivery methods. Findings revealed that nurses and other health care workers (HCWs) had (a) greater confidence (Morita, 2014; Milic et al., 2015); (b) improved self-perceived knowledge (Pesut et al., 2015); (c) increased objective knowledge scores (Ersek et al., 2010; Machira et al., 2013); and (d) improved attitudes (Machira et al., 2013) after completing face-to-face workshops on palliative and EOL care.

Online education. Five UCBA studies examined the effect of online/computerized education programs alone on participants' palliative care knowledge (Broglio & Bookbinder, 2014; Ersek & Wood, 2008; Haut, Moloney-Harmon, & Michael, 2012; Petersen et al., 2017; Wittenberg-Lyles et al., 2014). Findings revealed that online educational programs (a) increased participants' palliative care knowledge (Broglio & Bookbinder, 2014; Ersek & Wood, 2008; Haut et al., 2012; Petersen et al., 2017; Wittenberg-Lyles et al., 2014); (b) improved participants' attitudes regarding palliative care (Haut et al., 2012); and (c) improved participants' competence scores (Petersen et al., 2017).

Two studies examined the effect of online programs combined with face-to-face education programs (Farrington, 2014; Morrison, Thompson, & Gill, 2012) on nurses' attitudes, knowledge, and confidence with palliative and EOL care. In an NRCT Morrison et al. (2012) found that the face-to-face workshop significantly increased participants' attitudes (p<.001), while the online module significantly increased participants' knowledge (p<.001). Farrington (2014) conducted an UCBA study, which did not compare the online education to the workshop portion, however results indicated an increase in knowledge.

Although mostly weak designs, consistency of results suggests online education could be effective in improving nurses' knowledge. However, there is not sufficient evidence to indicate if online education is in fact more effective than workshops.

Paper and pencil learning packages. Two studies examined the effect of paper and pencil self-learning modules. One examined the effect of a self-directed learning package in increasing palliative care knowledge and confidence for aged care workers (N=93) (Pitman, 2013). The mean knowledge scores (1.3-point increase; p=.003) and confidence scores (0.9-point increase, p=.001) increased significantly after completion of the self-directed learning package. The other study compared the effects of multimedia versus paper education on palliative care (Pan, Wu, Hung, Chu, & Wang, 2018). Knowledge and practice scores significantly increased after the intervention for both groups, however the increases were significantly greater in the multimedia experimental group at 3-months post intervention (knowledge: 1.0-point increase post-intervention and 0.7-point increase 3-months post; practice: 1.1-point increase post-intervention and 1.0-

point increase 3-months post) compared to the traditional paper education control group (knowledge: 0.7-point increase post-intervention and 0.3-point increase 3-months post-intervention; practice: 0.7-point increase post-intervention and 0.6 point increase 3-months post).

With only two studies examining the effect of paper and pencil self-learning modules, one of which was a weak design (Pitman, 2013), it can be concluded that there is limited evidence to support this education delivery method.

Simulation. Two studies examined the effect of simulation-based palliative and EOL care education interventions (Fabro, Schaffer, & Scharton, 2014; Goldonowicz, Runyon, & Bullard, 2018), both of which used a weak design, therefore, there is limited evidence to support this education delivery method. However, the limited evidence suggests that simulation-based education (a) is a valuable learning experience (Fabro et al., 2014); and (b) may help to improve confidence ($p<0.0001$) (Goldonowicz et al., 2018).

Pocket cards. Only one study examined the effect of EOL care management pocket reference cards (Balkin, Ort, Goldsby, Duvall, & Kim, 2017). Findings revealed that pediatric residents demonstrated significant improvement in (a) knowing what language to use to tell a family that their child has died ($p=0.02$); (b) comfort managing pain ($p=0.02$), nausea/vomiting ($p=0.03$), secretions ($p=0.04$), and symptoms other than pain at EOL ($p=0.005$); (c) knowing the steps in performing a death examination ($p=0.02$); (d) comfort in carrying out the documentation process after death ($p=0.02$), and (e) pain management knowledge ($p=0.03$). With only one UCBA examining the effect of pocket cards it is difficult to draw conclusions on this type of education delivery method. However, this study suggests the use of pocket cards warrants further investigation as an educational strategy.

Key topics. Three major topics were commonly identified in the literature as learning needs: communication, pain control, and management of other symptoms.

Communication. Problems with communication have been identified in the literature as a barrier to providing patients with optimal palliative and EOL care (Davies et al., 2018; Hendricks-Ferguson et al., 2015; Price et al., 2017; Wittenberg-Lyles et al., 2014). For example, in an uncontrolled before-after study conducted by Wittenberg-Lyles et al., (2014) nurses rated EOL care as the most challenging communication topic they face. Furthermore, in a qualitative study conducted by Hendricks-Ferguson et al. (2015) participants discussed a perceived tension inherent in EOL discussions among children, families, and other health care providers, identified as an "elephant in the room" (Hendricks-Ferguson et al., 2015). Novice oncology nurses also identified tensions related to the uncertainty of their role in talking about palliative care and EOL concerns with the child and their parents.

Pain control. Another major topic identified in the literature was pain control (Amery, 2012; Davies et al., 2018; Fabro et al., 2014). Qualitative data from the study conducted by Fabro et al. (2014) revealed that the component of a *good death* most frequently identified by nursing students was pain control (Fabro et al., 2014), however, Amery (2012) reported that nurses were less confident than doctors in pain control and symptom management, although mean scores and p values were not provided. Results from a survey conducted by Davies et al. (2018) revealed that 30% of 240 healthcare respondents reported insufficient education in pain as a barrier to providing palliative care to their patients.

Symptom management. Lastly, symptom management, including the process of death, was identified as a priority topic in the literature. For example, in a qualitative study conducted by Hendricks-Ferguson et al. (2015), participants identified feeling that they lacked the necessary skills to care for patients at EOL as the process of death was unfamiliar. Additionally, Amery (2012) reported that nurses were less confident than doctors in symptom management for palliative patients (Amery, 2012).

Delivery Methods and Preferences

Findings. Throughout the literature many different education delivery methods were found to be effective at improving confidence, knowledge, attitudes, practice, and skills pertaining to palliative and EOL care. For example, all interventions except for simulation education were effective at improving knowledge (Balkin et al., 2017; Broglio & Bookbinder, 2014; Farrington, 2014; Haut et al., 2012; Machira et al., 2013; Morrison et al., 2012; Pan et al., 2018; Pesut et al., 2015; Pitman, 2013). Only one study evaluated the effect of online education on practice but did find an improvement (Pan et al., 2018); similarly, only one study evaluated the effect of pocket reference cards on communication skills but also find an improvement (Balkin et al., 2017).

It is difficult to determine which interventions are more effective than others at improving confidence, knowledge, attitudes, practice, and communication skills as only one study did a direct comparison and the evidence was weak. Furthermore, many of the studies were conducted on nursing home staff, nursing students and medical students, not nurses (Balkin et al., 2017; Fabro et al., 2014; Farrington, 2014; Goldonowicz et al., 2018; Morrison et al., 2012). Without evidence for which intervention is most effective compared to others, decisions on which modality should be based on feasibility and preferences.

Preferences. When it comes to nurses' preferences for education delivery there were mixed findings in the literature. For example, participants from the American study conducted by O'Shea et al. (2017) stated they would most prefer to receive palliative care education in an on-site small group seminar or as a web-based training (O'Shea et al., 2017), yet 60.8% of participants in the study conducted by Broglio and Bookbinder (2014) also in the United States stated they preferred live presentations to online training, so they could ask questions. Therefore, local preference and feasibility should both be considered when deciding which method to implement.

Conclusion from the Literature Review

Many conclusions can be drawn based on the findings of the literature review. Firstly, it is evident that pediatric nurses are lacking the required knowledge and skills to feel confident and competent at providing palliative and EOL care to children and their families (Akpinar et al., 2009; Amery, 2012; Hendricks-Ferguson et al., 2015; Jacobs et al., 2009; Price et al., 2017). Secondly, the majority of pediatric nurses have never received formal education on palliative or EOL care (Banazadeh, Iranmanesh, & Forozy, 2015; Jacobs et al., 2009; O'Shea et al., 2017; Price et al., 2017). However, the small percentage of nurses who have received formal education on pediatric palliative and EOL care are in turn more confident, competent, and knowledgeable in providing palliative and EOL care to children and their families (Banazadeh et al., 2015; Dickens, 2009; Haut et al., 2012; Knapp et al., 2009; O'Shea et al., 2017). Thirdly, communication, pain control, and symptom management have been identified as priority topics for education thus formal education programs should focus on these areas. (Davies et al., 2018; Hendricks-Ferguson et al., 2015; Price et al., 2017). Finally, although the evidence was weak, it did suggest that online, face-to-face workshops, and traditional paper and pencil educational interventions may be effective in improving nurses' knowledge, confidence, attitudes, comfort, and competence in providing palliative and EOL care to patients.

Consultations

A brief summary of the consultations is discussed below. The full consultation report can be found in Appendix II.

Sample

Six registered nurses on the medicine unit at the Janeway were consulted, three of whom were senior and three of whom were novices. Two experts were also consulted: the clinical educator and the Janeway Association of Pediatric Hematology Oncology Nurses (APHON) coordinator.

Data Collection, Management, and Analysis

Data were collected via individual semi-structured interviews using open-ended questions. Participants were asked about the current quality of care provided on their unit, how comfortable they were with providing palliative and EOL care to children, and for recommendations for education delivery methods to facilitate learning on this topic. Interviews were approximately 20 minutes long and took place both face-to-face and over the phone. Field notes were written during the interviews.

Content analysis was used to analyze data collected from the interviews. Participants' responses were summarized by question, and common and single responses were identified. Findings from the consultation data were compared with findings from the literature review and used to develop the learning resource.

Ethical Considerations

The checklist from the Health Research Ethics Review Board (HREB) was used to identify whether the consultations were research or quality improvement. The completed checklist can be found in Appendix D of the consultation report found in Appendix II. It showed that the project met the criteria for quality improvement and therefore did not require review by the HREB. Approval for this project was granted by the unit manager. Participants verbally confirmed agreement prior to beginning the interview and were informed that they could stop the interview at any point, and that they could skip or refuse to answer any questions. A numeric code was assigned to each participant to ensure that data collected was confidential and non-identifiable.

Key Results: Nurses

The results from the consultations with the nurses are reported using four main themes: current quality of care, participants' comfort levels, education, and learning resource.

Current quality of care. When participants were asked to describe the current quality of palliative and EOL care provided to patients on their unit, five of the six nurse participants identified concerns, using words such as "inadequate," "disorganized," "not good," and "poor." When asked to elaborate on why they believed the quality of care was lacking, a number of reasons were identified, such as "lack of communication between staff and families," "inadequate pain control," "discomfort discussing EOL," and "lack of knowledge regarding symptom management."

Challenges regarding palliative and EOL care identified by participants included communication with families, nurses' lack of knowledge, nurses' lack of experience, nurses being uncomfortable with pain management, and nurses being unable to recognize when a patient has reached the EOL stage. Strengths regarding palliative and EOL care identified by participants included teamwork, individualized patient care, and the nurses' ability to build good relationships with the families.

Participants' comfort levels. The nurse participants discussed their comfort levels regarding six topics: providing palliative care, determining the EOL stage, controlling pain, managing symptoms, discussing EOL care with patients and families, and discussing EOL with colleagues and other team members.

Providing palliative care. Three nurse participants reported feeling comfortable or fairly comfortable caring for palliative patients on their unit, while two participants reported feeling not comfortable, and one stated that it would depend on her relationship with the patient/family. Reasons for feeling comfortable included previous experience caring for palliative children and supportive co-workers. Reasons for feeling uncomfortable included lack of training/education and lack of experience.

Determining the EOL stage. Three participants reported feeling uncomfortable determining when a patient has reached the EOL stage, while one participant stated she would be comfortable as long as the parents were "on the same page." Reasons for being uncomfortable included lack of training/education and lack of experience.

Controlling pain. Five out of six participants reported being comfortable with controlling pain. However, they all voiced concerns regarding the availability of a doctor's order for pain medications. The single participant who reported being uncomfortable with controlling pain for palliative patients reported trouble determining when a child who cannot communicate is in pain as the reason.

Managing symptoms. All six participants reported being uncomfortable both identifying and managing the following symptoms: secretions, seizure, and massive hemorrhage. Three participants reported being uncomfortable with sedation, three participants reported being uncomfortable with dyspnea and one participant reported discomfort with confusion/delirium. Participants identified both lack of experience and education as reasons for being uncomfortable with these symptoms.

Discussing EOL care with patients and families. Three participants stated they were very uncomfortable discussing EOL with patients and families, two participants stated they were somewhat uncomfortable, and one participant stated she was comfortable with familiar families but was uncomfortable with new families. Reasons for being uncomfortable included not knowing what to say, fear of saying the wrong thing, or fear of the patient/family getting upset or angry.

Discussing EOL with colleagues and other team members. Four participants reported feeling comfortable discussing EOL with colleagues and other team members. One participant reported feeling "mediocre," and one participant reported feeling very comfortable discussing EOL with her fellow nurses, however stated she is less comfortable with the physicians.

Education. The nurse participants were asked about education on palliative and EOL care, specific topics for education, and education delivery methods.

Palliative and EOL care. All participants believed that they could use more education on palliative and EOL care. When asked who else they believed could use education on palliative and EOL care all participants stated "everyone" referring to all health care professionals on their unit who care for palliative patients. None of the participants knew of any educational materials presently available on the unit.

Specific topics. When participants were asked specifically which topics they would like more education on, suggestions included communication such as discussing palliative and EOL care with patients and their families, pain medications and dosing, management and treatment of symptoms (particularly secretions at EOL), comfort measures that are non-pharmacologic, and signs and symptoms to identify when death is getting closer.

Delivery methods. Participants were asked what types of education delivery methods they thought would best facilitate their learning on this topic. Three participants stated a self-learning module would be helpful, while the other three participants stated they would not find it helpful. Four participants stated that they believed case studies would be helpful, while two stated they did not. Only one participant believed that role playing exercises would facilitate learning on this topic. All participants agreed that discussions and self-quizzes would be beneficial to facilitate learning on this topic.

Learning resource. All participants agreed that a learning resource such as a binder would be useful for providing information on palliative and EOL care. When asked how/when the binder would be used, for example, to look up info on a specific topic as needed, or to learn about the topic in general (not as a response to a problem), four participants stated the binder would be used both as needed and to learn about the topic in general, while two participants stated it would be used only as needed due to time constraints.

Key Results: Experts

The results from the consultations with the experts are reported using three main themes: questions/concerns, care delivery, and education delivery.

Questions/concerns. Both experts reported that the most common questions and concerns they receive from staff regarding palliative and EOL care relate to pharmacological management of symptoms (e.g., what medications should be given for particular symptoms) and communication (e.g., what to say to patients and their families at EOL). Other questions reported by the experts were to do with the legal documentation required at the time of death.

Care delivery. In response to a question about optimal care, both experts said that optimal palliative and EOL care meant that all symptoms were controlled so that the patient was not suffering unnecessarily. When asked what is required of staff to provide optimal palliative and EOL care, an interdisciplinary approach, clear communication between all staff members, good teamwork, maintaining a professional relationship with the patients and their families, and self-awareness of one's own thoughts and beliefs were all mentioned.

Both experts identified communication amongst the multidisciplinary team members as a challenge to providing optimal palliative and EOL care. Other challenges mentioned included ethical dilemmas, knowledge of medications, and identifying when a patient is close to death.

Both experts stated that a strength on the unit is the compassion that the nurses show the families. For example, it was mentioned that the nursing staff does a good job at involving the families in the plan of care, keeping them well informed, and allowing them to make decisions.

Education delivery. Both experts agreed that all nurses could benefit from more education on palliative and EOL care, stating that nurses, both novice and senior, have voiced being uncomfortable with this topic. When asked about specific topics related to palliative and EOL care to focus education on, the experts suggested symptom management, communication, difference between palliative and EOL care, and knowledge of supports in the communities.

When asked about specific education delivery methods, both experts stated that in the past staff have not been engaged in self-learning modules. Both agreed that role playing, case studies, and group discussions would be helpful for learning on this topic. One expert liked the idea of self-quizzes, while the other did not.

When asked about a learning resource such as a binder kept at the nursing desk both experts agreed it would be useful for providing information on palliative / EOL care to nurses. Both experts believed that the binder would mostly be used on a need to know basis, for example “if something came up, for example a palliative patient was in pain, the nurse could flip to that section of the binder to look up different ways to manage it.”

Conclusion from the Consultations

Results from the consultations clearly indicate that the participants have a learning need for information on palliative and EOL care. Identified key topics were communication, symptom management and treatment, and what to expect at the EOL stage. Although participants had mixed feelings on self-learning modules, all participants did believe that a learning resource such as a binder kept at the nursing station would be a useful tool.

Environmental Scan

A brief summary of the environmental scan is discussed below. The full environmental scan report can be found in Appendix III.

Goal

The goal for the environmental scan was to determine what resources were already available on the topic of pediatric palliative care and whether they might be used or adapted to educate nurses at the Janeway.

Methods

Data collection consisted of four methods: (1) following up on two resources which were mentioned by participants during the consultation interviews; (2) conducting a general Google search for learning resources on the topic of pediatric palliative care; (3) scanning websites of appropriate organizations for any teaching or learning material on the topic of palliative care; and (4) contacting nurse educators and clinical nurse specialists at other children's hospitals across eastern Canada inquiring about any resources they have on palliative care.

Key Results

None of the targeted websites contained any learning resources suitable for use for this project. Following up on the resources discussed by consultants during interviews led me to two resources, while the Google search resulted in four resources. Of the five nurses whom I contacted from other children's hospitals across eastern Canada, I received a response from three. However only one nurse, the palliative care nurse specialist at Montreal Children's Hospital, had palliative care resources to share.

The environmental scan resulted in a total of 13 resources, yet none of them were suitable to directly adopt or adapt for this project. The resources were used instead to draw on for ideas, such as content, figures, algorithms and models for organization.

Overview of Learning Resource

Based on the findings of the literature review and the consultations a learning resource for nurses on pediatric palliative care was developed. The learning resource contains a general introduction to pediatric palliative care, and four self-learning modules, each of which contains learning objectives, information, tools for practice, documentation tips, reflection exercises, case studies and self quizzes. Each module also contains summary tables, short paragraphs, bullet points and color-coordinated text boxes to enhance user friendliness. The table of contents found at the beginning of the resource allows for the resource to be used as a quick reference guide to look up information quickly for in-the-moment learning. A brief summary of each module is discussed below. The entire learning resource can be found in Appendix IV.

Adult Learning Theory

Adult learning theory was used to guide the development of the resource. According to adult learning theory, adult learners are self-motivated and self-directed

(Knowles, 1984). Self-learning modules are learner-centered and require the learner to be self-motivated and self-directed thus, a self-learning module was developed. Adults also need to be involved in the planning of their learning (Knowles, 1984). My co-workers contributed to the planning of the resource by participating in the consultation interviews.

In agreement with adult learning theory, experience becomes an increasing resource for learning (Knowles, 1984), meaning that adults learn from their personal experiences including their mistakes. Thus, reflection exercises were incorporated throughout the self-learning modules to encourage the learner to reflect on their past experiences and apply the information in the modules to their own clinical experiences.

Just as adults are most interested in learning about topics that have immediate relevance and a direct impact on their job (Knowles, 1984), the content in the resource reflects common scenarios that nurses encounter daily. The resource also contains practical tips and tools for the learner to use in their everyday practice.

Module 1: Communication. The topic of communication was chosen for the first module as communication was a key topic identified both in the literature review and the consultations. The module on communication covers topics such as the principles of good communication, discussing death and dying with children in age appropriate ways, developmental considerations for communicating with children of various ages, different family communication systems and nursing interventions to facilitate healthy communication.

Module 2: Pain. The topic of pain management was chosen for the second module as pain management was also identified as a key topic in both the literature review and the consultations. The module on pain management covers topics such as defining pain, classifying pain, pain assessment on children of various ages, different pain measurement tools, pharmacological pain management and non-pharmacological nursing interventions for pain management in children of various ages.

Module 3: Symptom Management. The topic of symptom management was chosen as the topic for module 3 as it was identified as a key topic in both the literature review and the consultations. Specifically, the consultees requested user friendly information on how to manage symptoms, which they could use “in the moment.” Thus, each symptom is broken down in the module explaining the definition, possible causes, risk factors, how to assess a patient for the symptom, non-pharmacological management, and pharmacological management. Twelve symptoms which were identified by the consultees are covered in the module: anorexia, anxiety, constipation, cough, delirium, diarrhea, dyspnea, insomnia, nausea and vomiting, pruritis, respiratory congestion, seizure, and terminal hemorrhage.

Module 4: End-of-Life. Although the topic of EOL was not identified as a key topic in the literature, it was chosen as the topic for the fourth module due to being identified by the consultees as a priority topic. Specifically, consultees requested information on determining when a patient has reached the EOL stage, the signs and symptoms to identify when death is getting closer, and what to expect during the last days/hours of life. Module 4 contains information on the physical signs that death is near, nursing interventions for various physical symptoms of the dying process, how to provide families with emotional support during their child's dying process, post-mortem care according to the guidelines at the Janeway, normal responses to grief, strategies to prevent staff burnout, and how to document appropriately and accurately the death of a patient.

Implementation Plan

Following the completion of this practicum project, the learning resource will be presented to the manager and clinical educator of the Medicine Unit at the Janeway for revision and approval. Upon approval, the resource will be made available on the unit. Staff working on the unit will be made aware of and provided with a brief overview of the resource during a "coffee session." Currently, orientation to the unit does not include any education or information on palliative care. Therefore, implementing the learning resource during orientation of new nurses to the unit would also be an excellent way to implement the resource.

Evaluation Plan

Self-evaluation components such as true and false questions, case study questions, and short answer questions are found throughout the learning resource with answers provided in the appendices. One way to evaluate the learning resource would be to distribute anonymous surveys to all staff on the unit six months after implementation of the learning resource to assess staff use and learner satisfaction. Outcomes such as self-perceived comfort and confidence with palliative and EOL care could also be evaluated by distributing anonymous surveys to staff who have used the learning resource.

Advanced Nursing Practice Competencies

One of my objectives for the practicum project was to demonstrate advanced nursing practice (ANP) competencies. Throughout the practicum project I demonstrated both research and leadership ANP competencies.

Research

Advanced nursing practice research competencies are defined as generating, synthesizing, critiquing, and applying research evidence to advance nursing practice (CNA, 2019). Throughout the practicum project I have demonstrated an understanding of research as evidenced by critiquing, interpreting and synthesizing current research findings surrounding pediatric palliative care in the literature review.

Although I did not conduct research, I utilized different research methods during the consultations. For example, I collected data using semi-structured interviews, and I analyzed data collected from the interviews using content analysis. By summarizing participant's responses, identifying common and single responses, I generated information. Findings from the consultation data were compared with findings from the literature review and used to develop the learning resource.

Leadership

Advanced nursing practice leadership competencies are defined as being an agent of change and seeking new ways to practice and improve care (CNA, 2019). Throughout the practicum project I have demonstrated leadership by identifying learning needs of nurses on my unit and developing a resource to meet those needs, and by identifying problems on my unit and initiating change to address them (CNA, 2019). The learning resource which I have developed will advance the palliative care knowledge of my co-workers, which will in turn improve their practice and ultimately enhance the care which palliative care children in Newfoundland and Labrador receive at the Janeway.

Conclusion

Pediatric palliative care is a special field of nursing (WHO, 2018) which requires specialized education and training. Nurses providing the children of Newfoundland and Labrador with palliative care must be well prepared and educated. A learning resource, such as the self-learning modules which have been developed for this practicum project, is one way in which nurses can enhance their pediatric palliative care knowledge which will in turn enhance their practice.

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Appendix I: Literature Review

Pediatric Palliative Care Literature Review

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Palliative care has been defined by the World Health Organization (WHO) as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness” (World Health Organization, 2018). WHO has identified pediatric palliative care as a special field of palliative care which begins when a child is diagnosed with a life-threatening illness and continues until end-of-life (EOL), regardless of whether or not the child is receiving treatment for the illness (WHO, 2018). Although pediatric palliative care can take place in tertiary healthcare facilities, community health centers, or in the child’s home, statistics show that 59.4% of pediatric deaths occur in hospitals in either critical care, labor and delivery, or general units (Widger et al., 2016). Furthermore, nurses spend more time with palliative patients and their families than any other health professional (Schroeder & Lorenz, 2018). Therefore, it is vital that nurses in hospital settings are educated and well prepared to provide patients and their families with optimal palliative and EOL care.

The purposes of this literature review are to support the need for a learning resource for nurses on pediatric palliative and EOL care, to identify issues and key content to be addressed in the learning resource, and to determine which type of resource should be developed.

Literature Search

The CINAHL database was searched for literature using the key words “nurs*,” “palliative,” “end-of-life,” and “pediatric.” The key question that guided the search was, “What does the current literature tell us about pediatric nursing and palliative care in the hospital setting?” Multiple combinations of the key words produced over 700 results. The search was confined by limiting the results to articles published in the last ten years, academic journals, and the English language. Both analytic and descriptive articles were included. The abstracts of all articles were scanned for relevance to the research question. A total of 28 articles were selected and critically analyzed for inclusion in this integrative literature review. The Critical Appraisal Toolkit (2014) of the Public Health Agency of Canada was used to critically analyze quantitative studies, while the Critical Appraisal Skills Programme (2017) qualitative research checklist was used to critically analyze qualitative studies. The articles will be discussed in this paper according to purposes: support for the need of a learning resource, key issues and content to be addressed in the learning resource, and education delivery methods and preferences. Literature summary tables for the articles can be found in Appendix A. A glossary of abbreviations used throughout this paper and the literature summary table can be found in appendix B.

Of the 28 articles included in this literature review, 19 were intervention studies, eight were surveys, and one was a qualitative study. Eleven intervention studies evaluated the effect of education interventions on nurses’ and nursing assistants’ knowledge, confidence, skills, and attitudes (Broglio & Bookbinder, 2014; Ersek & Wood, 2008; Ersek et al., 2010; Haut, Moloney-Harmon, & Michael, 2012; Jacobs, Ferrell, Virani, & Malloy, 2009; Machira, Kariuki, & Martindale, 2013; Milic et al., 2015; Morita et al., 2014; Pan, Wu, Hung, Chu, & Wang, 2018; Petersen et al., 2017; Pitman, 2013). Three intervention studies evaluated the effect of education interventions on mixed healthcare workers’ (HCWs) confidence, understanding, knowledge, and competence (Farrington, 2014; Pesut et al., 2015; Wittenberg-Lyles, Goldsmith, Ferrell, & Burchett, 2014). Five intervention studies evaluated the effect of education interventions on medical residents', medical students' and nursing students' comfort, knowledge, and attitudes (Balkin, Ort, Goldsby, Duvall, & Kim, 2017; Fabro, Schaffer, & Scharton, 2014; Goldonowicz, Runyon, & Bullard, 2018; Morrison, Thompson, & Gill, 2012; Paneduro et al., 2014).

Seven of the intervention studies assessed the effectiveness of face-to-face workshops (Ersek et al., 2010; Jacobs et al., 2009; Machira et al., 2013; Milic et al., 2015; Morita, 2014; Paneduro et al., 2014; Pesut et al., 2015). Six of these studies used an uncontrolled before-after (UCBA) design (Ersek et al., 2010; Jacobs et al., 2009; Machira et al., 2013; Milic et al., 2015; Paneduro et al., 2014; Pesut et al., 2015), which is a weak design, while one (Morita, 2014) was a randomized controlled trial (RCT). All were medium quality except for the study by Jacobs et al. (2009) which was low.

Five of the intervention studies assessed the effectiveness of online learning modules (Broglio & Bookbinder, 2014; Ersek & Wood, 2008; Haut et al., 2012; Petersen et al., 2017; Wittenberg-Lyles et al., 2014). Four of these studies were UCBA design (Broglio & Bookbinder, 2014; Ersek & Wood, 2008; Haut et al., 2012; Petersen et al., 2017), while one was an uncontrolled post-test (Wittenberg-Lyles et al., 2014). All were medium quality except for the study by Wittenberg-Lyles et al. (2014) which was low.

Two intervention studies assessed both face-to-face workshops and online modules combined (Farrington, 2014; Morrison et al., 2012), one of which was a non-randomized controlled trial of medium quality (Morrison et al., 2012), while the other was an UCBA of low quality (Farrington, 2014).

One UCBA study assessed paper-based learning modules (Pitman, 2013), and a cluster-randomized controlled trial assessed both paper and multimedia education combined (Pan et al., 2018). Two UCBA studies assessed simulation activities (Fabro et al., 2014; Goldonowicz et al., 2018), and one UCBA assessed reference cards (Balkin et al., 2017). All were medium quality.

Two surveys assessed self-identified palliative care education needs of health care providers (Amery, 2012; O’Shea, Lavalee, Doyle, & Moss, 2017), two surveys assessed health care providers’ perceived confidence providing palliative care to children (Dickens, 2009; Price et al., 2017), one survey examined health care providers’ attitudes towards providing EOL care to children (Akpinar, Senses, & Er, 2009), one survey explored barriers to palliative care experienced by health care providers (Davies et al., 2018), while another survey explored supportive behaviors (Banazadeh, Iranmanesh, & Forozy, 2015), and one survey determined nurses’ knowledge of palliative care (Knapp et al., 2009). Two of the surveys were high quality (Banazadeh et al., 2015; Knapp et al., 2009), five were medium quality (Amery, 2012; Davies et al., 2018; Dickens, 2009; O’Shea et al., 2017; Price et al., 2017) and one was low quality (Akpinar et al., 2009).

The single qualitative study explored the experiences of novice pediatric oncology nurses providing palliative and EOL care (Hendricks-Ferguson et al., 2015). The study was deemed credible, according to the criteria of the Critical Appraisal Skills Programme (2017).

Results and Discussion

Support for the Resource

Results from the literature review revealed that (a) nurses lack education and training on pediatric palliative and EOL care; (b) nurses lack confidence in providing palliative and EOL care to children; and (c) education is effective in increasing nurses' knowledge and skills. Although the studies in this literature review are cross-sectional and therefore a weak design, there was a mixture of high and medium quality studies across a variety of settings, suggesting jurisdictions should review the learning needs of their own staff. The studies that support these conclusions are discussed in the next sections.

Need for education.

Results from several studies revealed that nurses have received little to no formal education on pediatric palliative and EOL care. For example, in the cross-sectional survey by Price et al. (2017) 100% of nurses in acute care had never received any formal education on palliative or EOL care. In the cross-sectional survey conducted by O'Shea et al. (2017) 54% of 139 participating HCWs had not received any palliative care education in the past 5 years, while in the cross-sectional survey conducted by Knapp et al. (2009) 86% of 279 nurses reported never having received palliative care training ever. Furthermore, in the correlational study conducted by Banazadeh et al. (2015), 77.5% of 151 nurses reported they had never received any education on EOL care. Additionally, in the cross-sectional survey conducted by Davies et al. (2018) 30% of 240 participants reported insufficient education as a barrier to providing palliative care to children.

Low self-confidence.

Results from three cross-sectional surveys revealed that nurses have low self-confidence when it comes to providing palliative care to children (Akpinar et al., 2009; Amery, 2012; Price et al., 2017). The surveys looked at nurses' confidence in different aspects of palliative and EOL care, and two of them compared confidence in different groups. For example, a worldwide survey conducted by Amery (2012) in which participants completed an online questionnaire self-rating their confidence levels in caring for children with palliative care needs revealed that the overall mean confidence score in providing palliative care to children was 3.2 out of 5. Amery also reported that nurses were less confident with controlling pain and other symptoms at EOL than doctors were, however mean scores or p values were not provided.

Price et al. (2017) found that nurses in pediatric intensive care units were much more confident than pediatric nurses in acute care ($p<0.0001$). It is interesting to note that the nurses in intensive care had received palliative care education in their orientation program, and the nurses in acute care had not. Akpinar et al. (2009) examined PICU nurses' self-confidence related to making decisions at EOL. Findings revealed that more than half of participants (53%) felt unable to help families in making critical decisions to do with EOL care. Similar findings were reported in a qualitative study that used focus groups with 14 novice oncology nurses (Hendricks-Ferguson et al., 2015). They were asked about their perceptions and experiences in providing palliative and EOL care to children and identified feeling that they lacked the necessary skills to act independently when providing palliative and EOL care to children.

Benefits of education.

As previously discussed, Price et al. (2017) found that health care professionals who had received formal education on palliative and EOL care had significantly higher levels of confidence. One other cross-sectional survey also found that those who had received formal education on palliative and EOL care had higher levels of confidence (Dickens, 2009). Dickens' (2009) survey of health care providers at a children's hospital in Western Michigan who provide pediatric EOL care found that 17.1% of respondents who did receive education on palliative care during training felt well prepared, whereas only 3.8% of respondents who did not receive education during training felt well prepared to care for children at EOL. These findings were statistically significant (p=0.006), however, the study was conducted at a single children's hospital with extremely experienced palliative care providers, therefore it may only be generalizable to similar hospitals with extremely experienced providers. Other important factors that were also found to have an influence on confidence were age (Dickens, 2009), and years of nursing experience (Dickens, 2009; Price et al., 2017).

Two studies assessed different self-reported skills as an outcome (O'Shea et al., 2017; Banazadeh et al., 2015). Results from the survey conducted by O'Shea et al. (2017), which used the End-Of-Life Professional Caregiver Survey (EPCS) to assess palliative and EOL educational needs of pediatric health care providers in the state of Connecticut, found that participants who had received education on palliative care in the past five years had significantly higher mean scores ($p<0.001$) on the EPCS. Higher scores on the EPCS reflect greater palliative and EOL care knowledge and skills. Results from the descriptive cross-sectional study conducted by Banazadeh et al. (2015) reported a positive association between previous education on death and dying and nurses' perception of supportive behaviors. Furthermore, Banazadeh et al. found that nurses who had previous education on death and dying perceived supportive behaviors as more important (mean score 3.84 out of 9) than did those with no previous education (mean score 2.7 out of 9) ($p=0.05$).

Further evidence about the benefits of education comes from intervention studies in which effectiveness was assessed in terms of key outcomes such as knowledge, confidence, attitudes, and behaviors. The effectiveness as well as details about the interventions will be discussed in the next sections.

Effectiveness of Different Types of Education Interventions

Workshops.

Six studies examined the effects of face-to-face facilitated workshops on palliative and EOL care (Ersek et al., 2010; Jacobs et al., 2009; Machira et al., 2013; Milic et al., 2015; Paneduro et al., 2014; Pesut et al., 2015). The length of face-to-face workshops ranged from 4-hour seminars (Paneduro et al., 2014) to 5-day workshops (Ersek et al., 2010), however the majority of the workshops were 1-2 days (Jacobs et al., 2009; Machira et al., 2013; Milic et al., 2015; Morita, 2014; Pesut et al., 2015).

Four studies examined the effect of workshops on participants' self-reported confidence, competence, and knowledge in palliative and EOL care (Jacobs et al., 2009; Milic et al., 2015; Morita, 2014; Pesut et al., 2015). For example, Morita (2014) conducted a randomized controlled trial of medium quality which evaluated the effect of an educational workshop on nurses' self-reported confidence, practice, attitudes, burnout, meaning of life, and knowledge. The interactive workshop was two days long and consisted of lectures, demonstrations, role-playing, and groupwork. Findings revealed that the workshop had significant effects on nurse-reported confidence (p=.003), with an effect size of 0.8 or more. For Group 1, confidence scores went from 3.6 pre-intervention to 4.5 post-intervention. For Group 2, confidence scores went from 4.1 pre-intervention to 4.9 post-intervention. The workshop was not found to have significant effects on any of the other outcome measurements.

Milic et al. (2015) conducted an UCBA study of medium quality which evaluated the impact of an 8-hour workshop on 82 critical care nurses' self-perceived confidence and skill in palliative care using a Likert-type scale. The workshop consisted of presentations, discussions, role-playing and reflections. Compared to before the workshop, immediately after the workshop nurses reported greater skill and confidence for 14 survey items (p < .001), which were sustained 3 months later.

Similarly, Pesut et al. (2015) conducted an UCBA study of medium quality which evaluated the outcomes of a 1.5-day workshop on nurses' and other HCWs self-perceived competence and knowledge. The palliative care workshop consisted of didactic content and case study discussions on topics such as pain, other physical symptoms, psychological needs, social needs, spiritual needs, needs related to functional status, ethical and legal issues, interprofessional collaboration and communication, personal and professional issues, and last hours of life. Findings revealed that HCWs had statistically significant improvements across 7 of 10 domains in self-perceived competence; pain (p=0.044), spiritual needs (p=0.016), functional status (p=0.007), ethical and legal issues (p=0.030), inter-professional collaboration and communication (p=0.045), personal and professional issues (p=0.002), and last hours of life (p=0.004). No statistically significant changes in self-perceived competence in any of the 10 dimensions for nurses. However, normative comparison data suggested they were below the provincial average pre-test but were equivalent to the provincial average on post-test. HCWs has statistically significant improvements across 6 of 12 domains in self-perceived knowledge: disease management (p=0.034), pain (p=0.020), other physical symptoms (p=0.014), needs related to functional status (p=0.023), ethical and legal issues (p=0.046), last hours of life (p=0.005). Nurses' self-perceived knowledge showed statistically significant improvements in 3 of 12 domains; spiritual needs (p=0.010), ethical and legal issues (p=0.007), personal and professional issues (p=0.008). Qualitative data indicated improvements in familiarity with the resources available for palliative care, communication among the nursing team, and confidence having conversations with patients/families around palliative care.

Jacobs et al. (2009) conducted an UCBA study which surveyed nurses before and after completing a two-and-a-half-day course known as the End-of-Life Nursing Education Consortium (ELNEC) on pediatric palliative care (PCC), which consisted of 10 modules that address the care of children and their families when facing life-limiting illness. Topics included communication, ethical/legal issues, cultural considerations, pain management, symptom management, care at the time of death, and loss/grief. Participants rated the overall helpfulness of ELNEC-PPC curriculum at 9.06 out of 10. Prior to completing the course, participants were asked to rate their perceptions of the current pediatric palliative care delivery in their institutions. Findings revealed that participants believed their own institutions were only moderately effective in caring for a dying child and their family. Participants did however perceive palliative care education to be very important to pediatric nursing and something they would be very receptive to. Participants also stated that prior to attending the ELNEC-PPC course, they had never received an educational program surrounding PPC, identifying a gap between their apparent need for PPC education, and the availability.

The other two studies examined the effect of workshops on palliative and EOL care objective knowledge (Ersek et al., 2010; Machira et al., 2013). Machira et al. (2013) also reported on changes in attitudes. For example, Ersek et al. (2010) conducted an UCBA study of medium quality which evaluated an interdisciplinary palliative care workshop in Botswana on 47 HCWs palliative care knowledge and skills. The workshop was five days long and consisted of lectures, case studies, and group discussions. Findings revealed that palliative care knowledge mean scores increased from 14.4 at baseline to 16.7 post-workshop ($p<.001$), and self-evaluation of palliative care skills mean scores increased from 6.7 at baseline to 8.4 post-workshop ($p<0.001$).

Similarly, Machira et al. (2013) conducted an UCBA study which evaluated the effects of an educational pain management workshop on nurses' (N=9) pain knowledge and attitudes in patients with terminal illness. At baseline, 44% of the nurses scored less than 20, and none scored more than 30 identifying a deficit in knowledge and attitudes. However, findings indicated that the workshop was effective in improving both participant's knowledge and attitudes (p=0.007). Mean scores were 18.44 out of 40 at baseline, 28 out of 40 post intervention and 27.56 out of 40 at 2-week follow up.

Although the six studies discussed above all evaluated workshops, the interventions varied in terms of length, content, and delivery methods. Only one study was an RCT and provided medium quality evidence that the workshop was effective in terms of improving confidence, but not other measures. Although the study had an adequate sample size (N=76), key limitations were no discussion of response rate or validity and reliability (V&R) of scales.

The other studies were all UCBA and provided weaker evidence, but Milic et al. (2015) found an increase in skill and confidence, and Ersek et al. (2010), Machir et al. (2013), and Pesut et al. (2015) all found an increase in knowledge scores. However, there was some inconsistency as Pesut et al. (2015) found an improvement in knowledge scores in 6 of 12 domains for HCWs but only in 3 of 12 domains for nurses. Furthermore, Pesut et al. (2015) found an improvement in competence for HCWs but no improvement in competence for nurses. Overall, there is unclear evidence about the effectiveness of workshops on skill, knowledge, and competence, but the trends indicate they may improve some outcomes and should be further researched.

Online education.

Five studies examined the effect of online/computerized education programs alone on participants' palliative care knowledge (Broglio & Bookbinder, 2014; Ersek & Wood, 2008; Haut et al., 2012; Petersen et al., 2017; Wittenberg-Lyles et al., 2014), while two studies examined the effect of online combined with face-to-face education programs (Farrington, 2014; Morrison et al., 2012). Broglio and Bookbinder (2014), and Ersek and Wood (2008) both conducted uncontrolled before-after studies which examined the impact of online educational interventions on participants' palliative care knowledge. In Broglio and Bookbinder's study participants' knowledge scores significantly increased from 57.6% pre-intervention to 72.2% after the educational intervention ($p<.001$) and were maintained at 70% at the 3-week follow-up ($p=.003$). Likewise, findings from Ersek and Wood's study revealed significant increases in scores ($p<.001$) from 72.4% pre-intervention to 78.9% post-intervention.

Wittenberg-Lyles et al. (2014) also conducted an uncontrolled before-after study evaluating the impact of an online palliative care communication curriculum on health care professionals' (N=177) clinical communication experiences related to palliative care. Mean scores for nurses on the post-module knowledge quizzes ranged from 70% to 86%, however knowledge quizzes were not conducted pre-intervention for comparison.

Furthermore, Haut et al. (2012) conducted an UCBA study to evaluate the impact of a pediatric palliative care online educational program on the attitudes and knowledge of pediatric nurses (N=25). The educational program consisted of nine modules which included topics such as communication, ethical, legal, and cultural considerations, pain and symptom management, and grief and loss issues. The researchers found that the educational program was associated with a significant increase in pediatric nurses' knowledge (mean difference of 0.42; p=.02) and improved attitudes (mean difference of 0.96; p=.001) regarding pediatric palliative care. Additionally, Petersen et al. (2017) conducted an UCBA study which evaluated the impact of an online spiritual care educational program not only on pediatric nurses' (N=112) knowledge, but also on their attitudes toward spiritual care and their competence to provide spiritual care to children at the end of life. Findings revealed that participants' spiritual care competence scores went from 98.3 at baseline to 113.18 post-intervention and 115.70 at 3-month follow-up (p<.0005). Similarly, spiritual knowledge scores rose from 69.58 at baseline to 75.45 post-intervention and were maintained at 75.27 at 3-month follow-up (p<.0005).

Two studies incorporated both face-to-face seminars and online components (Farrington, 2014; Morrison et al., 2012). Morrison et al. (2012) conducted a non-randomized controlled trial which assessed the impact of a multiple component educational intervention on medical students' (N=157) palliative care pain knowledge and end-of-life attitudes. The educational intervention was an 8-hour workshop plus an online module. Group one received both the workshop and the online component at baseline, while group two received the workshop only at baseline, and the online component 5.5 months later. Findings revealed that the workshop significantly increased participants' attitudes (p<.001), while the online module significantly increased participants' knowledge (p<.001). Group one's mean attitude scores significantly increased post-intervention (from 4.66 at baseline to 5.34 post-intervention), and group two's mean attitude scores significantly increased post-workshop (from 4.83 at baseline to 5.22 post-workshop). No significant difference was found between attitude scores post-online component for Group two. Group one's mean knowledge scores significantly increased post-intervention (from 4.79 at baseline to 6.08 post-intervention), and group two's mean knowledge scores significantly increased post-online component (from 5.51 at baseline to 6.94 post-online component). Farrington (2014) conducted an UCBA study of low quality which evaluated the impact of a blended (e-learning and face-to-face workshops) training course on health care workers' (N=20) understandings of and confidence in delivering end of life care in a nursing home. Quantitative data revealed a mean knowledge score increase of 0.8, however qualitative data identified substantial improvements in participants' knowledge of and confidence towards end of life care.

The five studies that assessed online education alone were all UCBA and all resulted in improved knowledge (Broglio & Bookbinder, 2014; Ersek & Wood, 2008; Haut et al., 2012; Petersen et al., 2017; Wittenberg-Lyles et al., 2014). Of the two studies that combined online education with face-to-face workshops, one was an NRT (Morrison et al., 2012) while the other was a UCBA. The NRT (Morrison et al., 2012), which is a stronger design, compared the online education to the workshops and found that the online portion improved knowledge while the workshop portion improved attitudes. The UCBA study (Farrington, 2014) did not compare the online education to the workshop portion, however results indicated an increase in knowledge. Although mostly weak designs, consistency of results suggests online education could be effective in improving nurses' knowledge. However, there is not sufficient evidence to indicate if online education is in fact more effective than workshops.

Paper and pencil learning packages.

One study examined the effect of a self-directed learning package (Pitman, 2013), while another study compared the effects of multimedia versus paper education on palliative care (Pan et al., 2018). Pan et al. (2018) conducted a cluster-randomized controlled trial of high quality which compared the effects of multimedia and paper-based education on the topic of palliative care. Although knowledge and practice scores significantly increased after the intervention for both groups, the increases were significantly greater in the multimedia experimental group at 3-months post intervention(knowledge: 1.0-point increase post-intervention and 0.7-point increase 3-months post; practice: 1.1-point increase post-intervention and 1.0-point increase 3-months post) compared to the traditional paper education control group (knowledge: 0.7-point increase post-intervention and 0.3-point increase 3-months post-intervention; practice: 0.7-point increase post-intervention and 0.6 point increase 3-months post). There were no reported changes in attitude for either group. Pitman (2013) conduced an UCBA study of medium quality which evaluated the effectiveness of a self-directed learning package in increasing palliative care knowledge and confidence for aged care workers (N=93). Mean knowledge scores (1.3-point increase; p=.003) and confidence scores (0.9-point increase, p=.001) increased significantly after completion of the self-directed learning package.

With only two studies examining the effect of paper and pencil self-learning modules, one of which was a weak design, it can be concluded that there is limited evidence to support this education delivery method.

Simulation.

Two studies examined the effect of simulation-based palliative and EOL care education interventions (Fabro et al., 2014; Goldonowicz et al., 2018). Fabro et al. (2014) developed, implemented, and evaluated an end-of-life simulation for senior nursing students ($N=21$) in an uncontrolled post-test only study. Results indicated that the students perceived that the simulation was a valuable experience. Goldonowicz et al. (2018) conducted an uncontrolled before-after study which investigated the value of a simulation-based palliative care educational intervention for medicine residents ($N=40$). After the simulation intervention participants reported feeling more confident with initiating palliative care discussions and treatment in the emergency department ($p<0.0001$).

With only two studies examining the effect of simulations, both of which used a weak design, it can be concluded that there is limited evidence to support this education delivery method. However, although the interventions were different, the limited evidence suggests that participants may perceive simulation as a valuable learning experience and may help to improve confidence.

Pocket cards.

One study examined the effect of EOL care management pocket reference cards (Balkin et al., 2017). Balkin et al. (2017) conducted an UCBA study in which they tested a portable reference card to improve pediatric resident education in comprehensive care for children nearing end of life. Both first and second year residents participated in the study (N=26), and findings revealed that the pocket reference cards had different effects on the residents depending on their year. First year residents demonstrated significant improvement in knowing what language to use to tell a family that their child has died (p=0.02), while second year residents demonstrated significant improvements in comfort managing pain (p=0.02), nausea/vomiting (p=0.03), secretions (p=0.04), symptoms other than pain at EOL (p=0.005), knowing the steps in performing a death examination (p=0.02), comfort in carrying out the documentation process after death (p=0.02), and pain management knowledge (p=0.03). With only one UCBA examining the effect of pocket cards it is difficult to draw conclusions on this type of education delivery method. However, this study suggests the use of pocket cards warrants further investigation as an educational strategy.

Key Topics

Three major topics were commonly identified amongst the literature as learning needs: communication, pain control, and management of other symptoms. Although the evidence from the literature is weak, as it came from surveys and may not be generalizable or unbiased, these three major topics still need to be seriously considered, and thus will be discussed below.

Communication.

The first major topic identified was communication (Davies et al., 2018; Hendricks-Ferguson et al., 2015; Price et al., 2017; Wittenberg-Lyles et al., 2014). Nurses have identified problems with communication as a barrier to providing their patients with optimal palliative and EOL care (Davies et al., 2018). For example, results from a cross-sectional study conducted by Davies et al. (2018) which surveyed pediatric nurses and physicians from a children's hospital in Western United Stated on their perceived barriers to providing palliative care to children revealed that 30% of respondents reported problems with communication. Additionally, in an uncontrolled before-after study conducted by Wittenberg-Lyles et al., (2014) nurses rated EOL care as the most challenging communication topic they face.

Furthermore, in a qualitative study conducted by Hendricks-Ferguson et al. (2015) which was also mentioned earlier, participants identified a perceived tension inherent in EOL discussions among children, families, and other health care providers, identified as an "elephant in the room" (Hendricks-Ferguson et al., 2015). Novice oncology nurses also identified tensions related to the uncertainty of their role in talking about palliative care and EOL concerns with the child and their parents.

Likewise, qualitative findings from a survey conducted by Price et al. (2017), which included open ended questions for participants to identify any concerns surrounding the provision of palliative care for children, revealed that nurses in both intensive care and acute care settings had concerns regarding a need for improved communication behaviors between physicians and patients/families regarding patients' prognoses.

Pain control.

The second major topic identified was pain control (Amery, 2012; Davies et al., 2018; Fabro et al., 2014). Qualitative data from the study conducted by Fabro et al. (2014) revealed that the component of a *good death* most frequently identified by nursing students was pain control (Fabro et al., 2014), however, Amery (2012) reported that nurses were less confident than doctors in pain control and symptom management, although mean scores and p values were not provided. Results from a survey conducted by Davies et al. (2018) revealed that 30% of 240 healthcare respondents reported insufficient education in pain as a barrier to providing palliative care to their patients.

Symptom management.

Thirdly, symptom management, including the process of death, was identified as a priority topic. In a qualitative study conducted by Hendricks-Ferguson et al. (2015), participants identified feeling that they lacked the necessary skills to care for patients at EOL as the process of death was unfamiliar. Additionally, Amery (2012) reported that nurses were less confident than doctors in symptom management for palliative patients (Amery, 2012).

Delivery Methods and Preferences

Findings

As previously discussed, the evidence was generally weak. However, all types of educational interventions were effective at improving confidence (Balkin et al., 2017; Farrington, 2014; Goldonowicz et al., 2018; Machira et al., 2013; Morrison et al., 2012; Pan et al., 2018; Pesut et al., 2015; Pitman, 2013). All interventions except for simulation education were effective at improving knowledge (Balkin et al., 2017; Broglio & Bookbinder, 2014; Farrington, 2014; Haut et al., 2012; Machira et al., 2013; Morrison et al., 2012; Pan et al., 2018; Pesut et al., 2015; Pitman, 2013). Online education (Farrington, 2014; Haut et al., 2012; Morrison et al., 2012) and face-to-face workshop (Farrington, 2014; Machira et al., 2013; Morrison et al., 2012) interventions were effective at improving attitudes. Only online education (Pan et al., 2018) interventions were found to be effective at improving practice, and only pocket reference cards were found to be effective at improving communication skills (Balkin et al., 2017).

It is difficult to determine which interventions are more effective than others at improving confidence, knowledge, attitudes, practice, and communication skills as only one study did a direct comparison and the evidence was weak. Pan et al. (2018) compared a multimedia education intervention to a more traditional paper and pencil education intervention and found that although both interventions improved participants palliative care knowledge and practice, the increases were more significant with multimedia intervention group. Additionally, although the study by Morrison et al. (2012) did not directly compare interventions, findings did indicate that knowledge increases were seen after the online module, while attitudinal improvements were seen after the workshop.

It is worth noting that the two studies which blended face-to-face workshops with online modules were conducted on nursing home staff and medical students, not nurses (Farrington, 2014; Morrison et al., 2012). The two studies evaluating simulation education activities were conducted on medical and nursing students, not nurses (Fabro et al., 2014; Goldonowicz et al., 2018). And the study examining the use of pocket reference cards was conducted on medical students (Balkin et al., 2017). No studies examining palliative care simulations or pocket reference cards have been conducted on nurses thus far to my knowledge.

Without evidence for which intervention is most effective compared to others, decisions on which modality should be based on feasibility and preferences.

Preferences

When it comes to nurses' preferences for education delivery there were mixed findings in the literature. Participants from the American study conducted by O'Shea et al. (2017) stated they would most prefer to receive palliative care education in an on-site small group seminar or as a web-based training (O'Shea et al., 2017), yet 60.8% of participants in the study conducted by Broglio and Bookbinder (2014) also in the United States stated they preferred live presentations to online training, so they could ask questions. In the study conducted in England by Farrington (2014) a small number of participants did report problems from the computer-based course component such as “no access to computer” and “computer screen hurts my eyes” (Farrington, 2014).

Nursing students in the American study conducted by Fabro et al. (2014) stated that they perceived the simulation to be a valuable learning experience. When medical students in the American study by Goldonowicz et al. (2018) were asked to rate methods of learning palliative care bedside teaching and small group learning were rated best, while lecture format and online modules were rated least favorite. When American medical students were asked, on a 5-point Likert scale how helpful pocket reference cards were in managing patients at end of life, participants reported an average of 3.92 out of 5 (Balkin et al., 2017).

As consensus has not been reached on nurses’ preference for education delivery, local preference and feasibility should both be considered when deciding which method to implement.

Summary of Findings

Many conclusions can be drawn based on this review of the current literature surrounding nursing and palliative care. Firstly, it is evident that nurses are not comfortable or confident in providing palliative and EOL care to children and their families (Akpinar et al., 2009; Amery, 2012; Hendricks-Ferguson et al., 2015; Jacobs et al., 2009; Price et al., 2017). Secondly, the majority of pediatric nurses have never received formal education on palliative or EOL care (Banazadeh et al., 2015; Jacobs et al., 2009; O’Shea et al., 2017; Price et al., 2017). However, the small percentage of nurses who have received formal education on pediatric palliative and EOL care are more confident, competent, and knowledgeable in providing palliative and EOL care to children and their families (Banazadeh et al., 2015; Dickens, 2009; Haut et al., 2012; Knapp et al., 2009; O'Shea et al., 2017). Thirdly, novice nurses with less experience are less confident and competent in providing palliative and EOL care to children (Dickens, 2009; Price et al., 2017). Fourthly, communication, pain control, and symptom management have been identified as priority topics for an educational resource for nurses (Davies et al., 2018; Hendricks-Ferguson et al., 2015; Price et al., 2017). Finally, although the evidence was weak, it did suggest that online, face-to-face workshops, and traditional paper and pencil educational interventions may be effective in improving nurses' knowledge, confidence, attitudes, comfort, and competence in providing palliative and EOL care to patients.

Conclusion

In conclusion, it is evident that pediatric nurses are lacking the required knowledge and skills to feel confident and competent at providing palliative and EOL care to children and their families. It is also evident that nurses who have received formal education on pediatric palliative and EOL care are in turn more knowledgeable, confident and comfortable with providing palliative and EOL care to seriously ill children and their families.

Communication, pain, and symptom management have been identified as topics for education thus formal education programs should focus on these areas. Because novice nurses were found to be less confident and competent than nurses with more years of experience, educational programs should focus on, but not be exclusive to, novice nurses. Recommendations include offering palliative and EOL care education as part of staff orientation to all pediatric nurses who may care for dying patients (Haut et al., 2012).

The evidence, though weak, supports a conclusion that by providing education specifically on communication, pain, and symptom management, pediatric nurses will have the opportunity to increase their knowledge, skills and confidence and thus be able to provide seriously ill children and their families with the nursing care they deserve.

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Appendix A

Table 1 Studies Examining Palliative Care Education

Study/Objective	Sample and Methods	Key Results	Conclusions
Akpinar et al., 2009 **Design: Cross-sectional survey** **Objective:** Collect and analyze information about ICU nurses' attitudes to EOL decisions.	-Turkey -N=155 PICU nurses -Surveys were distributed to all nurses who attended two conferences -Response rates: • First conference: 70% (n = 54) • Second conference: 28% (n = 101) -Self-administered 18-item questionnaire to measure personal and professional characteristics of nurses, and attitudes to EOL decisions • No info on V&R	-No statistically significant relationship between nurses' characteristics and their attitudes to EOL -53% of nurses reported they felt unable to help families in making critical decisions -Referring to a case study about a newborn 41% of nurses said decisions about treatment should be left to the family -Referring to a case study about a child 65% of nurses said decisions about treatment should be left to the child/family	**Strength of Design: Weak** **Quality: Low** **Key limitations:** • No data on V&R of questionnaire • Self-report • Participants limited to those who attended conference only so not generalizable
Amery, 2012 **Design: Cross-sectional online survey** **Objective:**	-Worldwide -N=346 healthcare professionals: • Doctors n=109 • Nurses n=75 • Others n=162	-Overall mean confidence score in providing palliative care to children was 3.2/5 -Respondents' mean confidence scores increased with the number of palliative children they saw per year:	**Strength of Design: Weak** **Quality: Medium** **Key limitations:** • No data on V&R of questionnaire

Study/Objective	Sample and Methods	Key Results	Conclusions
Determine educational needs of professionals who provide palliative care to children.	-All professionals who downloaded a free textbook on children's palliative care had to complete the survey before they could download the book -Respondents were asked to self-rate their confidence in 26 palliative care subject areas using a 5-point Likert scale No info on V&R	- >50 children per year 3.54/5 - 10-50 children per year 3.31/5 - <10 children per year 2.84/5 -Author reported nurses were less confident than doctors in pain control and symptom management but mean scores or p values were not provided	- Self-report - Did not control for confounding variables - Participants limited to those who downloaded book so not generalizable
Balkin et al., 2017 **Design: Uncontrolled before-after** **Objective:** To create and test a portable reference card to improve pediatric resident education in comprehensive care for children nearing end of life.	-California, USA -N= 26 first and second year pediatric residents -Pre and post intervention (6-months later) surveys: - 5-point Likert scales - Questions focused on self-reported understanding of palliative care principles and comfort in performing end-of-life symptom management - V&R not discussed -An hour-long didactic session was held at time of	-First-year residents demonstrated significant improvement in: - knowing what language to use to tell a family that their child has died (pre-score 2.64 post score 3.55; p=0.02). -Second-year residents demonstrated significant improvement in: - comfort managing symptoms other than pain at EOL (pre-score 2.53 post score 3.33; p=0.005)	**Strength of Design: Weak** **Quality: Medium** **Key Limitations:** - Single institution - Small sample size - V&R of survey not discussed

Study/Objective	Sample and Methods	Key Results	Conclusions
	card distribution which included a review of the card's content and intended use -Response rates: • Pre-intervention survey: 57% of first year residents and 82% of second year residents • Post-intervention survey: 69% of first year residents and 65^ of second year residents who completed the pre-intervention survey	• knowing the steps in performing a death examination (pre-score 2.47 post score 3.67; p=0.02) • comfort in carrying out the documentation process after death (pre-score 1.85 post score 2.93; p=0.02) • pain management knowledge (pre-score 2.80 post score 3.40; p=0.03) and comfort (pre-score 2.67 post-score 3.29; p=0.02) • comfort managing secretions (pre-score 1.93 post score 2.50; p=0.04) • comfort managing nausea/vomiting (pre-score 2.60 post score 3.29; p=0.03) -When first and second year residents were combined significant changes were noted in:	

Study/Objective	**Sample and Methods**	**Key Results**	**Conclusions**
		- response to titrating a dying patient's pain medication (pre-score 250 post score 3.12; p=0.03) - knowing what language to use to tell a family that their child has died (pre-score 2.62 post score 346; p=0.008) - secretion management knowledge (pre-score 1.96 post score 2.50; p=0.02) and comfort (pre-score 1.84 post score 2.28; p=0.04) -When asked, on a 5-point Likert scale how helpful the card was in managing patients at end of life participants reported an average of 3.92	
Banazadeh et al., 2015 **Design: Cross-sectional survey** **Objective:**	-Iran -N=151 pediatric nurses -Surveys were distributed to all nurses working in pediatric units at two hospitals	-77.5% reported they had never received education about EOL care -Providing a peaceful dignified bedside scene for family members was rated	**Strength of design: Weak** **Quality: High** **Key Strengths:** - High response rate

Study/Objective	**Sample and Methods**	**Key Results**	**Conclusions**
Determine the correlation between nurses' demographic factors and their perception of supportive behaviors in providing pediatric end-of-life care.	-Response Rate: 87.2% -Translated modified version of *The National Survey of Critical Care Nurses Regarding End-of-Life* questionnaire was used for participants to rate supportiveness of behaviors in end-of-life care • Reliability coefficient 0.91 • Validity coefficient 0.92	most supportive behavior (5.75/9) -Letting religious leader take primary care of the grieving family was rated least supportive behavior (1.08/9) -Positive association between previous education on death and dying and nurses' perception of supportive behaviors was reported but no correlation coefficient given -Nurses who had previous education on death and dying perceived supportive behaviors as more magnified (3.84/9) than did those with no previous education (2.7/9) however this was not statistically significant (p=0.05)	• Multisite
Broglio & Bookbinder, 2014 **Design: Uncontrolled before-after** **Objective:**	-USA (northeastern) -N=23 -All nurses on a general medicine unit were invited to participate -Response rate: 89% -2 participants lost to follow-up	-PCQN mean scores: • 57.6% pre-intervention • 72.2% post-intervention • 70% 3-week follow-up	**Strength of Design: Weak** **Quality: Medium** **Key Strengths:** • High response rate

Study/Objective	**Sample and Methods**	**Key Results**	**Conclusions**
Examine the impact of an online educational intervention on nurses' palliative care knowledge.	-Intervention consisted of a 30-minute online audio-recorded PowerPoint presentation - Palliative Care Quiz for Nursing (PCQN): • 20-item quiz which measures knowledge • V&R confirmed	-Statistically significant improvement between the pre-intervention and post-intervention mean scores ($p<.001$) -Statistically significant improvement between the pre-intervention and 3-week follow up mean scores ($p=.003$) -60.8% of participants stated they preferred live presentations to online training, so they could ask questions - The pre-intervention mean score (57.6%) of the PCQN indicates a deficiency in palliative care nursing knowledge.	**Key Limitations:** • Small sample size • No control group
Davies et al., 2018 **Design: Cross-sectional survey** **Objective:** Explore barriers to palliative care experienced by pediatric health care providers caring for seriously ill children.	-San Francisco, USA -N=240 health care providers • Nurses n=117 • Physicians n=81 • Others n=42 -All pediatric staff members at the San Francisco Children's Hospital were asked to respond	-54.6% of participants listed "uncertain prognosis" as a barrier that frequently/almost always occurred -51.5% of participants listed "family not ready to acknowledge incurable condition" as a barrier that frequently/almost always occurred	**Strength of design: Weak** **Quality: Medium** **Key Limitations:** • Convenience sample • Not generalizable

Study/Objective	Sample and Methods	Key Results	Conclusions
	-Self-reported questionnaire was developed by the researchers • Survey V&R were established -Response rate: 34%	-30% of respondents reported problems with communication and insufficient education in pain and palliative care as barriers.	
Dickens, 2009 **Design: Cross-sectional survey** **Objective:** Determine what factors influence healthcare provider confidence in managing eleven different end-of-life care issues.	-A single children's hospital in Western Michigan -N=157 healthcare providers • Nurses n=71 • Physicians n=45 • Others n=41 -Participants were invited by e-mail. It is estimated that 800 healthcare providers received the e-mail. -Estimated Response rate: • 10% for nurses • 45% for physicians -Survey consisted of 34 questions and used a 5-pooint Likert scale • No info on V&R	-Factors associated with higher confidence levels included: • Age (Older responders reported more confidence than their younger colleagues) (OR 3.3-26.1 on eight issues) • Male gender (OR 3.6-11.2 on five issues) • Experience (OR 2.7-4.6 on five issues) • Not being religious (OR 3.1-3.4 on three issues) -17.1% of respondents who did receive education on palliative care felt well prepared, where only 3.8% of respondents who did not receive education felt well prepared	**Strength of design: Weak** **Quality: Medium** **Key Limitations:** • Study conducted at a resource-dense institution with extremely dedicated and experienced palliative care providers. Not generalizable • Low response rate for nurses (10%) • No info on V&R

Study/Objective	**Sample and Methods**	**Key Results**	**Conclusions**
Ersek et al., 2010 **Design: Uncontrolled before-after** **Objective:** Development and evaluation of an interdisciplinary palliative care workshop in Botswana.	-Botswana, Africa -N= 47 healthcare workers (nurses, social workers, physicians, pharmacists, chaplains) -5-day workshop consisting of lectures, case studies, and group discussions -Overall workshop evaluation tool: • Likert scale -Palliative Care Self-Evaluation tool: • Likert scale • Assess participants' judgment of their knowledge and skill -Brief Test of Palliative Care Knowledge: • 20-item true/false test	- Comparison of pre-and post-workshop scores for the Palliative Care Self-Evaluation tool showed a significant increase ($p<0.001$): • mean pre-workshop score 6.7 • mean post-workshop score 8.4 -Brief Test of Palliative Care Knowledge mean scores increased modestly but significantly ($p<.001$): • Baseline 14.4 • Post-workshop 16.7	**Strength of Design: Weak** **Quality: Medium** **Key Limitations:** • V&R of tools not discussed • Small sample size
Ersek & Wood, 2008 **Design: Uncontrolled before-after** **Objective:** Describe/evaluate a computer-based palliative care curriculum for nursing assistants.	- USA (Seattle, Cleveland, Pittsburgh) -N=65 nursing assistants -EOL knowledge and confidence was assessed before and after the computer curriculum use -Participants recruited by flyers in hospitals and nursing homes.	-Mean baseline self-evaluation scores were 7.7/10. Post-curriculum self-evaluation scores increased significantly ($p<.001$) by 0.8 (8.5/10). -Significant increases were found between pre and post-knowledge exam scores ($p<.001$). The average	**Strength of design: Weak** **Quality: Medium** **Key Limitations:** • Response rate not discussed • No control group

Study/Objective	Sample and Methods	Key Results	Conclusions
	-Response rate not discussed -End-of-life care knowledge exam: • Reliability coefficient = 0.83 -Self-evaluation of EOL clinical skills: • Reliability coefficient = 0.90	percentage increase in scores was 6.5 (72.4% vs 78.9%).	
Fabro et al., 2014 **Design: Uncontrolled post-test** **Objective:** An end-of-life simulation for senior nursing students was developed, implemented, and evaluated.	-USA -N=21 nursing students -Students participated in a palliative care simulation facilitated by nursing instructors followed by a debriefing -Following the simulation students completed a reflection assignment on the experience -Both quantitative and qualitative approaches were used to evaluate student learning -Educational Practices Questionnaire: • 16-items pertaining to active learning, collaboration, diverse	-The majority of participants "agreed" or "strongly agreed" on both scales -Educational Practices Questionnaire mean scores: • active learning 4.4 • collaboration 4.7 • diverse ways of learning 4.3 • high expectations 4.6 -Student Satisfaction and Self-Confidence in Learning tool mean scores: • satisfaction of current learning 4.5 • and self-confidence in learning 4.4 -Results indicate that the students perceived that the simulation was a valuable experience	**Strength of Design: Weak** **Quality: Low** **Key Limitations:** -No data collected before the intervention -V&R of tools not discussed

Study/Objective	Sample and Methods	Key Results	Conclusions
	ways of learning, and high expectations • 5-point Likert-type scale -Student Satisfaction and Self-Confidence in Learning tool: • 13 items, • 5-point Likert-type scale	-Qualitative data revealed the most frequently identified component of a "good death" was pain control. The importance of comfort measures, creating a peaceful environment, addressing spiritual needs, and promoting family presence were also mentioned.	
Farrington, 2014 **Design: Mixed-methods uncontrolled before-after** **Objective:** Evaluate the impact of a blended (e-learning and facilitated workshops) training course on participants' understandings of and confidence in delivering end of life care in a nursing home.	-England -N=20 nursing home staff -Response rate: 29% -40% drop out rate -Intervention consisted of online component: • Six modules (1 hour each) and a workshop component: • Discussions focusing on the online content -Pre and post course self-completion questionnaires, semi-structured interviews, and participant observation. -SHA questionnaire: • Likert scale to measure confidence • V&R confirmed	-Overall average improvement in mean confidence levels was 0.8 post course (pre-course 2.8 post course 3.6) (no p value given) -Qualitative findings revealed substantial improvements in participants' knowledge of and confidence towards end of life care. Participants expressed positive opinions regarding the course's impact on their understandings of EOL care, which became both more detailed and holistic.	**Strength of design: Weak** **Quality: Low** **Key Limitations:** • Small sample size • No p values given for findings • Low response rate • High drop-out rate • No attempt to assess V & R of free text questionnaire

Study/Objective	Sample and Methods	Key Results	Conclusions
	-Free text questionnaire: • Open-ended questions • No attempt to assess V&R	-A small number of participants did report problems from the computer-based course component: • "No access to computer" • "Computer screen hurts my eyes"	
Goldonowicz et al., 2018 **Design: Uncontrolled before-after** **Objective:** Investigate the value of a novel simulation-based palliative care educational intervention within an emergency medicine residency curriculum.	-USA -N=40 medical residents -Response rate 92% -Participants attended 1-hour palliative care simulation sessions, in groups of 5–6. A 45-min debriefing session and small group discussion followed the simulation, facilitated by a trained faculty member. -Participants completed an anonymous pre/post education intervention survey: • developed by the researchers • 7-items • 0-100 (0=strongly disagree 100=strongly agree) • V&R not evaluated	-Following the intervention, participants rated the following statements higher compared with the pre-intervention survey: • The role of the emergency medicine physician in palliative care is important (pre-score 71.5, post score 76; p = 0.0003) • I feel confident in my ability to determine a patients decision-making capacity (pre-score 63.5, post score 68.5; p = 0.0005) • I feel confident with initiating palliative care discussions and treatment in the emergency	**Strength of Design: Weak** **Quality: Medium** **Key Strengths:** • High response rate **Key Limitations:** • V&R of survey not evaluated • Small sample size

Study/Objective	Sample and Methods	Key Results	Conclusions
		department (pre-score 59.5, post score 72; p < 0.0001) - Palliative care education is an important component to my residency training (pre-score 76, post score 75; p = 0.0013) - Simulation is an effective educational tool to learn palliative care skills (pre-score 54, post score 74.5; p < 0.0001) -Participants were asked what the best method of learning palliative care is (1=best 5=least): - Bedside teaching 1.55 - Small group learning 1.94 - Simulation 2.31 - Lecture format 3.42 - Online asynchronous module 4.10	
Haut et al., 2012	-Large urban hospital -Location not provided -N=25 nurses	-The educational intervention increased pediatric nurses' knowledge scores (mean	**Strength of design: Weak** **Quality: Medium**

Study/Objective	Sample and Methods	Key Results	Conclusions
Design: Uncontrolled before after **Objective:** investigate pediatric nurses' knowledge and attitudes about pediatric palliative care, and evaluate the impact of an online educational program on the attitudes and knowledge of pediatric nurses	-Response Rate: 45% -Compared knowledge and attitude scores before and after an online education program was utilized -20-item self-reported assessment using a 7-point Likert scale was used as the pretest and posttest • Validity (0.94) • Reliability (0.73 knowledge; 0.71 attitude)	difference of 0.42; p=.02) and improved attitude scores (mean difference of 0.96; p=.001) regarding palliative care	**Limitations:** • Small sample size • Pilot study
Hendricks-Ferguson et al., 2015 **Design: Phenomenology** **Objective:** Describe the perspectives and experiences of novice pediatric oncology nurses.	-3 major pediatric hospitals located in the Midwest region of the United States -N=14 nurses with less than one-year experience -Audiotaped focus group interviews were transcribed verbatim by a professional transcriptionist - Colaizzi's (1978) phenomenological 8-step method was used to analyze the data	-Participants explained a perceived tension inherent in EOL discussions among children, families, and other health care providers, identified as an "elephant in the room" -Participants identified feeling that they lacked the necessary skills to act independently, and that the process of death was unfamiliar	**Credible study** **Strengths:** • Multisite study
Jacobs et al., 2009 **Design: Uncontrolled before after**	-Country not indicated -N=169 -Response rate 80%	-Pre-course participants rated:	**Strength of design: Weak** **Quality: Low**

Study/Objective	Sample and Methods	Key Results	Conclusions
Objective: Evaluation of the End-of-Life Nursing Education Consortium (ELNEC) Pediatric Palliative Care (PPC) program.	-Nurses who attended a 2.5-day ELNEC-PPC course consisting of 10 modules that are specific to the care of children and their families facing life-limiting illness -Pre-course survey and 12-month post-course survey	- palliative care as very important to pediatric nursing (9.8/10) - their own institution as only moderately effective in caring for a dying child (6/10) - their continuing education program as minimally effective in teaching palliative care content (5.1/10) -Post course participants rated the overall helpfulness of ELNEC-PPC curriculum at 9.06/10	**Key Strengths:** - High response rate
Knapp et al., 2009 **Design: Cross-sectional survey** **Objective:** Determine pediatric nurses' knowledge of palliative care and factors that affect their knowledge**.**	-Florida, USA -Multisite -Both mailed and online surveys -N=279 nurses -Response rate 61% -Palliative care quiz for nursing (PCQN) - 20-item quiz - V & R confirmed	-Only 14% of nurses had received palliative care training in the past -Mean score on the PCQN was 10.9/20 -Previous completion of formal palliative care training significantly increased a nurse's score by 1.4 points.	**Strength of design: Weak** **Quality: High** **Strengths:** - High response rate - Multisite - Tool (PCQN) valid & reliable
Machira et al., 2013 **Design: Uncontrolled before-after**	-Kenya -N= 9 nurses: - Intervention group n=9	-At baseline, 44% of the nurses scored less than 20, and none scored more than	**Strength of Design: Weak** **Quality: Medium**

Study/Objective	Sample and Methods	Key Results	Conclusions
Objective: Evaluate the effects of an educational pain management program (PMP) on nurses' pain knowledge and attitudes in patients with terminal illness.	-Response rate: • baseline: 90% • follow-up: 100% -Intervention was 7 hours of focused education on pain management for adult patients with terminal illness, consisting of lectures, discussions, and group activities -Nurses' Knowledge and Attitudes Survey Regarding Pain (NKASRP): • Baseline (pre-intervention), immediately post-intervention and 2-week follow-up • 40-item questionnaire • Total score >30 indicates a good understanding of pain and appropriate attitude • Total score <20 indicated poor pain knowledge and attitude • V&R confirmed	30 identifying a deficit in knowledge and attitudes -The nurses who received the PMP scored significantly higher compared to baseline on the NKASRP following the PMP -Mean scores: • Baseline 18.44 out of 40 • Post intervention 28.00 out of 40 • 2-week follow up 27.56 out of 40	**Key Strengths:** • Random sampling • High response rate **Key Limitations:** • Study took place in a developing country, limiting generalizability • Small sample size

Study/Objective	Sample and Methods	Key Results	Conclusions
Milic et al., 2015 **Design: Uncontrolled before-after** **Objective:** To improve critical care nurses' skills and confidence to engage in discussions with patients' families and physicians about prognosis and goals of care by using a focused educational intervention.	California, USA -N=82 critical care nurses -Education intervention was an 8-hour workshop on communication including role-playing and a reflection session -Participants completed surveys before, immediately after, and 3 months after their workshop, rating their confidence and skill in performing key tasks. -The workshop was evaluated by using surveys of the participants and discussions with a focus group. -Response rates: • Baseline 100% • Post-workshop 98% • 3-month follow-up 52%	-Compared with before the workshop, after the workshop, nurses reported greater skill and confidence for 14 survey items (p < .001). -Increases were sustained 3 months after the workshop.	**Strength of Design: Weak** **Quality: Medium** **Key Limitations:** • Low response rate for 3-month follow-up • V&R of tools not discussed
Morita et al., 2014 **Design: Randomized controlled trial** **Objective:**	-Japan -N=76 nurses • Control n=36 • Intervention n=40 -8 participants dropped out of the study -Response rate not discussed	-There were significant intervention effects in nurse-reported confidence (p=0.003) -Group 1 confidence mean scores: • Baseline 3.6	**Strength of design: Strong** **Quality: Medium** **Key Limitations:** • Response rate not discussed

Study/Objective	Sample and Methods	Key Results	Conclusions
Determine the impact on nurses of a novel two-day education program focusing on care that addresses patients' feelings of meaninglessness.	-Confidence scale -Self-reported practice scale -Scales of nursing attitudes toward caring for patients who experience feelings of meaningless -Maslach burnout scale -Knowledge scale -Overall evaluation: • Respondents were asked to rate their overall evaluation of the usefulness of the program -Intervention consisted of a two-day interactive education program including lectures, demonstrations, role-playing, and discussions. -Wait-list control used. -Data collected at baseline, T2 and T3. -Group 1 received intervention between baseline and T2. -Group 2 received intervention between T2 and T3.	• T2 (post-intervention) 4.5 • T3 4.7 -Group 2 confidence mean scores: • Baseline 3.9 • T2 4.1 • T3 (post intervention) 4.9 -Significant intervention effects were observed in nurse-reported confidence, with effect sizes of 0.8 or more. -No significant intervention effects in practice, attitudes, burnout or knowledge. -The percentages of nurses who evaluated this program as useful or very useful were 95% (understanding the conceptual framework) and 85% (helping to learn how to provide care for patients feeling meaninglessness in clinical practice).	• V&R of some scales not discussed
Morrison et al., 2012	-USA -N=157 medical students	-Statistically significant increases in knowledge and	**Strength of Design: Strong**

Study/Objective	Sample and Methods	Key Results	Conclusions
Design: Non-randomized Controlled Trial **Objective:** Assess the impact of a multiple component educational intervention on medical students' palliative care pain knowledge and end-of-life attitudes.	• Group 1 n=68 • Group 2 n=89 -Response rate 54 % -Education intervention was approximately 8 hours consisting of a palliative care workshop, a patient experience, an online pain management module, and a reflective essay. -Knowledge and attitudes were assessed at baseline, 5.5 months (T2), and 11 months (T3) -Palliative care pain knowledge: • 15-item multiple choice • Summed total score calculated by total number answered correctly out of 15 • V&R confirmed -Palliative care attitudes: • Thanatophobia Scale seven item Likert scale • V&R confirmed -Both groups had the workshop at baseline	improvements in attitudes ($p < 0.001$) across the time points -Attitudinal improvements were seen after the workshop -Knowledge increases were seen after the patient experience, online pain module, and reflective essay -Group 1 mean attitude scores: • Baseline 4.66 • T2 5.34 • T3 5.23 -Group 1 mean knowledge scores: • Baseline 4.79 • T2 6.08 • T3 6.14 -Group 2 mean attitude scores: • Baseline 4.83 • T2 5.22 • T3 5.37 -Group 2 mean knowledge scores: • Baseline 5.21 • T2 5.51 • T3 6.94	**Quality: Medium** **Key Limitations:** • Low response rate • Participants recruited from single source • Random allocation not used

Study/Objective	Sample and Methods	Key Results	Conclusions
	-Group 1 also had the patient experience at baseline -Group 2 had the patient experience between T2 and T3		
O'Shea et al., 2017 **Design: Cross-sectional survey** **Objective:** Assess palliative and EOL educational needs of pediatric health care providers.	-Connecticut, USA -N=139 healthcare professionals • n=72 nurses -Online survey -Multiple recruitment strategies were used -Response rate not discussed -End-Of-Life Professional Caregiver Survey • 28-item survey using a 5-point Likert scale including 3 factors [patient centered care (PCC), culture/ethics (CE) & care delivery (CD)] • V & R confirmed • Higher scores on the survey reflect greater palliative and EOL skills	-46% of participants had received palliative care education in the past 5 years -Mean scores were significantly higher for participants who had received palliative care education in the past 5 years (p<0.001) -Mean scores for participants who received education: PCC 35.7, CE 22.8, CD 20.1 -Mean scores for participants who did not receive education: PCC 30.0, CE 17.6, CD 14.9 -Physicians had significantly lower scores compared with nurses on all 3 factors • Family centered care: physicians 29.2, nurses 34.4, p=.01 • Culture/ethics: physicians 16.4, nurses 21.0, p<.001	**Strength of design: Weak** **Quality: Medium** **Strengths:** • Multiple recruitment strategies **Key Limitations:** • Response rate not discussed

Study/Objective	**Sample and Methods**	**Key Results**	**Conclusions**
		• Care delivery: physicians 15.2, nurses 18.5, p=.010 -Participants would most prefer to receive palliative care education in an on-site small group seminar or as a web-based training	
Pan et al., 2018 **Design: Cluster-randomized controlled trial** **Objective:** Investigate the long-term effectiveness of two educational methods on knowledge, attitude, and practice about palliative care among nurses.	-Northern Taiwan -N=180 nurses • Experimental (multimedia) n=88 • Control (paper) n=92 -Data collected using KAP-PCCS questionnaire before education, immediately after, and 3rd and 6th month after education • V&R confirmed • Reliability ranged from .86 to .93 -Experimental group response rates: • Immediately after 100% • 3rd month 93% • 6th month 85% -Control group response rates:	-Knowledge and practice significantly increased immediately after, and at the 3rd month after education for both the experimental and control groups. -No change in attitudes for either group. -Increase in knowledge immediately (1.0-point increase; 0.7-point increase) and 3rd month after education (0.7-point increase; 0.3-point increase) was greater in the multimedia experimental group compared to traditional paper education control group (p<.001). -Increase in practice immediately (1.1-point increase; 0.7-point increase)	**Strength of design: Strong** **Quality: High** **Key Strengths:** • High response rates • Controlled for confounding variables • Good V&R of tools

Study/Objective	**Sample and Methods**	**Key Results**	**Conclusions**
	• Immediately after 100% • 3rd month 89% • 6th month 85%	and 3rd month after education (1.0-point increase; 0.6-point increase) was greater in the multimedia experimental group compared to traditional paper education control group (p<.001).	
Paneduro et al., 2014 **Design: Uncontrolled before-after** **Objective:** To develop a pain management and palliative care seminar for med students and evaluate its impact on knowledge over time.	-Toronto, Ontario -N=292 medical students • Post-test n=277 • Follow-up test n=90 -Response rates: • Post-test 95% • Follow-up test 31% -Education intervention was a 4-hour seminar which included didactic and case-based instruction and group discussions -10-item test on knowledge regarding pain and palliative care topics: • Administered before the seminar, immediately following the seminar and up to one year following the seminar	-Mean scores: • Pre-test 51% • Post-test 75% • 1-year follow-up 73% - Mean test scores at post-test and follow-up were significantly higher than pretest scores (all P<0.001) -No significant difference was observed in mean test scores between follow-up and post-test (P=0.559), indicating students retained knowledge	**Strength of Design: Weak** **Quality: Medium** **Key Limitations:** • V&R not discussed • No control group

Study/Objective	Sample and Methods	Key Results	Conclusions
	• V&R not discussed		
Pesut et al., 2015 **Design: Uncontrolled before-after (mixed method)** **Objective:** Evaluate the outcomes of an educational intervention in a palliative approach for rural nurses and health-care workers.	-British Columbia, Canada -N= 35 health care workers • Nurses n= 22 • HCWs n=13 -Palliative Care Nursing Self-Competence (PCSNC) scale: • Evaluates self-perceived competence in 10 dimensions of palliative care • 6-point Likert scale • V&R confirmed -Self-Perceived Palliative Care Knowledge instrument: • 12-item knowledge instrument using a 5-point Likert scale • V&R confirmed -No control group however participant scores were compared to normative provincial data -Response rate not discussed -5 participants dropped out -Educational intervention was delivered in a 1.5-day workshop followed by monthly 2-hour education	-HCWs had statistically significant improvements across 7 of 10 domains in self-perceived competence: • pain (p=0.044) • spiritual needs (p=0.016) • functional status (p=0.007) • ethical and legal issues (p=0.030) • inter-professional collaboration and communication (p=0.045) • personal and professional issues (p=0.002) • last hours of life (p=0.004) -No statistically significant changes in self-perceived competence in any of the 10 dimensions for nurses. However, normative comparison data suggested they were below the provincial average pre-test but were equivalent to the	**Strength of design: Weak** **Quality: Medium** **Key Limitations:** • Small sample size • Response rate not discussed

Study/Objective	Sample and Methods	Key Results	Conclusions
	sessions over a period of 4 months.	provincial average on post-test. -HCWs has statistically significant improvements across 6 of 12 domains in self-perceived knowledge: • disease management (p=0.034) • pain (p=0.020) • other physical symptoms (p=0.014) • needs related to functional status (p=0.023) • ethical and legal issues (p=0.046) • last hours of life (p=0.005) -Nurses' self-perceived knowledge showed statistically significant improvements in 3 of 12 domains: • spiritual needs (p=0.010) • ethical and legal issues (p=0.007) • personal and professional issues (p=0.008)	

Study/Objective	Sample and Methods	Key Results	Conclusions
		-Qualitative data indicated improvements in: • familiarity with the resources available for palliative care • communication among the nursing team • confidence having conversations with patients/families around palliative care	
Petersen et al., 2017 **Design: Uncontrolled before-after** **Objective:** Evaluate the impact of an online spiritual care educational program on pediatric nurses' attitudes toward and knowledge of spiritual care and their competence to provide spiritual care to children at the end of life.	-USA -N=112 nurses -All members of the Association of Pediatric Hematology/Oncology Nurses (APHON) were invited to participate -Response rate not discussed -40% attrition -Intervention consisted of a 3-hour online self-study program -Spiritual Care Competence Scale (SCCS): • Higher score indicated higher perceived level of competence	-Participants' spiritual care competence scores significantly improved after the intervention and were maintained at 3-months post intervention (p<.0005). Mean scores: • Baseline 98.3 • Post-intervention 113.18 • 3-month follow-up 115.70 -Participants' attitudes toward and knowledge of spirituality improved after the intervention and were maintained at 3-months post	**Strength of Design: Weak** **Quality: Medium** **Key limitations:** • No control group

Study/Objective	**Sample and Methods**	**Key Results**	**Conclusions**
	- V&R confirmed -Spirituality and Spiritual Care Rating Scale (SSCRS): - Explores nurses' attitudes towards and knowledge of spiritual care - V&R confirmed	intervention (p<.0005). Mean scores: - Baseline 69.58 - Post-intervention 75.45 - 3-month follow-up 75.27	
Pitman, 2013 **Design: Uncontrolled before-after** **Objective:** Evaluate the effectiveness of a self-directed learning package in increasing palliative care knowledge and confidence for aged care workers.	-Australia -N=93 aged care workers from 3 different care facilities -Pilot study -Pre- and post-package knowledge and confidence questionnaires with a 6-month follow-up. Response rates: - 36% post package - 22% at 6-month follow up -Self-directed learning package (2-hours to complete) on palliative care philosophy, pain assessment and bowel management. - Knowledge and confidence measurement tool developed by the researchers: - V&R not confirmed	-Statistically significant mean increase in knowledge (1.3-point increase; p=.003) and confidence (0.9-point increase; p=.001) after completion of the self-directed learning package. -Knowledge (2.1-point increase; p=.001) but not confidence increases were maintained after 6 months.	**Strength of design: Weak** **Quality: Medium** **Key Limitations:** - Low response rate - No control group - V&R not confirmed - Small sample size

Study/Objective	Sample and Methods	Key Results	Conclusions
Price et al., 2017 **Design: Cross-sectional survey** **Objective:** Assess nurses' perceived competency regarding palliative and EOL care to patients.	-USA -Both quantitative and qualitative data -N=583 both adult and pediatric nurses -Response rate 27% -End-Of-Life Care Questionnaire (EOLC-Q) • 5-point Likert scale and open-ended questions • V & R confirmed	-Perceived competency of EOL care was significantly higher in ICU nurses (p<0.0001). Mean scores: • Adult ICU 3.72 • Ped. ICU 3.61 • Adult Acute 3.55 • Ped. Acute 3.35 -Perceived competency sig. higher with > 10 yrs experience (p<0.0001) -ICU nurses received palliative and EOL care education in their orientation program -Qualitative data identified concerns regarding need for improved communication behaviors, decision making, and facilitation of continuity of care	**Strength of design: Weak** **Quality: Medium** **Key Limitations:** • Low response rate **Strengths:** • Large sample • Mixed methods
Wittenberg-Lyles et al., 2014 **Design: Uncontrolled post-test** **Objective:** Assess the utility of a palliative care	-Kentucky, USA -N=177 healthcare professionals: • Nurses n=105 • Physicians n=25 • Others n=47 -Response rate not discussed	- Nurses rated EOL care as the most challenging communication topic and discussion about treatment options the least challenging. -Mean scores for nurses on the post-module knowledge quizzes were: • Communication 86%	**Strength of design: Weak** **Quality: Low** **Key Limitations:** • Response rate not discussed • V&R not discussed

Study/Objective	Sample and Methods	Key Results	Conclusions
communication curriculum offered online and examine health care professionals' clinical communication experiences related to palliative care.	-Four palliative care communication online modules: • Communication • Orientation • Family • Team -Each module 50-60 mins long -Pre-module surveys and post-module evaluation knowledge quizzes • V&R not discussed	• Orientation 70% • Family 83% • Team 80% -Nurses rated/evaluated the online modules as 4.5 out of 5	• Did not measure knowledge pre-intervention • No info on participant demographics

Appendix B

Glossary of Abbreviations

ELNEC: End-Of-Life Nursing Education Consortium

EOL: End-of-life

PC: Palliative care

PPC: Pediatric palliative care

WHO: World Health Organization

Appendix II: Consultations

Consultation Report

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August 2, 2018

The purpose of this practicum project is to develop a learning resource for nurses on the medicine unit at the Janeway Children's Health and Rehabilitation Center (Janeway) to support them when providing palliative care to children. There is currently no pediatric palliative care unit in the province of Newfoundland and Labrador, therefore most children with life-threatening illnesses are admitted to the medicine unit at the Janeway for palliative and end-of-life care. As a nurse working on this unit I have often felt unprepared when providing palliative care to my patients, as palliative care is a special area of nursing and I have never received any special education or training on this topic. Learning needs were a common issue reported in the literature reviewed, and informal discussions with my coworkers indicated they feel the same way.

My goal for the consultation was to consult with my colleagues on Janeway Medicine as part of a needs assessment, to gain a better understanding of the learning needs of my co-workers. My specific objectives for the consultation were to identify the learning needs of my coworkers, identify key themes to guide the content of my resource, and identify the preferred delivery method process for my learning resource.

Sample

Six registered nurses on the medicine unit at the Janeway were consulted, three of whom were senior and three of who were novices. I chose to include both novice and senior nurses to identify any differences in learning needs amongst them. Two experts were also consulted: the clinical educator and the Janeway Association of Pediatric Hematology Oncology Nurses (APHON) coordinator. The clinical educator was consulted as I believed she would be able to provide expert opinion on learning needs, and teaching strategies, while the APHON coordinator was chosen as she is an expert on the topic of palliative care.

Recruitment and Data Collection Methods

All persons were first sent an invitation letter by email with information about the consultations. I then followed up in person at which time I verbally asked them to participate using the following script: “I would like to talk to you about your experiences with pediatric palliative care. Please see the invitation letter I have sent you by e-mail for details.” See Appendix A for the invitation letter which was provided.

Data collection consisted of individual semi-structured interviews using open-ended questions. Appendices B and C contain the questions asked of nurses and the clinical educator/APHON coordinator, respectively. They were asked about the current quality of care provided on their unit, how comfortable they were with providing palliative and end-of-life (EOL) care to children, and for recommendations for education delivery methods to facilitate learning on this topic. Interviews were approximately 20 minutes long and took place both face-to-face and over the phone, depending on the consultant’s preference. Face-to-face interviews were conducted outside of work hours at a location determined by the consultants. The interviews were not audio recorded. Field notes were collected during the interviews.

Data Management and Analysis

A descriptive approach was used. Content analysis was used to analyze data collected from the interviews. During the interviews field notes were taken (typed) on my personal laptop as collated notes. The typed field notes were shared with the practicum supervisor for verification of analysis. Participant's responses were summarized by question, and common and single responses were identified. Findings from the consultation data were compared with findings from the literature review and used to develop the learning resource.

Ethical Considerations

The checklist from the Health Research Ethics Review Board (HREB) was used to identify whether this project was research or quality improvement. It met the criteria for quality improvement and therefore did not require review by the HREB. The complete checklist can be found in Appendix D. Approval for this project was granted by the unit manager. Consultation participants were asked to verbally confirm agreement prior to beginning the interview. A numeric code was assigned to each participant to ensure that data collected was confidential and non-identifiable. Interview notes were stored, and password protected on my personal laptop which only I had access to. Participants were informed that they could stop the interview at any point, and that they could skip or refuse to answer any questions. However, none of the participants chose to skip any questions.

Results from Nurses

Results from nurses are reported below by summarizing the answers to the questions asked by topic such as quality of care currently provided, comfort with providing palliative and EOL care to children, and recommendations for education delivery methods to facilitate learning on this topic.

Current Quality of Care

When participants were asked to describe the current quality of palliative and end-of-life (EOL) care provided to patients on their unit, five of the six nurse participants identified concerns, using words such as “inadequate,” “disorganized,” “not good,” and “poor.” When asked to elaborate on why they believed the quality of care was lacking, a number of reasons were identified, such as “lack of communication between staff and families,” “inadequate pain control,” “lack of acceptance from parents,” “discomfort discussing EOL,” and “lack of knowledge regarding symptom management and recognizing when a patient has reached the EOL stage.” One participant did describe the quality of care as “pretty good,” however, it is important to note that this participant also reported never having actually cared for a patient at the EOL stage before.

Strengths.

When asked to identify the strengths of palliative and EOL care on their unit, participants identified that the nurses on their unit work well together as a team, support one another, are compassionate, put the child’s dignity first, and build good relationships with the families. Individualized patient care was also identified as a strength.

Challenges.

Challenges to providing optimal palliative and EOL care identified by participants were communication with families, communication between disciplines, patients being too young or unable to communicate, lack of a palliative care team, nurses’ lack of knowledge, nurses’ lack of experience, nurses being uncomfortable with pain management, and nurses being unable to recognize when a patient has reached the EOL stage.

Participants' Comfort Levels

Providing palliative care.

When participants were asked how comfortable they felt caring for palliative patients on their unit three participants (one experienced nurse, two novice nurses) reported feeling comfortable or fairly comfortable, two participants (one novice, one experienced) reported feeling not comfortable, and one (experienced nurse) stated that it would depend on her relationship with the patient/family.

Participants who reported feeling comfortable identified experience caring for palliative children and supportive co-workers as reasons for feeling comfortable. Participants who reported feeling uncomfortable identified lack of formal training/education, lack of experience, and difficult families as reasons for feeling uncomfortable. When asked what would make them feel more comfortable, participants stated formal education/training, experience, and better communication between the nurses, families and physicians.

Determining the EOL stage.

When participants were asked how comfortable they felt determining when a patient has reached the EOL stage, three participants (two novice nurses, one experienced nurse) identified feeling uncomfortable, while one participant (experienced nurse) stated she would be comfortable as long as the parents were "on the same page."

Participants who reported being uncomfortable with the EOL stage reported this was due to never having received training or education on the topic and lack of experience. One participant stated, “I’ve never had that experience before; I really wouldn’t even know what signs to look for.”

Controlling pain.

When participants were asked how comfortable they were with controlling pain for palliative patients, five out of six participants reported being comfortable (3 novice nurses, 2 experienced nurses). However, they all voiced concerns regarding the availability of a doctor’s order for pain medications. For example, one participant stated “I am fine with controlling pain, it’s just a matter of which orders are there. If there is nothing ordered for pain, then I can’t give it. Sometimes it’s like the doctors don’t trust the nurses’ judgement. We call them saying we need more pain meds ordered and they are reluctant to give more. I’m not sure why.”

One participant (experienced nurse) reported being uncomfortable with controlling pain for palliative patients, stating she has trouble determining when a child who cannot communicate is in pain. This participant stated that more education on ways to identify pain in young children would improve her comfort with pain management.

Managing symptoms.

All participants reported being uncomfortable both identifying and managing the following symptoms: secretions, seizure, and massive hemorrhage. Three participants reported being uncomfortable with sedation, three participants reported being uncomfortable with dyspnea and one participant reported discomfort with confusion/delirium. Participants identified both lack of experience and education as reasons for being uncomfortable with these symptoms. When participants were asked what they would need to feel more comfortable, experience and education were identified. Specifically, one participant stated "There needs to be a hand book or a guide or something that is well laid out and says this is the symptom, this is how you manage it, both pharmacological and non-pharmacological methods. Who to call and when to call and stuff like that." Similarly, another participant stated, "We need a resource we can refer to when they symptoms are happening, and you don't know what to do or how to treat them."

Discussing EOL care with patients and families.

Three participants stated they were very uncomfortable discussing EOL with patients and their families, two participants stated they were somewhat uncomfortable, and one participant stated she was comfortable with families she knows/has built a relationship with but was uncomfortable with new families. Specifically, participants identified being uncomfortable discussing death with children and their families due to not knowing what to say, or fear of saying the wrong thing or them getting upset and/or angry. "Every family is different and copes differently. If you don't know a family and what they like, it's hard to know what to say because you don't want to upset them or make it worse". When participants were asked what they would need to feel more comfortable they identified a need for more education and more experience. Having specific strategies of what to say when or working through case scenarios were education strategies suggested by one participant.

Discussing EOL with colleagues and other team members.

Four participants reported feeling comfortable stating “everyone on the unit is open and accepting” and “as a team we are able to discuss this fairly well amongst each other”. One participant reported feeling “mediocre” stating “some colleagues are helpful and kind while others make you feel stupid or inadequate if you don’t know how to do something.” One participant reported feeling very comfortable discussing EOL with her fellow nurses, however stated she is less comfortable with the physicians as they can be intimidating and hard to approach.

Education

Palliative and EOL care.

All participants believed that they could use more education on palliative care and on identifying when a patient has reached the EOL stage. When asked who else they believed could use education on palliative and EOL care all participants stated “everyone” referring to all health care professionals on their unit who care for palliative patients. When asked specifically if patients and their families could benefit from education participants agreed that they would, however one participant stated “This isn’t really a nursing responsibility. Doctors should give education and we will be more of a supportive role.” None of the participants knew of any educational materials presently available for patients and their families, but all agreed that something of the sort would be useful as long as a discussion with the physician would accompany the resource. “As long as there was a discussion to go with it, we can’t just give them a book. If there was something we could give to them after having a conversation like here’s a book for you to keep so you know what to look out for, then I think that would be helpful. As long as there is a discussion in there somewhere.”

Specific topics.

When participants were asked specifically which topics they would like more education on, suggestions included communication such as discussing palliative and EOL care with patients and their families, pain medications and dosing, management and treatment of symptoms (particularly secretions at EOL), how to handle disagreements between physicians and parents regarding treatment plans, comfort measures that are non-pharmacologic, signs and symptoms to identify when death is coming, and what to expect as death gets closer.

Delivery methods.

Participants were asked what types of education delivery methods they thought would best facilitate their learning on this topic. Three participants stated a self-learning module would be helpful, while the other three participants stated they would not find it helpful. For example, one participant stated “self-modules are helpful, I enjoy learning on my own time on computers” while another participant stated, “something like this needs to be discussed and personally, the self-modules I’ve done I usually forget them after I read them.” Four participants stated that they believed case studies would be helpful, while two stated they did not. Only one participant believed that role playing exercises would facilitate learning on this topic. The rest of the participants stated things like “I don’t know how seriously people take role playing” and “I forget it all if I don’t have the information somewhere to refer to afterwards.” All participants agreed that discussions and self-quizzes would be beneficial to facilitate learning on this topic.

Learning Resource

All participants agreed that a learning resource such as a binder would be useful for providing information on palliative and EOL care. Participants were asked how/when the binder would be used, for example, to look up info on a specific topic as needed, or to learn about the topic in general (not as a response to a problem). Four participants stated the binder would be used both as needed and to learn about the topic in general. For example, one participant stated, “It would be great to have something to run to during a situation, but I would also read it during down time on the unit to learn about the topic in general.” Two participants stated it would be used only as needed due to time constraints, stating “I don’t always have an hour to sit on the unit and read an entire binder but in the moment, I would use it.”

Results from Experts

Results from experts are reported below by summarizing the answers to the questions asked by topic such as the most common questions/concerns from staff, care delivery, and recommendations for education delivery on this topic.

Questions/Concerns

When the experts were asked about the most common questions and concerns they receive from staff regarding palliative and EOL care, both experts discussed pharmacological management of symptoms, and communication. Specifically, both experts had received questions surrounding which medications should be given for particular symptoms, and which doses and routes are recommended. They both also described receiving many questions surrounding knowing what to say to patients and their families at EOL.

One expert received questions from stuff surrounding the legal documentation required at the time of death, while the other expert received questions from staff surrounding who needs to be present at the time of death, in regard to calling in the physician and/or the medical resident.

Care Delivery

Optimal care.

When asked to describe optimal palliative and EOL care both experts discussed all symptoms being controlled so that the patient is not suffering unnecessarily, specifically symptoms being controlled at EOL in order to give them the best death possible. One expert also discussed improving the patient's quality of life, and aiming to fulfill the patient's hopes, goals, wishes, and desires to make the best of his or her last days or weeks.

When asked what is required of staff to provide optimal palliative and EOL care both experts discussed an interdisciplinary approach and clear communication between all staff members. One expert also stated that “staff need an in-depth knowledge of symptom management, and complimentary therapies.” Good teamwork, maintaining a professional relationship with the patients and their families, and self-awareness of one’s own thoughts and beliefs were all mentioned as well.

Challenges.

Both experts identified communication amongst the multidisciplinary team members as a challenge to providing optimal palliative and EOL care. One expert also discussed ethical dilemmas as a major challenge, stating “sometimes the nurses feel that they are enhancing the patient’s suffering because the family may not be accepting of the child’s current condition and may be advocating on more aggressive treatments.” Knowing which medications to use and when to use them, identifying when a patient has reached the EOL stage, busy unit/heavy workload, and self-care for staff were also mentioned as challenges.

Strengths.

Both experts identified the nursing staff as a strength on the unit, stating they “have a strong desire to do their best for each and every patient” and “staff have excellent relationships with the families and do whatever they can to meet their needs.” One expert also stated that the staff does a good job at involving the families in the plan of care, keeping them well informed, and allowing them to make decisions. It was also mentioned that the staff is respectful of the patient/family's wishes. One expert identified good teamwork amongst the nursing staff while the other expert identified the multidisciplinary team as a strength, stating "each team member is quite strong with lots of knowledge."

Education Delivery

Target learners.

Both experts agreed that all nurses could benefit from more education on palliative and EOL care, stating that nurses, both novice and senior, have voiced being uncomfortable with this topic. One expert stated, "this is such a big topic, you could do a full course on this and still not know everything you want to know and although senior nurses have more experience they've only received the same formal education as the newer nurses" while the other expert stated "as more evidence-informed knowledge becomes available staff need to be aware of that." One expert also stated that she believed not only nurses, but all disciplines could use more education on the topic stating "everyone can always benefit from more education."

Specific topics.

When asked about specific topics related to palliative and EOL care to focus education on, the experts suggested symptom management, communication, difference between palliative and EOL care, and knowledge of supports in the communities.

Education delivery methods.

Both experts stated that in the past staff have not been engaged in self-learning modules. Both agreed that role playing, case studies, and group discussions would be helpful for learning on this topic. One expert liked the idea of self-quizzes stating they are a good way for learners to identify their understanding and what they need to learn, while the other expert stated that in the past staff have not used the self-quizzes on this topic that were available to them.

When asked about a learning resource such as a binder kept at the nursing desk both experts agreed it would be useful for providing information on palliative / end-of-life care to nurses. Both experts believed that the binder would mostly be used on a need to know basis, for example “if something came up, for example a palliative patient was in pain, the nurse could flip to that section of the binder to look up different ways to manage it.” One expert stated that the binder would have to be user friendly, easy to read, and clearly labelled with tabs.

Conclusion

Results from the consultations clearly indicate that the participants have a learning need for information on palliative and EOL care. Identified key topics to guide the content of my resource were communication, symptom management and treatment, and what to expect at the EOL stage. Although participants had mixed feelings on self-learning modules, all participants did believe that a learning resource such as a binder kept at the nursing station would be a useful tool and would help facilitate their learning. It was clear that participants also believed discussions and self-quizzes would facilitate their learning on this topic.

Appendix A

Invitation Letter

Dear potential participant,

As part of the requirements for completion of my Master of Nursing degree at Memorial University of Newfoundland, I am developing a learning resource on pediatric palliative care for nurses. This learning resource will provide nurses at the Janeway with education on both palliative and end-of-life care. I have completed a literature review on pediatric palliative care to identify relevant educational topics and am now looking to speak with both novice and experienced pediatric nurses to further identify educational needs.

I am inviting you to share your experiences on providing palliative care to children. I would appreciate the opportunity to meet with you either face to face or over the phone, for approximately 20 minutes, to discuss your views on pediatric palliative care. By sharing your professional experience in working with palliative children and their families, you will contribute to improving the quality of palliative care provided to children and their families at the Janeway.

If you agree to participate, you may refuse to answer any questions asked or end the interview at any time. All information collected is confidential and will be stored under password protection on my personal laptop until this project is complete, and then it will be destroyed. Only myself, and my practicum supervisor, Dr. Donna Moralejo will have access to any information you provide.

If you have any questions regarding this project or your role as a participant, please contact Sarah Lewis, BNRN, at (709)771-4549 or via email at snl456@mun.ca.

Thank-you,

Sarah Lewis, BN RN

Appendix B

Open-ended questions to ask novice/experienced nurses during interviews

1. How would you describe the current quality of palliative and EOL care provided to patients on your unit?
2. What do you believe are the strengths of palliative and EOL care on your unit?
3. What do you believe are the challenges of providing optimal palliative and EOL care on your unit?
4. How comfortable do you feel caring for palliative patients on your unit?

Probes:

- Why do you feel that is?
- What are you comfortable/not comfortable with?
- What would you need to feel more comfortable?

5. How comfortable are you with controlling pain for palliative patients?

Probes:

- Why do you feel that is?
- What are you comfortable/not comfortable with?
- What would you need to feel more comfortable?

6. How comfortable are you with symptom management for palliative patients?

Probes:

- Why do you feel that is?
- What are you comfortable/not comfortable with?
- What would you need to feel more comfortable?

7. How comfortable are you discussing care surrounding end of life with patients and their families?

Probes:

- Why do you feel that is?
- What are you comfortable/not comfortable with?
- What would you need to feel more comfortable?

8. How comfortable are you discussing care surrounding end of life with your colleagues and the other team members?

Probes:

- Why do you feel that is?
- What are you comfortable/not comfortable with?
- What would you need to feel more comfortable?

9. Do you believe you could use more education on palliative care?
10. Which specific topics surrounding palliative care would you like more information on?
11. Do you think a learning resource such as a binder kept on the nursing unit would be useful for providing information on palliative and end of life care?

Probes:

- How/when would you use the binder? For example, would you look up info on a specific topic as needed, or to learn about the topic in general (not as a response to a problem)?

12. What types of education delivery methods do you think would best facilitate your

learning on this topic?

Probes: Do you think the following would be helpful:

- Self-learning module
- Case studies
- Role playing exercises
- Discussions
- Self-quiz

13. Who do you think would most benefit from education on this topic?

Appendix C

Open-ended questions to ask nurse educator/APHON coordinator during interviews

1. What are the most common questions you get asked regarding palliative care?
2. What are the most common issues you see regarding palliative care?
3. How would you describe optimal palliative care? What is required for a patient to receive optimal palliative care?
4. What do you believe are the common challenges of providing optimal palliative and EOL care on the unit?
5. What do you believe are the common strengths of providing palliative and EOL care on the unit?
4. Do you believe the nurses on the unit could use more education on palliative care? Why or why not?
5. Which specific topics surrounding palliative care do you think the nurses could use more information on?
6. Do you think a learning resource such as a binder kept on the nursing unit would be useful for providing information on palliative and end of life care to nurses?

Probes:

- How/when would the nurses use the binder? For example, to look up info on a specific topic as needed, or to learn about the topic in general (not as a response to a problem)?

7. What types of education delivery methods do you think would best facilitate learning on this topic?

Probes: Do you think the following would be helpful:

- Self-learning module
- Case studies
- Role playing exercises
- Discussions
- Self-quiz

8. Who do you think would most benefit from education on this topic?

Appendix D
Health Research Ethics Authority Screening Tool

	Question	Yes	No
1.	Is the project funded by, or being submitted to, a research funding agency for a research grant or award that requires research ethics review	☐	■
2.	Are there any local policies which require this project to undergo review by a Research Ethics Board?	☐	■
	IF YES to either of the above, the project should be submitted to a Research Ethics Board. **IF NO** to both questions, continue to complete the checklist.	☐	☐
3.	Is the primary purpose of the project to contribute to the growing body of knowledge regarding health and/or health systems that are generally accessible through academic literature?	■	☐
4.	Is the project designed to answer a specific research question or to test an explicit hypothesis?	☐	■
5.	Does the project involve a comparison of multiple sites, control sites, and/or control groups?	☐	■
6.	Is the project design and methodology adequate to support generalizations that go beyond the particular population the sample is being drawn from?	☐	■
7.	Does the project impose any additional burdens on participants beyond what would be expected through a typically expected course of care or role expectations?	☐	■
LINE A: SUBTOTAL Questions 3 through 7 = (Count the # of Yes responses)		1	
8.	Are many of the participants in the project also likely to be among those who might potentially benefit from the result of the project as it proceeds?	■	☐
9.	Is the project intended to define a best practice within your organization or practice?	■	☐
10.	Would the project still be done at your site, even if there were no opportunity to publish the results or if the results might not be applicable anywhere else?	■	☐
11.	Does the statement of purpose of the project refer explicitly to the features of a particular program, Organization, or region, rather than using more general terminology such as rural vs. urban populations?	■	☐
12.	Is the current project part of a continuous process of gathering or monitoring data within an organization?		No
LINE B: SUBTOTAL Questions 8 through 12 = (Count the # of Yes responses)		4	
	SUMMARY A=1 B=4 **See Interpretation Below**		

Interpretation:

If the sum of Line B is greater than Line A, the most probable purpose is **quality/evaluation**. Proceed with locally relevant process for ethics review (may not necessarily involve an REB).

This project does not require review by REB.

These guidelines are used at Memorial University of Newfoundland and were adapted from ALBERTA RESEARCH ETHICS COMMUNITY CONSENSUS INITIATIVE (ARECCI). Further information can be found at: http://www.hrea.ca/Ethics-Review-Required.aspx.

Appendix III: Environmental Scan

Environmental Scan Report

Sarah N. Knox

Memorial University of Newfoundland

April 7, 2019

The purpose of this practicum project is to develop a learning resource for nurses on the medicine unit at the Janeway Children's Health and Rehabilitation Center (Janeway) to support them when providing palliative care to children. There is currently no pediatric palliative care unit in the province of Newfoundland and Labrador, therefore most children with life-threatening illnesses are admitted to the medicine unit at the Janeway for palliative and end-of-life care. As a nurse working on this unit, I have often felt unprepared when providing palliative care to my patients, as palliative care is a special area of nursing and I have never received any special education or training on this topic.

My goal for the environmental scan was to determine what resources are already available on the topic of pediatric palliative care and whether they might be used or adapted to educate nurses at the Janeway. Before conducting the environmental scan, I revisited the literature review and the consultations conducted in N6660. The literature review did not reveal anything new however the consultations revealed two resources for me to find. My plan for the environmental scan was to go back and find the resources mentioned in the consultations, as well as identify any learning resources that are currently being used in similar settings at other hospitals in eastern Canada on the topic of pediatric palliative care.

Data Collection

Data collection consisted of four approaches: (1) viewing specific targeted websites, (2) following up on the resources discussed by consultants during interviews, (3) conducting a general Google search using the search terms "pediatric," "palliative care," and "resource," and (4) contacting nurse educators and clinical nurse specialists for targeted clinical sites. The targeted websites were the Association of Pediatric Hematology Oncology Nurses (APHON), Children's Oncology Group, Canadian Network of Palliative Care for Children, Canadian Hospice Palliative Care Association and Canadian Virtual Hospice, along with the websites for children's hospitals across eastern Canada: IWK Health Centre (IWK), Children's Hospital of Eastern Ontario (CHEO), Montreal Children's Hospital (MCH), The Hospital for Sick Children (SickKids), and CHU Sainte-Justine. The targeted clinical sites were IWK Health Centre, CHEO, MCH, SickKids, and CHU Sainte-Justine.

On January 11, 2019 I sent an e-mail (Appendix A) to the nurse manager of learning and development at IWK, the director of nursing practice at CHEO, the palliative care nurse specialist at MCH, the nursing education department at SickKids, and the clinical nurse specialist for pediatric palliative care at CHU Sainte-Justine.

Results

Unfortunately, none of the targeted websites mentioned above contained any learning resources suitable for use for this project.

Following up on the resources discussed by consultants during interviews led me to two resources: Pediatric Palliative Care & End-of-Life Issues (APHON, 2012), and Towards an Understanding of the Final Days of Life (Eastern Health, 2011). Although the second resource was not created for pediatrics, much of the information is applicable to children. See table 1 for more information on these resources.

The Google search resulted in four resources on palliative care which I believe will be useful for this project: A Practical Guide to Palliative Care in Paediatrics (Children's Health Queensland Hospital and Health Service, 2014), Beating Pain (African Palliative Care Association, 2010), B.C. Inter-Professional Palliative Symptom Management Guidelines (BC Centre for Palliative Care, 2017), and End-of-Life Care for Children (Texas Cancer Council, 2000). Although two of the resources were created for adults, much of the content is also applicable to children. The other two resources were pediatric specific and contain much important information on pediatric palliative care. See table 1 for more information on these resources.

I received a response from three of the five nurses whom I contacted. Two of the responding nurses provided me with information on staff training in their hospitals, however they did not have any learning resources to share.

The palliative care nurse specialist at Montreal Children's Hospital provided me (via e-mail) with multiple palliative care resources which they use at MCH, such as, a caring for the family of a child at end-of-life checklist, (Proulx, 2015), Interventions for when a Child is Dying in the Hospital (Proulx, 2011), Memory Box (Ouellet, 2016), A Dying Baby (MCH, 2018), Pediatric Pain and Symptom Management Guidelines (Hauer, Duncan, & Fowler Scullion, 2014), Guidelines for Assessment and Management of Nausea and Vomiting (Fowler Scullion, Lynch, Nabati, & Abraham, 2014), Pain Management Tables and Guidelines (Kematick et al., 2017), and Bereavement Debriefing Sessions (Keene, Hutton, Hall, & Rushton, 2010). See table 1 for more information on these resources. She also informed me that every nurse who works at MCH has special training in palliative care as part of their orientation. Additionally, they have a palliative care team who manage all palliative care children regardless of which unit they are admitted to.

Table 1. Resources

Resource	Overview	Usefulness
Pediatric Palliative Care & End-of-Life Issues	APHON PowerPoint presentation on pediatric palliative and end-of-life care	• Pediatric specific content and facts
Towards an Understanding of the Final Days of Life	Eastern Health pamphlet for families of dying patients	• Information on what to expect during the final hours Note: Developed for adults but applicable to children
A Practical Guide to Palliative Care in Paediatrics	Education resource for clinicians caring for palliative children with both cancer and non-cancer conditions	• Content for all modules • Model for layout • Ideas for tables and figures
Beating Pain	Pocket guide for pain management in Africa (both adults and children)	• Content on pain (physiology, assessment, management) • Pediatric specific considerations
B.C. Inter-Professional Palliative Symptom Management Guidelines	Guidelines for clinicians, physicians, nurses and allied health staff involved in palliative care	• Content for symptom management module • Model for layout • Ideas for tables and figures Note: developed for adults but applicable to children
End-of-Life Care for Children	Booklet developed to bridge the gap between aggressive treatment and palliative care	Content about: • physical care for the child at end-of-life • providing support to families • talking about death • supporting professionals caring for dying children
Caring for the family of a child at end-of-life	A checklist of nursing interventions for when a child is dying	• Content for end-of-life module

Resource	Overview	Usefulness
Interventions for when a Child is Dying in the Hospital	Nursing interventions for before, during and after death	• Content for end-of-life module
A Dying Baby	MCH NICU death guidelines	• Content for end-of-life module
Pediatric Pain and Symptom Management Guidelines	MCH guidelines for pain and symptom management in palliative care children	• Content for pain and symptom management modules • Model for medication tables
Guidelines for Assessment and Management of Nausea and Vomiting	MCH guidelines for management of nausea and vomiting in palliative care children	• Content for management of nausea and vomiting
Pain Management Tables and Guidelines	MCH guidelines for pain management in palliative care children	• Content for pain module • Model for medication tables • Assessment tools (Numerical Rating Scale, Visual Analogue Scale, Faces Scale, Neonatal Infant Pain Scale, and FLACC) • Algorithm for when to give Naloxone
Bereavement Debriefing Sessions	Journal article on an intervention to support health care professionals in managing their grief after the death of a patient	• Content for end-of-life module

Conclusion

None of the resources discovered from this environmental scan were suitable for direct use or adaptation for this practicum project. However, they will all be used to draw on ideas for the development of my learning resource such as, content for the modules, ideas for organization, layout, and user friendliness, models for creating tables and algorithms. See table 1 for more information on specific ideas that were taken from each resource.

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Appendix A

Invitation Letter

Hello,

As part of the requirements for completion of my Master of Nursing degree at Memorial University of Newfoundland, for my practicum project I am developing a learning resource on pediatric palliative care for nurses. This learning resource will provide nurses at the Janeway Children's Health and Rehabilitation Centre with education on both palliative and end-of-life care. I have completed a literature review on pediatric palliative care and am now conducting an environmental scan to determine what resources are already available on this topic or are being used in similar settings in other hospitals in Canada.

I am writing you to inquire about any education or training that is provided to nurses in your hospital on the topic of palliative and end-of-life care. Is there a particular learning resource which is used to educate nurses in your hospital on this topic? If so, would you be willing to share the learning resource with me for my review? Any resources would only be shared with my practicum supervisor at this time. Once I have completed my review, I would follow up with you should I wish to adopt or adapt any suitable resources for use in my practicum project.

I look forward to hearing back from you. Should you prefer to discuss this by phone please let me know and we can arrange a phone call via email.

Thank-you,

Sarah Knox, BN RN

Appendix IV: Learning Resource

Learning Resource for Pediatric Palliative Care

Developed by: Sarah Knox

May 2019

Pediatric Palliative Care

Palliative care is defined as an approach of medical and nursing care which focuses on improving the quality of life of patients with life-threatening illnesses[1]. The World Health Organization (WHO) has identified pediatric palliative care as a special field of palliative care which focuses on total care of a child's body, mind and spirit, and also involves supporting the child's family.

Pediatric palliative care begins the moment a child is diagnosed with a life-threatening illness and continues until end-of-life (EOL), regardless of whether or not the child is receiving treatment for the illness[1].

Nurses who work with children requiring palliative care, referred to in this resource as *palliative care children*, must be educated and well prepared to provide patients and their families with the highest quality of care.

The purpose of this learning resource is to provide information about palliative and EOL care for pediatric patients. This resource can be used by registered nurses (RNs), licensed practical nurses (LPNs), and any other healthcare professionals who care for palliative care children. This resource may also be beneficial for anyone who simply wants to learn more on this topic.

Although this learning resource offers information for children of various ages and a variety of different palliative care illnesses, it is important to note that every clinical situation is unique, and that all children require an individualized approach[2].

This resource consists of four separate self-learning modules:
Module 1: Communication
Module 2: Pain
Module 3: Symptom Management
Module 4: End-of-Life

Each module can be used separately or in sequence depending on the purpose of use.

This resource can be used in two ways depending on the learner's needs:
1. As a self-learning module to learn more details about palliative care in a systematic way.
2. As a quick guide to look up specific palliative care information for in-the-moment learning.

A table of contents is located at the beginning of each module to assist with using the resource as a quick guide for in-the-moment learning.

Each module contains features to help present information so that it is easy to read, e.g., bullet points and tables, and easy to apply, e.g., key information, documentation tips, tools for practice, and EOL considerations.

The green text boxes contain special notes and key information.

Documentation
The blue text boxes contain information pertaining to documentation.

The purple text boxes contain mnemonics and tools for practice

EOL
The orange text boxes contain end-of-life considerations.

Each module also contains features to help promote reflection and learning, e.g., reflection exercises, case studies, and self-tests. Learning objectives are also located at the beginning of each module.

Reflection Exercise
The yellow text boxes contain refection exercises which encourage the learner to reflect on their own clinical experiences and apply new knowledge.

Case Study/Test Your Knowledge
The grey text boxes contain case studies, true/false, matching, and short answer questions.

Reviewing the material presented in this resource can help improve the learner's knowledge, skills, and confidence, ultimately improving the care that palliative children and their families receive at the Janeway Children's Health and Rehabilitation Centre.

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References

1. World Health Organization. (2018). WHO definition of palliative care. Retrieved from: www.who.int

2. Children’s Health Queensland Hospital and Health Service. (2014). A practical guide to palliative care in paediatrics. Retrieved from: www.health.qld.gov.au

Learning Resource for Pediatric Palliative Care

Module 1: Communication

Developed by: Sarah Knox

May 2019

Module 1: Communication

The purpose of this module is to provide information about communication with palliative care children and their families. This module can be used by registered nurses (RNs), licensed practical nurses (LPNs), and any other healthcare professionals who care for palliative care children. This module may also be beneficial for anyone who simply wants to learn more on this topic.

This module contains information, reflection exercises, case studies, documentation tips, tools for practice, and self-tests.

Learning Objectives:

Upon completion of this module, you will be able to:

1. Communicate effectively with patients and their families using the principles of good communication;
2. Discuss death and dying with palliative care children in an age appropriate way;
3. Recognize developmental considerations for communicating with children of various ages and implement appropriate nursing interventions accordingly;
4. Identify different family communication systems and implement appropriate nursing interventions to facilitate healthy communication; and
5. Document appropriately any significant conversations with patients and or their families on topics such as death or dying.

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Principles of Good Communication

Talking about death and dying with palliative care children and their families is never easy. It can be difficult to know how to approach it and what to say. However, good communication is essential to the nurse-patient relationship. Good communication allows the child and their family to talk openly about their feelings, fears and concerns, and can also be seen as a type of therapy[1].

General communication tips for health care provides[1]:

- Allow the patient to express their emotions
- Be aware of and respect the patient's ethnic, cultural and religious background
- Notice non-verbal communication such as facial expressions
- Allow the patient and family to ask questions
- Foster a non-judgmental attitude: treat people with respect and dignity and avoid criticizing them
- Respect confidentiality: every patient has a right to confidentiality and should feel secure as they communicate

There are some basic communication skills which can be helpful in any situation when communicating with patients and their families. See the table below.

Skill	Description
Active Listening[1]	Give the patient your full attention. Do not rush the patient. Pay attention to verbal and non-verbal messages that patient is communicating[1].
Check understanding[1]	Use paraphrasing, summarizing and reflecting to ensure you understand what the patient is trying to tell you[1].
Ask open-ended questions[1]	Ask questions to get information, assess knowledge, and understand the patient's thoughts and feelings. Use mainly open-ended questions, which invite the patient to talk and explain[1]. Use closed-ended questions only when necessary to obtain facts and not knowledge of feelings[1]. Avoid leading questions which suggest a preferred answer, for example "I know you are feeling a lot of pain, aren't you?"

A useful mnemonic to promote active listening is **ROLES**[1]:

Relax: do not rush the patient
Openness: be open and non-judgmental
Lean forward: lean in towards the patient
Eye contact: make eye contact with the patient
Sit near: sit down close to the patient

Effective communication:
- Is the foundation of the relationship between the nurse and the patient
- Provides basis for understanding the patient's perspective
- Generates trust between the nurse and the patient
- Provides professional satisfaction for the nurse

Communication between the nurse and the patient and/or the patient's family is effective when:
- The nurse has a good understanding of the patient's and/or family's perspective
- The patient and/or family has a good understanding of what the nurse has told them

Reflection Exercise

Think of the last conversation you had with a patient and/or a patient's family. Did you employ any of the basic communication skills listed above? If so, which ones? Are there any other skills you could have used? Was the communication effective? Was there anything you could have done to facilitate better communication?

Discussing Death with Children

Talking about death with children is difficult. However, communicating openly and honestly with children about death is important for many reasons.

Discussing death openly with children:
- Provides a sense of trust and confidence
- Allows them to express their feelings and concerns
- Relieves any sense of isolation
- Gives them the strength to cope with death
- Allows them to feel, express, and come to terms with emotions surrounding death

Note: Children are often more aware of their prognosis than adults realize. Changes in their bodies and their parents' emotions and behaviors give them clues.

Four principles for discussing death with a child[2]:

1. Begin on the child's level:
   - Consider the child's developmental stage
   - Begin with the child's experiences "You've told me you've been feeling really tired lately"

2. Let the child's questions guide the discussion:
   - Begin the conversation with basic information

  - Take cues from the child and let the child guide the discussion
  - Answer the child's questions about dying with calm, sensitive, truthful answers
  - If you do not know the answer, be honest about this and tell the child you will find out[1]

3. Allow the child to express their feelings:
   - Accept whatever emotion the child expresses
   - Use art, games, play, and music to allow expression of emotions

4. Ensure understanding:
   - Ask the child to summarize what has been said
   - Clarify any misunderstandings

There is no single approach for discussing death with children. Additional tips for nurses to promote healthy communication are:

- Provide literal explanations that distinguish fact from fantasy[2]
- Consider the child's developmental level; see section below on developmental considerations
- Use words the child is familiar with
- Modify explanations according to the child's understanding[2]
- Be clear that with death life stops, and death is irreversible[2]
- Use words like "die" and "dead[2]"
- Do not use words like "lost," "pass away," "sleeping," or "going on a long journey[2]"

Common topics for discussion with dying children[2]:

- Why treatment is being discontinued
- Death is part of the natural life cycle
- The family's spiritual belief of what happens after death
- The child will not be alone during death
- The child's life has had an impact on the life of others
- It is normal and okay to cry and feel sad
- It is normal and okay to feel angry
- If the child has any pain the health care team will do everything possible to relieve it
- Death itself will not hurt, and any pain will end

Reflection Exercise

Have you ever been included in a conversation with a palliative care child about death? Was the topic of death discussed openly? Who led the conversation? Which topics were discussed? How did the conversation make you feel? What could have been done differently?

Spirituality

Religion and spirituality are common topics when discussing death. The nurse should set aside his or her own spiritual and religious beliefs to support the child's beliefs. The nurse can provide basic spiritual support to the child and their family by simply listening to their fears and concerns, and by praying with them as appropriate and as requested[1]. Sometimes other more specialist support may be needed, such as specific rituals relating to their religion, or in-depth spiritual counselling[1].

Developmental Considerations

A child's age and cognitive development greatly impacts their understanding of death and dying. There are general considerations for nurses caring for children according to their age.

Characteristics[2]	**Nursing Interventions**[2]
Infancy and Toddlerhood (0-2 years):	
• Begins to develop trust in parents • Separation from parents is primary fear • No concept of death or dying • Influenced by the emotions of others, reacting as they see their family react • Hospitalization is extremely stressful	• Encourage parents to stay with the child as often as possible • If parents are not available, encourage them to find a consistent familiar adult to stay with the child • Encourage the family to maintain familiar routines • Encourage regular play activities
Early Childhood (3-5 years):	
• Begins to develop a conscience • Enjoys making decisions and expressing themselves • Enjoys self-sufficiency • World is viewed in terms of good or bad • Magical thinking leads them to believe they have a direct impact on the events in their lives • Death may be viewed as temporary or reversible • Illness and separation from parents may be viewed as a punishment • May develop feelings of guilt and responsibility for illness • May regress behaviorally in an attempt to feel secure	• Assure the child that they are not being punished • Provide honest explanations of the illness and treatments in terms the child will understand • Minimize separation from parents • Provide ways for the child to express their emotions for example, drawings and play

Characteristics[2]	**Nursing Interventions**[2]
Middle Childhood (6-9 years):	
• Peers are important • Returns to the security of home and family for comfort • Feelings of independence, self-confidence, and individuality begin to develop • Every act is thought to have either a punishment or reward • Hospitalization or illness may be viewed as a punishment • May display feelings of anger or confusion • May blame parents for the illness	• Provide child with concrete truthful details about their illness • Maintain interactions with friends • Minimize separation from parents • Involve the child in planning or carrying out treatment procedures when possible
Late Childhood (10-12 years):	
• Body-image, self-esteem and identity begins to develop • Peers are important • Privacy is extremely important • Wants more independence from parents • Realistic view of death as inevitable and permanent • May struggle with wanting to separate from parents and natural tendency to regress due to illness • Concerned about how illness will affect appearance	• Allow the child to be involved in decision-making regarding treatment • Encourage to share feelings and ask questions • Provide clear, honest, direct communication • Allow as much control and independency as possible • Encourage association with friends • Provide privacy
Teens (13-18 years):	
• Identity, self-esteem, and body image continues to develop • Sexual identity is being formed • Seeks independence from parents • An adult understanding of death exists however teens may believe they are invincible • Concerned they may not be able to attract a boyfriend or girlfriend • Concerned that peers will reject them • May be more concerned more about physical side effects of treatment than about dying • Concerned their independence from parents may be impeded	• Provide clear, honest, direct communication • Provide privacy • Offer ways to express emotion • Encourage association with friends • Allow as much control and independence as possible • Recognize issues of sexuality

Case Study

Answer the following questions related to the case study below. Answers can be found in Appendix A at the end of the module.

Ben is a 5-year-old boy with a terminal brain tumor. Over the past few months he has been receiving experimental chemotherapy, however recent scans have shown that the chemo has not been working. Ben's parents have decided to stop all treatment and are aware that Ben will not survive and likely has a few months left to live. Ben's parents have approached you saying they would like to discuss dying with Ben but are not sure how to approach it or how much he will understand.

1. Assuming Ben has had normal cognitive development, what would be his understanding of death and dying? What thoughts might he have or assumptions might he make regarding his illness and dying?
2. Are there any behaviors you should tell Ben's parents to expect?
3. What are some nursing interventions you could implement?

Other Methods of Communication

Children often use other methods of communication such as:

- Dramatic play
- Art
- Music
- puppetry
- Dance

The nurse should encourage and pay attention to these creative methods of communication as they can provide insight into the child's understandings of death and help them express their emotions[2].

Note: Children often communicate their needs through questions, interactions, and play.

Family Communication

Many different communication systems can exist among families. See the table below for descriptions of different communication systems and interventions for nurses.

Communication System	Description	Intervention
Open Communication System[2]	The child and the parents are aware that the child is dying, and they act on this communicating openly and honestly[2].	Encourage the parents to continue communicating openly.

Communication System	Description	Intervention
Mutual Pretense System[2]	The parents and the child know that death is inevitable, but they choose to act otherwise[2]. Each family member acts as if they are not concerned due to fear of upsetting one another[2].	Discourage this by confronting the parents gently and educating them on the importance of open and honest communication[2].
Suspected Awareness System[2]	The child suspects that they are dying and attempts to confirm or invalidate this suspicion often through play and school work[2].	Encourage the parents to have an honest, open discussion with the child.
Avoidance System[2]	The child has not been told of his or her impending death[2]. Parents believe that the less the child knows, the better[2].	Parents may benefit from a parent support group or from talking with a counselor for assistance in developing healthy and appropriate communication patterns[2].

Reflection Exercise

Think of the last palliative care child you cared for and their family. Which communication system existed amongst them? How did it affect the child? Did you implement any interventions? What could you have done to facilitate a better communication system amongst them?

Staff Burnout

Caring for a dying child and their family is a very intimate experience for a nurse. The nurse will be exposed to the family's most private moments of grief, suffering, and love. It can be challenging for nurses to develop the necessary intimacy with the family while also maintaining professional boundaries that allow the nurse to separate the family's grief from his or her own[2]. See more about this in module 4 on end-of-life.

Documentation

It is not possible to document every communication you have with a patient and/or their family. However, any significant conversation about death and/or dying should be documented in the progress note. Include the following:

Data:

- Who was present for the conversation
- Anything significant stated by the child or their family
- Direct quotes should be used wherever possible

Action:

- Any support you provided
- Direct quotes should be used to describe anything significant you said

Response:

- Any appropriate referrals such as pastoral care, social work, etc.

Test your Knowledge

Identify each statement as true or false. Answers can be found in Appendix B at the end of the module.

1. The best way to ask a toddler if they are scared is to say, “you feel scared, don’t you?” ___
2. When discussing death with children you should use the words “pass away” instead of “die.” __
3. Children typically develop a realistic view of death as inevitable and permanent during late childhood (10-12 years). __
4. In a suspected awareness communication system, the child suspects that they are dying and attempts to confirm or invalidate this suspicion often through play and school work. __
5. It is appropriate for the nurse to discuss death as part of the natural life cycle with a dying child. __
6. The nurse should refrain from praying with the child and/or their family. __

Test your Knowledge

Complete the following short answer questions. Answers can be found in Appendix D at the end of the module.

1. What does the mnemonic ROLES stand for?

2. What are the four principles for discussing death with a child?

3. What should you encourage the parents of a toddler to do to facilitate better coping with hospitalization?

4. What are some nursing interventions to consider for a teenager to promote their understanding of death and dying?

5. What should you include in your progress note after having a significant conversation with your patient about dying?

References

1. African Palliative Care Association. (2010). Beating pain. Retrieved from: www.africanpalliativecare.org

2. Texas Cancer Council. (2000). End-of-life care for children. Retrieved from: www.childendoflifecare.org

Appendix A: Answers to Case Study Questions on Page 139

1. At 5-years-old Ben is likely beginning to develop a conscience and may view the world in terms of good of bad. He probably enjoys being self-sufficient, making decisions and expressing himself. Magical thinking may lead him to believe that he has a direct impact on the events in his life, causing him to feel guilty or responsible for his illness. He may believe his illness is a punishment and he may view death as temporary or reversible. See page 137.

2. You should warn Ben's parents that he may regress behaviorally in an attempt to feel secure. See page 137.

3. You should advise Ben's parents to provide honest explanations of the illness and treatments in terms that he will understand, emphasizing that death is permanent and irreversible. You should also advise them to assure Ben that he is not being punished. You should minimize Ben's separation from his parents and provide ways for Ben to express his emotions for example, drawing and play. See page 137.

Appendix B: Answers to Test your Knowledge Questions

Answers to true and false questions on page 142

1. False. See Page 134.
2. False. See page 136.
3. True. See page 138.
4. True. See page 140.
5. True. See page 136.
6. False. See page 137.

Appendix C: Answers to Test your Knowledge Question

Answers to short answer questions on page 143

1. **Relax**: do not rush the patient, **Openness**: be open and non-judgmental, **Lean** forward: lean in towards the patient, **Eye** contact: make eye contact with the patient, **Sit** near: sit down close to the patient. See page 134.

2. Begin on the child's level, let the child's questions guide the discussion, allow the child to express their feelings, and encourage feedback. See pages 135 and 136.

3. Encourage the parents to stay with the child as often as possible, encourage the family to maintain familiar routines, and encourage regular play activities. See page 137.

4. Provide clear, honest, direct communication, provide privacy, offer ways to express emotion, encourage association with friends, allow as much control and independence as possible, and recognize issues of sexuality. See page 138.

5. Data: who was present for the conversation, direct quotes of anything significant stated by the child or their family
   Action: use quotes to describe any support you gave the child, or any answers you provided to their question
   Response: any referrals you made such as pastoral care, social work, etc. See page 141.

Learning Resource for Pediatric Palliative Care

Module 2: Pain

Developed by: Sarah Knox

May 2019

Module 2: Pain

The purpose of this module is to provide information about pain management in pediatric patients requiring palliative care (referred to in this module as palliative care children). This module can be used by registered nurses (RNs), licensed practical nurses (LPNs), and any other healthcare professionals who care for palliative care children. This module may also be beneficial for anyone who simply wants to learn more on this topic.

This module contains information, reflection exercises, case studies, documentation tips, tools for practice, and self-tests.

Learning Objectives:

Upon completion of this module, you will be able to:

1. Distinguish between acute, chronic, nociceptive, neuropathic, somatic, and visceral pain;
2. Identify how to conduct a pain assessment on palliative care children of various ages using appropriate pain measurement tools, and interpret the results;
3. Identify which medications should be used for pain in children in order to make recommendations, explain to parents, and question physician's orders;
4. Explain common misconceptions surrounding opioid use in children to parents;
5. Identify non-pharmacological nursing interventions for pain management in palliative care children; and
6. Document appropriately and accurately pain assessment, measurement, and management interventions.

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Pain

Pain is one of the most common symptoms experienced by palliative care children however, it is often under-recognized and under-treated[1]. Pain is a complex experience and there are many misconceptions surrounding pain in children. For example, a common myth is that children do not feel pain as intensely as adults. Children are not always able to express their pain as well as adults, however this does not mean that they do not experience pain to the same degree. In fact, research has shown that younger children experience even higher levels of pain than adults[2].

Pain can severely impact a palliative care child's quality of life and their end-of-life experience. However, pain is both treatable and preventable. It is imperative that palliative care nurses are able to properly assess, measure, and treat pain in children in order to provide palliative care children with the best possible quality of life, and a peaceful dignified death. The information in this module will provide palliative care nurses with the details they need to do this.

Definition

Pain is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage[1]. More simply put, pain is whatever the patient says it is[3]. This is important to remember because pain is an individual experience and no two children will experience pain the same.

Causes

Palliative care children experience pain for many different reasons depending on their underlying illness:

Common causes of pain in children with cancer[4]:

- tumor involvement such as direct tissue/nerve damage, compression of tissue/nerves, tumor invasion of bone and bone marrow, and increased intracranial pressure
- infection due to immunosuppression
- mucositis related to chemotherapy and radiotherapy
- procedural pain from investigations and surgical interventions

Common causes of pain in children with non-cancer diagnoses[4]:

- musculoskeletal issues such as scoliosis, dislocated hips, and fractures
- dystonia/muscle spasms
- gastrointestinal dysmotility
- surgical interventions
- orthotic devices

Classifying Pain

In order to assess, measure, and treat pain it is important to understand the physiology of pain. Different types of pain respond to different treatments; therefore, it is important for the nurse to know which type of pain a patient is experiencing in order to properly treat the pain[2]. Palliative care children often experience both illness associated pain and situational pain.

Illness associated pain is the pain which is expected to occur in a palliative care child due to their underlying illness. Illness associated pain can be classified according to:

- Duration
- Underlying Mechanism

Duration

Pain can be classified as either acute or chronic. Acute pain results from an acute illness or injury while chronic pain results from a chronic pathological process. As shown in the table below they differ in terms of onset, predictability, and benefits as well as the target and nature of treatment. Palliative care children may experience acute pain, chronic pain, or both.

	Acute Pain	**Chronic Pain**
Onset	Definite	Gradual or ill-defined
Duration	Limited	Persists longer than expected healing time
Predictability	Predictable	Unpredictable
Benefits	Protective benefits	No protective benefits, serves no purpose
Target	Acute injury or acute illness causing the pain	Underlying disease if possible
Treatment	Short-term use of analgesics	Regular use of analgesics and psychological supportive care

Underlying Mechanism

Regardless of whether pain is acute or chronic, the pain can be experienced as either nociceptive or neuropathic, depending on the underlying condition[2]. As shown in the table below, they differ in terms of type of damage, sensations, and opioid sensitivity.

Characteristic	**Nociceptive Pain**	**Neuropathic Pain**
Types of Damage	Actual or potential damage to non-neural tissue (tissue damage)[2]	Damage to somatosensory nervous system (nerve damage)[2]
Sensations	Described as sharp, aching, or throbbing pain[2]	Described as burning (dysaesthesia), shooting pain, aching sensation relieved by pressure applied to affected area, increased sensitivity to pain stimulus (hyperalgesia)

Characteristic	Nociceptive Pain	Neuropathic Pain
		or to a stimulus not normally painful (allodynia)[2]
Opioid Sensitivity	Opioid sensitive[2]	Only partially opioid sensitive[2]

There are two different types of nociceptive pain, somatic pain and visceral pain. As shown in the table below, they differ in terms of location and sensations. It is important to distinguish which type a patient is experiencing in order to treat the pain appropriately.

	Somatic Pain		Visceral Pain
	Superficial	Deep	
Location	Superficial pain in the skin, subcutaneous tissue, or mucous membranes	Deep pain in the muscles, tendons or joints	Internal pain arising from organs (bowel, cardiac, liver)
Sensations	Sharp and well localized	Diffuse and dull	Dull and poorly localized, often associated with autonomic responses (e.g. pallor, sweating, nausea)
Examples	Minor cuts and burns	Muscle sprains, broken bones	irritable bowel syndrome, gallstones and bladder pain

Situational pain is pain that is unexpected and caused by other factors and situations. The nurse should pay attention to the child's "usual" expected pain but should also be alert for any "unusual" unexpected pain, such as:

Breakthrough pain	Exacerbation of pain that occurs despite otherwise relatively controlled background pain[2]
Incident pain	Occurs only in certain circumstances for example, after a particular movement or action[2]
Procedural pain	Related to medical interventions or procedures[2]

Pain Assessment

What is the purpose of conducting a pain assessment?

The purpose of conducting a pain assessment is for the nurse to understand the pain that the patient is experiencing, in order to treat and manage the pain appropriately.

When should a pain assessment be completed?

A pain assessment should be completed:

- Every time the patient's vital signs are checked (as ordered by the physician). Pain is the 5th vital sign.
- After a pain management intervention is implemented (both pharmacological and non-pharmacological).
- Whenever the patient says they are in pain, the patient's caregiver believes they are in pain, or the nurse observes the patient exhibiting pain.

Note: The nurse should do a pain assessment in all of the above situations even if the patient has not reported pain, as they may be too sick, tired, or sore to indicate they are in pain[2].

What are the four components of a proper pain assessment?

The four major components of a proper pain assessment are[5]:

1. Patient self-report
2. Measurement
3. Physical examination
4. Behavioral observation

A simple acronym that can be used by nurses when setting up a care plan for a patient's pain is: **PAINED**[6]**.** In order to properly manage a patient's pain, the nurse must know the answers to the following questions about their patient's pain[6]:

Place: Where is the pain? Is it in more than one site?
Amount: What is the present and past intensity of the pain, at its worst and at its best? How often does it occur? Is it constant or intermittent? When did it begin?
Intensifiers: What makes the pain worse?
Nullifiers: What makes the pain better? What pharmacological and non-pharmacological approaches have been and are being used for the treatment of the pain? Were they and are they effective?
Effects: What side effects were/are experienced from past and present analgesics?
How does pain affect quality of life: physical, psychological and social function?
Description of pain: How does the pain feel? sharp, stabbing, burning, shooting, dull, aching, throbbing, crampy?

1. Patient Self-report

Pain is subjective, therefore, whenever possible ask the patient to describe their pain using their own words[2]. Their choice of words is important and can help identify the type of pain they are experiencing. For example, words such as shooting, burning, dull, or aching could refer to neuropathic pain[2].

Remember: It is important to correctly identify pain as neuropathic or nociceptive (somatic or visceral; deep or superficial) as this will help determine the drugs needed for

Limitations.

There are many limitations to patient self-report when working with palliative care children. For example:

- Infants and young children are often unable to verbalize or describe their pain. Just because a child does not report pain does not mean that they are not experiencing pain. Always include the parents/caregivers in the assessment, asking whether they believe that their child is in pain.
- Children who experience chronic pain may be so used to the pain that they do not report it.
- Children who are old enough to report their pain may not for several reasons, such as[2]:
    - Fear of talking to doctors
    - Fear of finding out they are sick
    - Not wanting to disappoint their parents/caregivers
    - Fear of treatment e.g. getting a needle
    - Not wanting to delay discharge from hospital
    - Not wanting to appear weak or different from their peers (adolescents particularly)

2. Measurement

Pain measurement provides the nurse with a score indicating the presence, intensity and duration of the patient's pain. Pain measurement scores make it easier for nurses to compare a patient's pain before and after management interventions (both pharmacological and non-pharmacological) to find out what is working for the patient and what isn't.

Measuring pain in infants and children is more complicated than in adults because children are not always able to properly verbalize or describe their pain[2]. Age-appropriate and validated pain-measurement tools should be used. A variety of measurement tools are available.

Older children.

For older children, the numerical rating scale and the visual analogue scale are recommended.

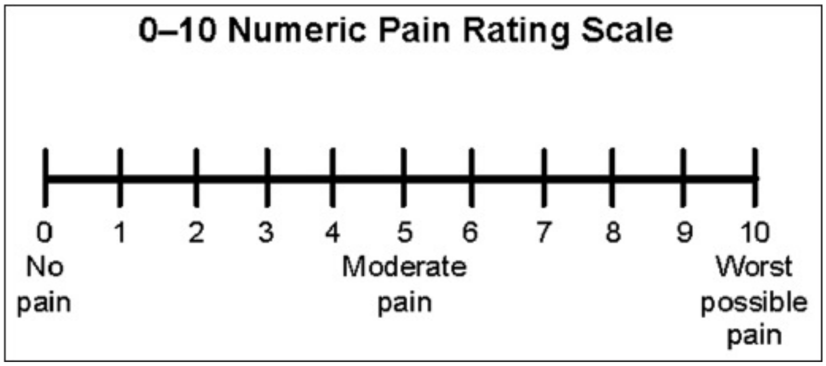
Numerical rating scale.

The nurse asks the patient to rate their pain intensity on a numerical scale that ranges from 0 (indicating no pain*)* to 10 (indicating the worst pain imaginable). The numerical rating scale is suggested for use in older children and teenagers who are numerate[2].

Also available is the visual analogue scale. However, there are not a lot of advantages to using the visual analogue scale over the numerical rating scale.

Visual analogue scale (VAS).

The visual analogue scale is similar to the numerical rating scale except there is a visual diagram. The nurse provides the patient with a picture of a straight line with the endpoints defining extreme limits no pain and worst pain imaginable and asks the patient to mark their pain level on the line between the two endpoints[7]. The distance between no pain and the mark then defines the patient's pain[7]. The VAS is suggested for use in older children who are numerate[2].

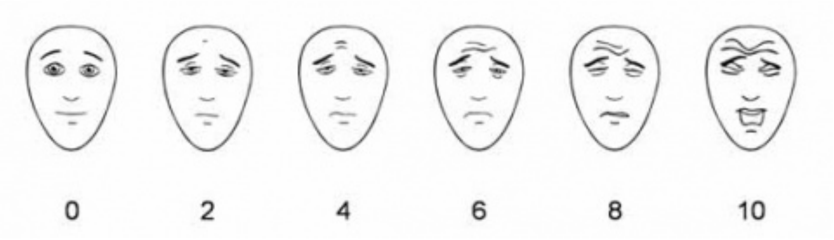


Younger children.

For younger children, the faces scale, neonatal infant pain scale, and FLACC are recommended.

Faces scale.

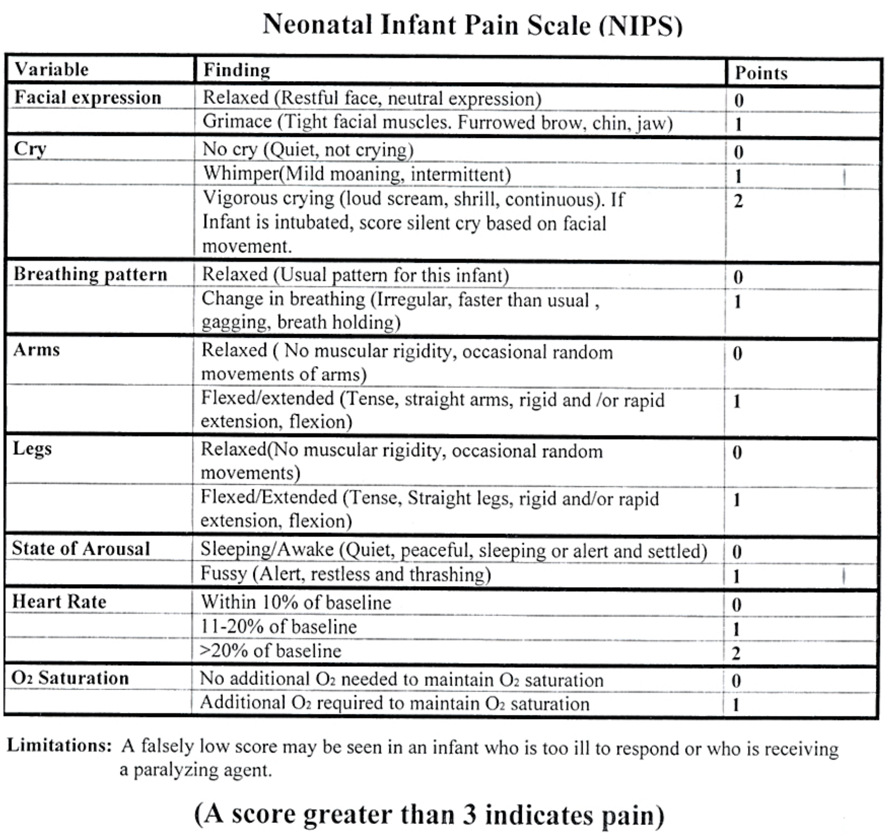
The patient is shown a scale of six cartoon faces, with expressions ranging from a big smile representing no hurt to a very sad face representing hurts worst[2]. The nurse asks the patient to point to a face that represents their pain. The nurse reminds the patient to ensure they are rating their pain and not their emotion[2]. The faces scale is suggested for use in children ages three and up[2].



Additional tools that are particularly useful with infants and non-verbal children include the neonatal infant pain scale and the FLACC.

Neonatal infant pain scale (NIPS).

The neonatal infant pain scale addresses eight variables (facial expression, cry, breathing pattern, arms, legs, state of arousal, heartrate and oxygen saturation), each of which is given a score. The scores are added at the end to give a final score. A final score greater than 3 indicates that the neonate is in pain.



Neonatal Infant Pain Scale (NIPS)

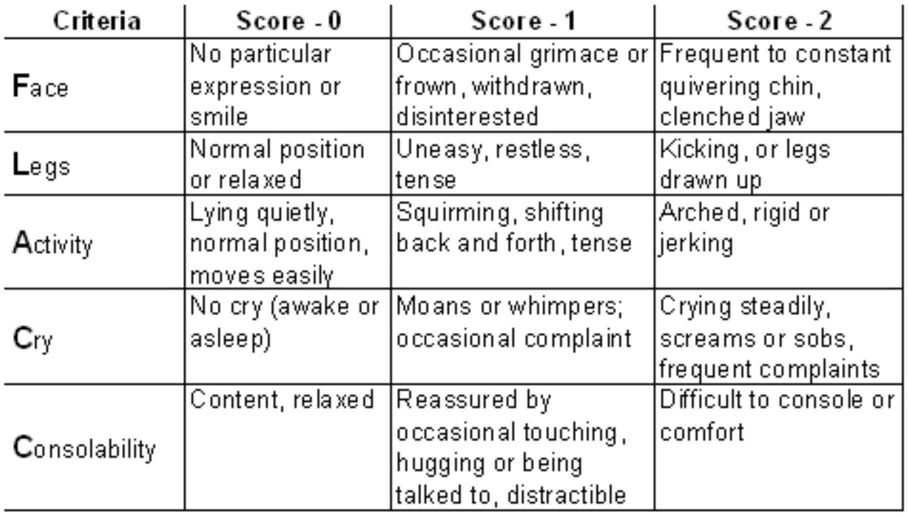
Variable	Finding	Points
Facial expression	Relaxed (Restful face, neutral expression)	0
	Grimace (Tight facial muscles. Furrowed brow, chin, jaw)	1
Cry	No cry (Quiet, not crying)	0
	Whimper(Mild moaning, intermittent)	1
	Vigorous crying (loud scream, shrill, continuous). If Infant is intubated, score silent cry based on facial movement.	2
Breathing pattern	Relaxed (Usual pattern for this infant)	0
	Change in breathing (Irregular, faster than usual , gagging, breath holding)	1
Arms	Relaxed (No muscular rigidity, occasional random movements of arms)	0
	Flexed/extended (Tense, straight arms, rigid and /or rapid extension, flexion)	1
Legs	Relaxed(No muscular rigidity, occasional random movements)	0
	Flexed/Extended (Tense, Straight legs, rigid and/or rapid extension, flexion)	1
State of Arousal	Sleeping/Awake (Quiet, peaceful, sleeping or alert and settled)	0
	Fussy (Alert, restless and thrashing)	1
Heart Rate	Within 10% of baseline	0
	11-20% of baseline	1
	>20% of baseline	2
O_2 Saturation	No additional O_2 needed to maintain O_2 saturation	0
	Additional O_2 required to maintain O_2 saturation	1

Limitations: A falsely low score may be seen in an infant who is too ill to respond or who is receiving a paralyzing agent.

(A score greater than 3 indicates pain)

FLACC.

The FLACC sale is used like an Apgar score. Each of the five items (face, legs, activity, cry, consolability) is given a score from 0-2, which results in a total score between 0 and 10. The higher the score, the higher the patient's pain. It is suggested for infants and children less than three years of age or older non-verbal children[2].



Criteria	Score - 0	Score - 1	Score - 2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant quivering chin, clenched jaw
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking, or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid or jerking
Cry	No cry (awake or asleep)	Moans or whimpers; occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging or being talked to, distractible	Difficult to console or comfort

No matter which pain measurement tool is being used, the nurse must have knowledge on the correct use of the measurement tool, understanding of the scoring process, and the ability to correctly interpret the score[2].

Pain measurements should be completed every time a child is assessed for pain. Pain can develop and change very quickly therefore routine assessment and measurements which can be compared are very important[2]. All pain scores should be clearly documented to evaluate intervention efficacy[2].

3. Physical Examination

When conducting a pain assessment always assess the patient for any changes in vital signs. An increase in blood pressure, heart rate, and/or respiration rate can be an indicator that the patient may be experiencing acute pain. However, no change in vital signs does not mean that the patient is not experiencing any pain. There will be few changes in vital signs with chronic pain.

It is important to believe the child and/or their parents. Just because you may not find a physical cause or indicator for the pain does not mean that the patient is not experiencing pain[2].

4. Behavioral Observation

Observe the child for behavioral factors associated with pain and anxiety such as crying, facial display of anxiety, fear, tenseness, and withdrawal[2].

Observe the way in which the child moves or holds their body, and the way their body is positioned when lying down[2]. Observe the patient for any signs of guarding which is an attempt to prevent anyone from touching a specific body area[2]. Children will often guard a painful body part.

Every child is different and will express pain in different ways. However, below is a table indicating some common behaviors according to age:

	Infant	Toddler	Young Child	School-age	Adolescent
Thrashing	✓		✓		
Crying intensely	✓	✓			
Irritability	✓				
Muscle rigidity / tension	✓			✓	✓
Aggressive / uncooperative		✓	✓		
Withdrawing		✓			
Guarding		✓			
Clinging to parent			✓		
Inability to sleep		✓	✓	✓	✓
Able to verbalize pain			✓	✓	✓
Nightmares				✓	

Be aware that just because a child is sleeping or is very quiet does not necessarily mean that they are pain free[2]. Movement could be painful, or the child could be too sick or too tired to move[2].

Reflection Exercise

Think of a palliative care patient you cared for recently who was experiencing pain. Reflect on the words they used to describe their pain and their behaviors. Would you categorize their pain as acute or chronic? Nociceptive or Neuropathic? Did you use a pain tool to assess their pain? Did the patient experience any change in their vital signs? Did the child display any behaviors associated with pain?

Documentation

Every time a pain assessment is conducted the nurse must document it in the progress note.

Data:

- Include in quotations any words that the patient (or their parent) used to describe their pain (burning, shooting, stabbing, etc.)
- Include any vital signs that may be abnormal for the patient indicating pain
- Include any behaviors you observed that may indicate the patient has pain (crying, withdrawing, tenseness, guarding, etc.)
- Indicate which measurement tool was used
- Indicate the patient's pain score

Action:

- Document any pain management interventions you implemented (pharmacological vs. non-pharmacological)

Response:

- Document the patient's response to the intervention by re-assessing them and measuring their pain after the intervention using the same measurement tool
- Compare their pain score pre and post intervention to determine intervention efficacy

Case Study

Answer the following questions related to the case study below. Answers can be found in Appendix A at the end of the module.

Molly is a 10-month-old infant with neuroblastoma. You enter her room to check her vital signs. You notice that Molly is asleep in her crib. You ask Molly's mother if she believes Molly is having any pain, and she responds, "No I don't think so, she hasn't been crying, she has been sleeping for the last two hours and hasn't stirred." While you check Molly's vital signs you notice that her facial muscles tighten, her brow furrows, and her arms and legs are tense and straight. Her heart rate and blood pressure have increased since the last set of vitals you took four hours ago.

1. Should you conduct a pain assessment on Molly at this time?
2. If yes, which pain measurement tool would you use to measure Molly's pain?
3. Do you believe that Molly is experiencing pain? Why or why not?
4. What would you document in your progress note on Molly's chart?

Pain Management

Once pain has been properly assessed and measured it can then be managed. Management will depend on the type and cause of the pain. Pain management must be holistic, and both pharmacological and non-pharmacological methods should be used[2].

The goal of pain management is prompt relief and prevention of recurrence, and for the patient to be free of pain at night, during the day, at rest, and during movement[2]. Acceptance of pain by healthcare providers, the patient and their family should be discouraged as pain is treatable and preventable[2]. It is better to prevent pain than to treat it once it has occurred[2].

Just as children express their pain differently depending on their age and development stage, management interventions will also vary[2].

Pain During Medical Procedures

Nurses often have to perform painful procedures on children. Below are some helpful tips in managing procedural pain in children[2]:

- Always question whether the procedure is necessary
- Gather your supplies and prepare yourself first
- Explain to the child and their family what is going to happen
- Encourage the parent/caregiver to be helpful and supportive
- Carry out the procedure in a child-friendly manner
- Use both pharmacological and non-pharmacological interventions to manage pain.
- After the procedure, compliment the child on how well they have done.
- Use topical analgesics, e.g. EMLA cream or local anesthetic agents when possible
- If the child is extremely anxious, sedate using a benzodiazepine (e.g. midazolam)
- If the procedure will be extremely painful administered an opioid in advance so that it has time to take effect

Pharmacological Management

When treating pain with medication it is important to first determine the severity, type, and cause of the pain to determine the most suitable medication[2]. For example, different medications are used to treat nociceptive pain vs. neuropathic pain[2].

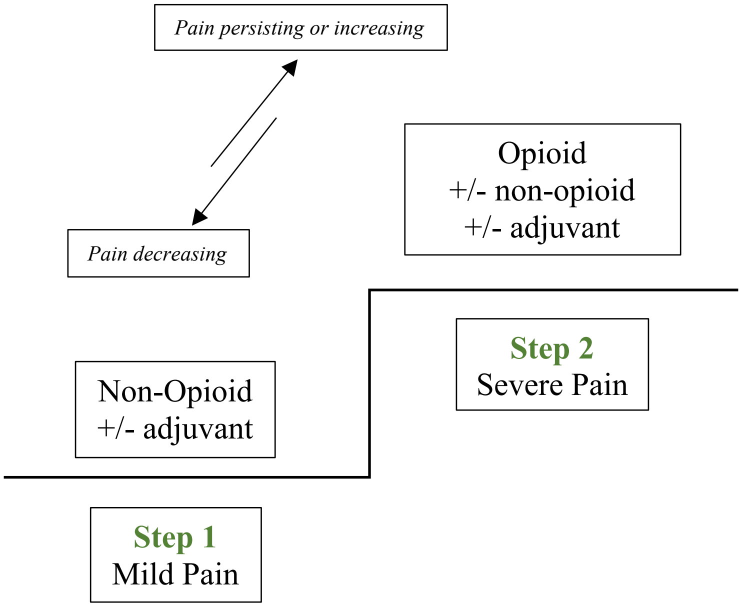
Pain medication dosing depends on the patient. The right dose of a pain medication is the one that relieves the patient’s pain[2]. Just like pain is unique to each patient, so is pain management.

Medication dosing is not discussed in this learning resource as the doses are so individualized based on the particular patient and their needs. The physicians are responsible for deciding / calculating the doses. There are drug books available on the unit should you need to look this information up. Janeway pharmacists are great resource persons should you have any questions regarding doses and/or conversions.

WHO analgesic ladder.

The World Health Organization (WHO) recommends a two-step approach for pharmacological pain management in children. Children with mild pain should be started on Step 1 and treated with a non-opioid (e.g. acetaminophen or ibuprofen) with or without an adjuvant. If the child's pain persists or increases the child should move to Step 2 and be treated with an opioid (e.g. morphine), with or without a non-opioid and/or an adjuvant[8]. Adjuvants and non-pharmacological pain management interventions should always be implemented before moving a child to Step 2[8]. Children who present initially in severe pain may be immediately started on Step 2[8].

Step 1: Mild pain treat with a non-opioid (e.g. acetaminophen or ibuprofen)
Step 2: Moderate to severe pain treat with an opioid (e.g. morphine)



Note: Non-opioids and opioids can be combined as they have different modes of action. However, multiple opioids should never be combined[2].

Medications

Pediatric palliative care nurses need to be familiar with medications used for pain management in order to:

- Make medication recommendations to physicians
- Question physicians' medication orders
- Know when to administer PRN mediations
- Explain the purpose, mechanism, and side effects of medications to patients and their parents/caregivers

Medications used for mild pain – Step 1 (mild analgesics)

Medication	Route	Comments
Acetaminophen	PO, PR	• Step 1 drug of choice in children[2] • Lack of significant side effects and excellent safety profile[9] • Benefit to all levels of pain[9] • Low risk of GI complications[6] • No effect on platelets[6]
Ibuprofen	PO	• Less contraindications compared to opioids[9] • Most commonly used NSAID in children[9] • Possible nephrotoxicity • Lowest risk of all NSAIDs for GI complications[6]
Naproxen	PO	• Increased incidence of hepatotoxicity[6] • Potent inhibitor of leukocyte function[6]
Ketorolac	PO, IV	• Contraindicated in children less than 16 years[9] • Increased incidence of nephrotoxicity and GI complications[6] • Do not use continuously for longer than 5 days[6]

Medications used for severe pain – Step 2 (Opioids)

Medication	Route	Comments
Morphine	PO, IV, Subcut	• Most commonly used opioid in children[6] • No ceiling (maximum) dose. Correct dose is the one that gives pain relief without side effects[2] • Urinary retention and pruritis are common side effects in children[2] • If morphine needs to be stopped reduce the dose gradually to avoid withdrawal symptoms (sweating, nausea, agitation)[2] • Morphine should not cause sedation. If sedation occurs reduce the dose or consider another medication[2]
Hydromorphone	PO, IV, Subcut	• A derivative of morphine with a higher potency • Often used at end-of-life or if a patient is allergic to morphine
Methadone	PO, IV, Subcut	• Synthetic opioid[2] • More potent than morphine on repeated use[2] • Used in drug rehabilitation as a substitute for heroin[2]

Medication	Route	Comments
		- Used for management of neuropathic pain[2] - Parenteral administration not recommended[9] - Safe option for patient with renal impairment[10] - Can cause prolonged QT waves[6]
Fentanyl	IV, Subcut	- Strong opioid for chronic pain[2] - 100 times stronger than morphine[9] - Often used for procedural pains in surgery due to its rapid onset and offset[9] - Available in skin patches which control the rate of delivery of the medication to the skin surface[2] - Absorption of fentanyl is increased in patients with fever due to increased skin permeability. Patients with fever should be monitored for opioid side effects[2] - Oral administration is not recommended due to nausea and vomiting side effects[2] - Safe option for patients with renal impairment[10]

Always choose the least invasive route, PO and SL preferred when possible.

Note: Codeine and tramadol are not recommended in children[8].

Documentation

Every time the nurse administers a medication for pain management it must be documented in the progress note.

Data:

- Provide information on pain assessment / pain measurement.

Action:

- Indicate which medication was administered, the dose, and the route.

Response:

- Indicate the patient's response to the medication by re-assessing / measuring their pain score and comparing to their pain score prior to the intervention.
- If the patient's pain was not adequately reduced by the medication, consider administering an adjuvant medication, moving up a step on the analgesia ladder, increasing the dose of the medication, and implementing non-pharmacological pain management interventions.
- Any side effects that the patient experienced should also be documented.

Kardex

- Pain management interventions which tend to work well for a patient should be clearly documented on the patient's Kardex/care plan

Reflection Exercise

Think of the last time you administered an analgesic to a palliative care child experiencing pain. Which medication did you administer? Was the medication appropriate according to the WHO two-step approach? Was the medication effective in controlling the child's pain? and how do you know? Were you / would you have been able to explain the purpose, mechanism, and side effects of the medication to the patient and their parents/caregivers?

General Use of Opioids

There are a few important things to keep in mind when managing a child's pain with opioids:

- For good control of chronic pain opioids should be administered q4h[2].
- Breakthrough opioid doses can be given as often as required and should always be available.
- Breakthrough opioid doses should ideally be the same dose as the regular dose[2].
- If a child is requiring frequent breakthrough doses, then their regular dose is not working and most likely needs to be increased.
- At the EOL stage, opioids are often administered as a continuous parenteral infusion.

Side Effects of Opioids

Possible side effects of pain medications should always be discussed with patients and/or their care givers[2]. Opioids especially can cause many side effects, such as[2]:

Side Effect	When	Possible Action	Comments
Constipation	Anytime	Start a bowel regimen	Administer regular Polyethylene glycol or lactulose
Nausea and Vomiting	First few days	Administer antiemetic on a fixed schedule for the first few days	Tolerance typically develops
Drowsiness	First few days	Hold sedatives and/or anxiolytics, Administer methylphenidate	Tolerance typically develops
Itching	Anytime	Treat with nalbuphine (antihistamines not effective for opioid induced itching) (Hauer, 2014)	Common in children
Delirium, Confusion, Hallucinations	Anytime	Reduce dose or rotate opioid	Consider haloperidol if agitation present
Urinary Retention	Anytime	Foley catheterization	Monitor output

When a patient experiences intolerable side effects from an opioid, consider opioid rotation (changing from one opioid to another)[10]. Inadequate pain management more commonly requires dose escalation, not opioid rotation[10].

Note: Hepatic and renal impairment is not a contraindication for the use of opioids however the interval between doses may be increased to q6, 8, or 12 h to reduce the risk of accumulation of medication[2]

Reflection Exercise

Think of a patient you cared for recently who was receiving opioids. Were they experiencing any side effects related to the medication? Which side effects? How did you manage them?

Myths about Morphine

A common reason for poor pain control in children is inadequate administration of opioids. Parental fear of respiratory depression and addiction to opioids often prevent children from receiving opioids, but the fact is opioids can be used safely in children[2].

Note: Children younger than six months are more sensitive to possible opioid induced respiratory depression, so they require a lower starting dose. This should not prevent use of opioids in these children[2].

Myth: Morphine causes children to stop breathing.

Reality: Severe respiratory depression does not occur if the right dose is given at the right time by the right route[2]. However, the nurse should always keep an eye out for signs of respiratory depression especially in patients who are opioid naïve and infants < 6 months.

Myth: Children receiving morphine will develop a tolerance to the drug requiring stronger doses.

Reality: The need for increasing doses of morphine is usually related to disease progression not tolerance. Concern for tolerance is not a reason to save the use of opioids until the end-of-life phase[2].

Myth: Children receiving morphine will become addicted to the drug.

Reality: Therapeutic use of morphine does not lead to addiction[2].

Myth: Giving palliative care children morphine will hasten their death.

Reality: When given correctly morphine does not hasten death. Morphine can be used long term and is compatible with a normal lifestyle[2].

Remember: When morphine is used correctly patients don't become dependent, tolerance is uncommon and respiratory depression doesn't usually occur[2].

Toxicity

Although morphine toxicity is rare, the nurse must be aware of the signs[2]:

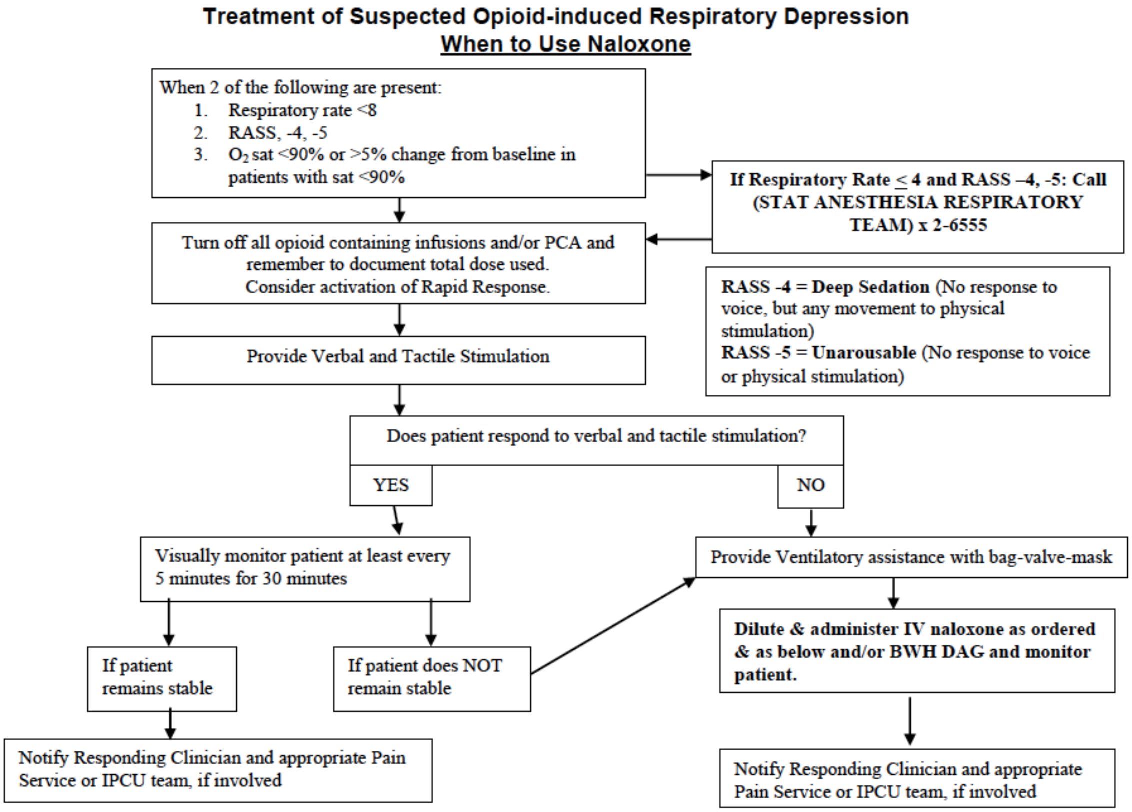
- Drowsiness that does not improve
- Confusion
- Hallucinations
- Myoclonus
- Respiratory depression (seldom seen with oral morphine)
- Pinpoint pupils

If a patient displays signs of having morphine toxicity the nurse should:

- Notify the resident / physician immediately
- Hold the next morphine dose
- Prepare Naloxone in case the physician wants to give it

Naloxone

Naloxone is an opioid antagonist which reverses sedation, respiratory depression, and analgesia[2]. Naloxone requires a physician's order and should only be administered for life-threatening respiratory depression which is unresponsive to dose reduction and appropriate respiratory support. Administration may cause opioid withdrawal symptoms and severe pain[6]. See the algorithm below for more information on when to administer Naloxone[6].



Adjuvant Analgesics

Some medications that have a primary purpose other than analgesia can also be used to relieve pain through other mechanisms, particularly for pain that is only partially sensitive to opioids such as neuropathic pain, bone pain, and muscle spasms. Adjuvant medications can be used alone or along with Step 1 and 2 analgesics[2].

Drug Class[2]	**Use**[2]	**Examples**[2]
Antidepressants	Neuropathic pain	Amitriptyline, nortriptyline, duloxetine, venlafaxine
Anticonvulsants	Neuropathic pain	Clonazepam, carbamazepine, sodium valproate, lamotrigine, topiramate, levetiracetam, phenytoin, gabapentin
Antispasmodics	Muscle spasms (e.g. colicky abdominal pain or renal colic)	Hyoscine butylbromide
Muscle relaxants/anxiolytics:	Muscle spasms and anxiety related pain	Diazepam, baclofen, metaxalone
Corticosteroids	Bone pain, neuropathic pain, increased intracranial pressure, edema, inflammation	Dexamethasone, methylprednisolone

Sucrose

Oral sucrose is another strategy used as a pain relief measure in newborns up to 1 month of age[9]. A drop of sucrose is placed in the newborn's mouth providing analgesic effects for approximately 3 to 5 minutes[9]. Sucrose is best used for procedural pain.

Case Study

Answer the following questions related to the case study below. Answers can be found in Appendix A at the end of the module.

Johnny is a six-year-old boy with Batten Disease who has been admitted to the hospital for increased irritability. You assess Johnny for pain using the FLACC scale and notice that he has a clenched jaw, his legs are tense, his body is jerking, he occasionally moans and whimpers, and he is difficult to console. You notify the physician who prescribes morphine for Johnny via his G-Tube. Johnny's dad expresses concern about giving Johnny morphine, stating "I usually just give him Tylenol for his pain. Do you really think his pain is bad enough for Morphine? Can't that stuff cause him to stop breathing?"

1. What pain score would you give Johnny using the FLACC scale?
2. Do you believe Johnny requires morphine for his pain? Why or why not?
3. How would you respond to Johnny's dad's concerns/questions?
4. Would you suggest any adjuvant pain medications be ordered for Johnny? If so, which medications would you suggest?

Non-Pharmacological Management

Non-pharmacological pain management is the management of pain without medications. Techniques are used to alter thoughts and focus concentration, to better reduce and manage pain[2]. Non-pharmacological approaches can be highly effective in children as they are easy to learn and give the child some control in the management of their pain[2]. There are many different methods of non-pharmacological pain management. Not all methods will be appropriate for any one child, and some methods may work better than others[2].

Note: Non-pharmacological methods of pain management should be used in conjunction with pharmacological methods, not instead of them[2].

Nursing Interventions

There are many non-pharmacological pain management interventions that the nurse can implement and teach the patient to do, such as:

Aromatherapy.

Aromatherapy is the use of essential oils to balance, relax, and stimulate the body, mind and soul. Different oils can have different effects, for example lavender oil can help with relaxation, and chamomile oil can help relieve stress[2].

Breastfeeding.

Like sucrose, breast milk has also been shown to decrease pain in infants during painful procedures[9].

Deep breathing.

Deep breathing is the focusing of patient's attention on breathing deeply. Deep breathing is an easy technique to use with children. The child is instructed to take a deep breath through the nose and blow it out through the mouth, while making a conscious effort to count their respirations[2]. For younger children, the nurse can encourage the child to pretend they are blowing bubbles or blowing out the candles on their birthday cake.

Distraction.

Distraction is focusing the patient's attention away from the pain. Simple distraction techniques such as counting, singing, looking at books, blowing bubbles, and watching television can be very effective in managing pain in children.

Hot and cold therapy.

Hot and cold therapy is the application of either a hot or cold compress to help decrease pain. Some types of pain improve best using heat, while other types of pain improve best with cold[2]. The nurse should apply the hot or cold compress wherever the patient would like it. Deciding on hot vs. cold may be trial and error and ultimately comes down to the patient's preference.

Positioning.

Positioning a patient is the strategical movement or, change of position of patients who are bedridden in order to prevent bed sores and injury[2].

Relaxation.

Teaching patients to train themselves to intentionally relax can greatly reduce stress and pain[2]. Guided imagery can be helpful to encourage relaxation.

Skin-to-skin contact.

Skin-to-skin contact has been shown to reduce pain in infants during procedures especially when combined with sucrose or breast milk[9].

Spiritual and religious support.

Providing patients with spiritual support is an important part of pain control. Depending on the patient's beliefs, prayer and medication may be helpful[2].

Touch.

Touch can also be a useful distraction technique in children. Stroking, patting and rocking infants and children can help reduce their distress[2].

Other Healthcare Practitioners

There are also other non-pharmacological pain management interventions that may be useful for palliative patients but do not fall under the scope of the nurse. Nurses can refer their patients to other health care professionals for interventions such as:

Acupuncture.

Acupuncture is the insertion of very thin needles, or the application of pressure at specific points on the body to alleviate pain[2].

Massage therapy.

Massage therapy is the rubbing and manipulation of muscles to increase blood circulation and enhance relaxation. Massage therapy can enhance a patient's feeling of comfort and well-being[2].

Music therapy.

Music therapy includes listening to music, creating music, playing an instrument or singing. Music therapy has been shown to relieve stress and anxiety; improve mood; lower heartrate, blood pressure, and breathing rate; relieve muscle tension and provide relaxation[2].

Physical therapy.

Physical therapy is the movement of the body to achieve and maintain a healthy state of physical fitness. Physical therapy has been shown to reduce anxiety and depression; reduce fatigue; improve blood flow; reduce pain; increase overall physical functioning; and improve self-esteem[2]. It is important to note that problems are possible if a patient exerts themselves too much. For patients who are bedridden, range-of-motion exercises can be helpful[2].

Radiotherapy.

Low doses of radiation are sometimes used for the palliation of pain in patients with advanced disease as local pain due to tumor infiltration usually responds to local radiotherapy[2].

Reflexology.

Reflexology is based on the belief that there are reflexes in the hands and feet that correspond to every part of the body. Application of pressure to the reflexes that correspond to the area of pain can help with pain relief[2].

Surgery.

Surgery can help to reduce the source of the pain, e.g. de bulking tumors[2].

Reflection Exercise

Consider a palliative care patient you have cared for recently who was experiencing pain. Reflect on the non-pharmacological pain management interventions that were being implemented for this patient. Were the interventions effective in relieving the patient's pain? Are there more interventions that could have been implemented? If yes, which ones?

Psychological Support

Psychological support is crucial to the non-pharmacological management of pain. Psychological distress related to pain often presents as:

- Anger
- Frustration
- Hopelessness
- Helplessness
- Denial
- Grief
- Sadness
- Withdrawal

Nurses can provide psychological support to their patients by practicing good communication (see module 1), providing patient education, and practicing culturally competent care[2].

Patient education.

Patient education should be an integral part of managing pain.

Educating children and their parents about the cause of their pain and possible management will[2]:

- allow them to have realistic expectations surrounding their care
- allow them to build a trusting relationship with the health care team
- help with patient adherence to medication
- reduce stress and anxiety for the patient and their family

When explaining pain to children use language and tools that children understand according to their age, for example[2]:

- Drawings
- Pictures
- Music
- Stories

Cultural care.

Culture and spirituality can play a major role in how a patient views and manages pain[2]. By using a sensitive approach to culture, ethnicity and language, the nurse can help reduce the patient's emotional distress[2].

Test your Knowledge

Identify each statement as true or false. Answers can be found in Appendix C at the end of the module.

1. A child with cancer who describes the pain in their feet as “tingling” is experiencing nociceptive pain. ___
2. The FLACC pain measurement tool is appropriate for a ten-year-old non-verbal child. ___
3. Codeine is an appropriate medication to administer to an eight-year-old palliative child whose pain score is 6 out of 10. ___
4. One hour after administering PO morphine to your patient, their pain score has not decreased. You should ask the physician to switch them to hydromorphone for better pain control. ___
5. Stroking, patting and rocking infants can help reduce their pain. ___

Test your Knowledge

Complete the following short answer questions. Answers can be found in Appendix D at the end of the module.

1. List six differences between acute and chronic pain:
   ____
   ____

2. A child on step one of the WHO two-step approach rates their pain using the numerical rating scale as 6/10. You administer Tylenol PO as ordered. Two hours later they rate their pain as 5/10. Are you satisfied with this? Why or why not? What should you do next?
   ____
   ____

3. You write a progress note on the child mentioned in question #2 that states the following:

   "Data: Pain assessment completed at 0900 hrs. Child's pain score was 6.
   Action: Medicated with Tylenol PO as ordered at 0915 hrs.
   Response: Pain score decreased to 5 at 1115 hrs."

   What else should be included in the progress note?
   ____
   ____

4. Your three-year-old patient was started on regular q4h morphine four days ago. His mother informs you that his pain is under control, but he has not had a wet diaper in 10 hours. Should you be concerned? What should you do?
   ____
   ____

5. Which non-pharmacological pain management nursing interventions would be appropriate for a six-month-old? Which would be appropriate for a 12-year-old?
   ____
   ____

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Appendix A: Answers to Case Study Questions on Page 161

1. Yes. A pain assessment is the 5th vital and should always be conducted when you do a patient's vital signs, regardless of whether or not the parent believes the child is in pain. See page 155.

2. The neonatal infant pain scale or the FLACC pain measurement scale would both be appropriate for Molly. See pages 159.

3. Yes. Although Molly's mother does not believe she is experiencing pain because she is sleeping and hasn't been crying, this does not necessarily mean that Molly is pain free. Molly may be experiencing too much pain to move. The elevation in Molly's blood pressure/heart rate, tightening of her face muscles, furrowing of her brow, and tense arms/legs are all signs that an infant is experiencing pain. See page 160.

4. Data: Document Molly's abnormal vital signs, the behaviors you observed (sleeping in crib, tightened facial muscles, furrowing brows, tense arms/legs). Indicate which pain measurement tool you used and what her pain score was. Action: Document any pain management interventions you implemented (pharmacological vs. non-pharmacological). For example, administering a PRN analgesic, encouraging Molly's mother to rock and cuddle her. Response: Document Molly's response to the intervention by re-assessing and measuring her pain after the intervention using the same measurement tool. Compare Molly's pain score pre and post intervention to determine intervention efficacy. See page 161.

Appendix B: Answer to Case Study Questions on Page 2.21 169

1. According to Johnny's described behavior he would be scored an 8 on the FLACC pain scale. See page 159.

2. Yes. With a pain score of 8 Johnny requires a step 2 analgesic such as morphine. See page 163.

3. Explain to Johnny's dad that according to the FLACC scale and based on Johnny's behavior his pain score is an 8 which requires an opioid medication stronger than Tylenol. See pages 2.11 and 2.15. Also explain to Johnny's father that although morphine can cause severe respiratory depression it is extremely rare and does not normally happen when the correct dose is given. See page 167.

4. Based on the clenched jaw, tense legs and jerking you observed, it would be appropriate to discuss starting Johnny on a muscle relaxant such as Baclofen. See page 169.

Appendix C: Answers to Test your Knowledge Questions

Answers to true and false questions on page 174

1. False. Tingling is a word often used to describe neuropathic pain. See page 153.

2. True. The FLACC pain measurement tool is recommended for use in children less than three years of age and older non-verbal children. See page 159.

3. False. Codeine is not recommended for use in children. See page 165.

4. False. Inadequate pain management commonly requires dose escalation, not opioid rotation. See page 166.

5. True. Research has shown that stroking, rocking, and cuddling infants is a great non-pharmacological pain management intervention. See page 171.

Appendix D: Answers to Test your Knowledge Questions

Answers to short answer questions on page 175

1. Onset: definite with acute pain, ill-defined with chronic pain. Duration: limited with acute pain, persists longer than expected with chronic pain. Predictability: acute pain is predictable, chronic pain is unpredictable. Benefits: acute pain offers protective benefits, while chronic does not. Target: for acute pain target the injury or illness causing the pain, for chronic pain target the underlying disease if possible. Treatment: short-term use of analgesics for acute pain, regular use of analgesics and supportive care for chronic pain.

2. No, you should not be satisfied with a pain score decreasing from 6 to 5 two hours after administering an analgesic. Clearly the child is still experiencing significant pain and the Tylenol did not help very much. You should discuss moving the child to step 2 with the physician.

3. When documenting a pain assessment, under "data" you should always identify which measurement tool was used. In this case it was the numerical rating scale. Under "response" you should compare the pain score pre and post intervention to determine intervention efficacy. In this case, the child's pain score only went from a 6 to a 5, indicating the intervention was not very effective. You should also state your plan, for example "will contact resident to discuss switching analgesic."

4. Yes, you should be concerned that the child has not voided in 10 hours. Urinary retention is a side effect of morphine which is more common in children than in adults. More investigation is needed regarding the child's intake. You should contact the physician and discuss doing a bladder scan, and perhaps inserting a Foley catheter.

5. Non-pharmacological pain management interventions that would be appropriate for a six-month-old are breastfeeding, distraction, positioning, skin-to-skin contact, and touch. Non-pharmacological pain management interventions that would be appropriate for a 12-year-old are deep breathing, distraction, hot and cold therapy, positioning, and relaxation.

Learning Resource for Pediatric Palliative Care

Module 3: Symptom Management

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Module 3: Symptom Management

The purpose of this module is to provide information about symptom management in pediatric patients requiring palliative care, referred to in this resource as palliative care children. This module can be used by registered nurses (RNs), licensed practical nurses (LPNs), and any other healthcare professionals who care for palliative care children. This module may also be beneficial for anyone who simply wants to learn more on this topic.

The symptoms covered in this module are: 1) anorexia, 2) anxiety, 3) constipation, 4) cough, 5) delirium, 6) diarrhea, 7) dyspnea, 8) insomnia, 9) nausea and vomiting, 10) pruritis, 11) respiratory congestion, 12) seizure, and 13) terminal hemorrhage. The symptoms appear in alphabetical order. Information about each symptom is provided including the definition, causes, patients at risk, assessment, non-pharmacological management, and pharmacological management.

This module also contains reflection exercises, case studies, documentation tips, and self-tests.

Note that documentation will be similar for each symptom and will therefore be discussed at the end of the module rather than repetitively under each symptom.

Learning Objectives:

Upon completion of this module, you will be able to:
1. Define the various palliative care symptoms experienced by children;
2. Identify children who are at risk for experiencing each palliative care symptom;
3. Assess children for various palliative care symptoms and interpret assessment findings;
4. Implement non-pharmacological nursing interventions for management of various symptoms in palliative care children;
5. Identify which medications should be used for various palliative care symptoms in children in order to make recommendations, explain to parents, and question physician’s orders; and
6. Document appropriately and accurately symptom assessment and management interventions.

Table of Contents

Symptom Management

Symptom management in palliative care is the prevention and treatment of symptoms of a life-threatening illness, and the side effects caused by treatment of that illness[1]. Symptom management encompasses not only the physical symptoms, but also psychological, social, and spiritual problems related to the illness.

Good symptom management can improve the quality of life of a child with a life-threatening illness[1].

Symptom management consists of[1]:

- Identifying the cause of the symptom, if possible
- Ongoing communication with the child and their family (e.g., explanation of symptoms and treatment options, establishment of goals of therapy)
- Implementing therapy (e.g., treatment of underlying cause, pharmacological, physical, psychological and complementary)
- Reviewing and modifying the treatment/management plan as needed

Anorexia

Definition

Anorexia is the absence of appetite or desire to eat leading to reduced caloric intake resulting in weight loss[2].

Causes

Anorexia is common in palliative care children. There are many causes of anorexia in a palliative care child. Primary causes are related to metabolic changes from the underlying disease.

Secondary contributing factors include[2]:

- Fatigue
- Pain
- Dyspnea
- Depression
- Anxiety
- Nausea/vomiting
- Constipation
- Gastritis
- Infection

Patients at Risk

All palliative care children are at risk for anorexia, especially children experiencing any of the secondary contributing factors listed above.

Assessment

It is important for the nurse to ask the patient and/or their family how their intake has been. If the nurse is concerned about the patient's intake, he or she should:

- Monitor the patient's intake by filling out a caloric intake record daily
- Monitor the patient's weight by measuring and charting daily
- Discuss any concerns with the physician

Non-Pharmacological Management

Strategy	Nursing Role
Encourage Intake[1]	• Offer child frequent meals high in calories • Offer child their favorite snacks • Encourage parents to do the same
Incorporate nutrition support[1]	• Consult dietician for recommendations such as Boost or Ensure • Discuss enteral and parenteral nutrition with physician

Pharmacological Management

- Treat any secondary causes of anorexia such as, nausea/vomiting, gastroparesis, depression, infection or pain with appropriate medications
- Corticosteroids have been shown to stimulate appetite however effects may disappear after 3 to 4 weeks. Use beyond 6 to 8 weeks is not recommended[2].
- Research has not shown appetite improvement from cannabinoids[2]

Nutrition at End-Of-Life

- Enteral (tube) feeding is NOT recommended to manage weight loss in children at EOL as evidence does not show improvements in quality of life or wound healing[2]. Providing a child with tube feeds at end-of-life can prolong their suffering.
- TPN is NOT recommended at EOL as there is small benefit and increased risk for infection[2].
- Gradual reduction in nutritional intake is a natural part of end-of-life and is not starvation.

Deciding whether or not to provide a child with enteral or parenteral nutrition at end-of-life can be difficult. When making the decision, benefit vs. burden on the child should be considered. When the chance of recovery for a child is low or non-existent, it is ethical to stop medically provided foods and fluids. Doing so will decrease the child's suffering and lessen distressing symptoms such as nausea, vomiting, excessive secretions and urinary incontinence.

Parents / caregivers often find this upsetting and fear that their child will starve to death. This is untrue. Children at end-of-life can survive significant time periods with little oral intake and have minimum complaints during this time. Emphasis on improving distressing symptoms should be communicated to the parents[1].

Reflection Exercise

Think of a patient you cared for recently who was experiencing anorexia. Which secondary factors were contributing to the anorexia? Did you implement any pharmacological or non-pharmacological interventions? Were they helpful? Why or why not?

Anxiety

Definition

Anxiety is defined as an uneasy feeling of worry or nervousness typically about an event with an uncertain outcome.

Causes

The stress and unpredictability of having a life-threatening illness can cause a great deal of anxiety in many children. Anxiety is to be expected in a child with a life-threatening illness, especially as the illness progresses and there is fear of the unknown[1].

Patients at Risk

All palliative care children are at risk for having anxiety, especially:

- Children with a history of an anxiety disorder
- Children whose parents have an anxiety disorder
- Children who suffer from an unpredictable illness
- Children near the end-of-life stage

Note: Anxiety will further contribute to a child's pain and

Assessment

The nurse should monitor the patient for signs of anxiety such as[2]:

- Restlessness
- Increased heart rate
- Hyperventilation
- Sweating
- Trembling
- Insomnia
- Crying
- Expressing feelings of worry or nervousness

If the nurse believes the child is experiencing anxiety, they should discuss it with the physician.

Note: Many of the physical signs of anxiety are similar to signs of pain. See module 2 on pain assessment.

The nurse should encourage non-pharmacological management strategies to reduce anxiety such as:

Strategy	Nursing Role
Relaxation techniques[1]	• Teach older children/teens relaxation techniques such as deep breathing, guided imagery, and/or meditation • Play relaxing music that the child enjoys • Consult psychologist and/or music therapist
Distraction[1]	• Distract younger children by counting, singings, playing games, etc.
Clear communication[1]	• Maintain clear communication between the healthcare team and the child/family, providing knowledge of the underlying disease, treatment and/or management[1]. Children and families are less anxious when they are kept in the loop and know what to expect[1].

Many of these non-pharmacological management strategies can also be used to manage pain. Refer to module 2 on pain management for more information on these management strategies.

Pharmacological Management

Not all palliative care children who experience anxiety will require medical management. Non-pharmacological management techniques should be tried first. If there is no relief of the anxiety with non-pharmacological management then the nurse should discuss medical management with the physician. See the table below for common medications used for anxiety in children.

Medication	Route	Comments
Lorazepam	PO, SL, IV, Subcutaneous	• Anxiolytic • Sedating, expect drowsiness • May have an opposite effect on children causing agitation, shaking, hallucinations
Clonazepam	PO	• Anxiolytic • Sedating, expect drowsiness • Increase every 3 days as needed
Haloperidol	PO	• Antipsychotic • Sedating, expect drowsiness • May cause prolonged QT wave, avoid use in children with known dysrhythmia
Risperidone	PO	• Antipsychotic • Sedating, expect drowsiness • May cause prolonged QT wave, avoid use in children with known dysrhythmia

Medication	Route	Comments
		• Titrate every 1-2 days as needed
Olanzapine	PO	• Antipsychotic • Sedating, expect drowsiness • Children may be more sensitive to increased appetite and weight gain • Increase weekly if needed

Constipation

Definition

Constipation is defined as difficulty, discomfort, or delay in passing a bowel movement, and refers to a significant variation from the child's normal bowel movement habit[1]. Normal bowel function can range from three bowel movements a day, to one bowel movement every three days, or one bowel movement in up to two weeks in breast fed infants[1].

Causes

Common factors which contribute to constipation include[1]:

- Poor dietary intake
- Poor fluid intake
- Immobility
- Medications (Opioids, Anticholinergics, Antidepressants, Anticonvulsants, Antiemetics)
- Local factors (Anal fissures/infection, Previous constipation, Electrolyte disturbance e.g. hypercalcaemia, hypokalaemia)
- Metabolic disturbances (dehydration, hyperglycemia, hypokalemia, hypercalcemia)

Patients at Risk

Constipation is a common symptom seen in many palliative care children regardless of underlying disease or diagnosis. Patients particularly at risk include[1]:

- Children with a neurologic impairment (poor tone and reduced mobility)
- Children receiving opioids
- Children with reduced fluid and food intake

Assessment

The nurse should:

- Monitor bowel movements every shift
- Find out what the patient's "normal" bowel movement pattern is
- Monitor food and fluid intake every shift
- Review current medications for any that may contribute to constipation (opioids)
- Assess abdomen for distension, tenderness, and diminished bowel sounds
- Alert the physician of any abnormal findings or concerns you may have

Non-Pharmacological Management:

Strategy	Nursing Role
Increase hydration[1]	• Encourage the child to drink fluids • Discuss parenteral hydration with the physician
Increase fiber[1]	• Encourage foods like wheat bran, prunes, licorice, pear and prune juice[1] • If receiving enteral feeds discuss switching to one with fiber with the physician
Promote privacy/dignity[1]	• Provide privacy and promote independence during toileting if possible[1] • Avoid use of bedpans if possible[1]
Promote motility[1]	• Encourage mobility/movement as tolerated

Note: Untreated constipation in a palliative care child contributes to abdominal pain, anorexia, nausea, vomiting and overflow diarrhea[1].

Pharmacological Management:

- Oral laxatives are the first line of treatment in children such as sennosides, lactulose, or polyethylene glycol (PEG). Effectiveness for these laxatives are the same, so choice should be based on patient preference[2].
- If oral laxatives do not relieve the constipation, a suppository or a small enema may be necessary. Glycerin suppositories and small volume enemas are often effective. Larger volume enemas can lead to fluid and electrolyte disturbances. For refractory constipation an oil retention enema is often used.
- If diarrhea occurs in a child who is receiving laxatives, and overflow incontinence has been excluded, the laxative treatment should be modified according to the child's needs[1].

See the table below for common medications used for constipation in children:

Medication	Action	Route	Comments
Lactulose[2]	Osmotic laxative	PO	• 1-2 days • Sweet taste can deter children • Can cause bloating and cramping
Polyethylene Glycol[2]	Osmotic laxative	PO	• 1-3 days • Dissolve in liquid such as juice or water • No taste
Sennosides[2]	Stimulant	PO	• 6-12 hours

Medication	Action	Route	Comments
			- May cause excessive bowel spasms
Glycerin Suppository[2]	Osmotic, Lubricant	PR	- 15-30 mins - Avoid in neutropenic and thrombocytopenic patients
Micro Enema[2]	Osmotic, Softener	PR	- 5-60 mins - Avoid in neutropenic and thrombocytopenic patients
Mineral Oil Enema[2]	Softener	PR	- For refractory constipation - 2-15 mins - Warm to room temp before use

Generally, Polyethylene Glycol is the preferred oral laxative for use in children, as it has no taste and does not cause cramping or bowel spasms[1]. If an oral laxative is unsuccessful in relieving the child's constipation, a glycerin tip suppository is then administered. Enemas are generally used as a last resort[1].

Note: Suppositories and enemas are generally avoided in oncology patients due to their increased risk for infection and bleeding.

Note: Treatment for opioid induced constipation may require both a stimulant (e.g., sennosides), and an osmotic laxative to moisturize and to soften stool (e.g., lactulose or polyethylene glycol[2].

Note: Laxatives should always be started with opioids and should continue for the duration of opioid use. Refer to module 2 on pain for more information.

Constipation at End-Of-Life

During the end-of-life phase, significant discomfort related to constipation is uncommon. As fluid and oral intake are decreased, oral laxatives should be discontinued. A suppository or enema may help reduce rectal discomfort arising from the urge to defecate or if there is overflow incontinence from fecal impaction[1].

Case Study

Answer the following questions related to the case study below. Answers can be found in Appendix A at the end of the module.

Susan is a five-year-old girl with leukemia. She normally has a good appetite but for the past few days she has been refusing to eat. Her father has become very frustrated and you walk in on him begging her to eat a meal of chicken and vegetables that her mother brought in from home. You check Susan's vital signs which are within normal range. You perform an abdominal assessment which reveals her abdomen is slightly distended and tight. Her bowel sounds are present but hypoactive. You ask Susan's father when her last bowel movement was and he says, "she had a little bit of diarrhea today."

1. Could Susan be constipated? Why or why not?
2. What are some non-pharmacological interventions you could implement to help with Susan's anorexia?
3. What would you document in your progress note for Susan?

Cough

Definition

A cough is defined as the action of expelling air from the lungs with a sudden sharp sound. Although less common than other palliative care symptoms, some palliative care children do experience frequent coughing which can disrupt their quality of life.

Causes

- Bronchospasm
- Infection (e.g., respiratory viruses, pneumonia)
- Heart failure
- Pulmonary edema

Patients at Risk

- Children who experience dyspnea
- Children with a history of respiratory conditions (e.g., asthma, cystic fibrosis), heart failure or pulmonary edema

Assessment

The nurse should:

- Perform a respiratory system assessment at least once a shift auscultating the lungs, noting any adventitious sounds (e.g., wheeze, crackle, rhonchi)
- Monitor respiratory rate and oxygen saturation every time the vital signs are checked

- Ask the child and/or their parents if they have been coughing (important to note if the cough is productive/non-productive or wet/dry)
- Notify the physician of any abnormal findings or concerns you have

Non-Pharmacological Management[1]

Strategy	Nursing Role
Humidification	• Use a humidifier or a vaporizer in the child's room to help with a dry cough
Positioning	• During a coughing spasm place the child in an upright position
Avoid triggers	• If the child is prone to coughing spasms avoid cold drinks as they can be triggering

Pharmacological Management[1]

Medication	Route	Comments
Cetirizine	PO	• Antihistamine • Non-sedating
Diphenhydramine	PO	• Antihistamine • Sedating, expect drowsiness
Morphine	PO	• Use for persistent dry cough
Salbutamol	Nebulized	• Use for cough caused by bronchospasm
Local anesthetic agents	Nebulized	• Use for intractable cough • Will impair gag reflex for 1-2 hours, so avoid drinking/eating

Delirium

Definition

Delirium is defined as an abrupt onset of disturbance in attention and awareness that is different from baseline status[2]. Characteristics include changes in cognitive function, psychomotor behavior, mood, sleep-wake cycle, and hallucinations.

There are three types of delirium[2]:

- Hyperactive: restless, agitated, hallucinations more common
- Hypoactive: drowsy and withdrawn
- Mixed subtypes: fluctuates between both

Causes

There are many possible causes for delirium in the palliative care child[2]:

- Infection
- Metabolic disturbances

- Hypoxia
- Pain
- Sleep deprivation
- Constipation
- Dehydration
- Organ failure

Patients at Risk

All palliative care children are at risk for delirium particularly as end-of-life is near. Delirium often occurs 24-48 hours before death.

Assessment

The nurse should:

- Monitor the patient for signs of delirium[2]:
  - Acute onset
  - Attention disturbance
  - Restlessness
  - Agitated
  - Angry
  - Lethargy
  - Disorientation to person, place, time
  - Sleep-wake cycle disturbance
  - Memory impairment
  - Hallucinations
- Notify the physician of any signs of delirium or concerns you may have

Non-Pharmacological Management[2]

Strategy	Nursing Role
Identify underlying causes	• Assess and manage a full bladder • Assess and manage pain
Promote sleep	• Facilitate a sleep conductive environment at night time • Cluster care
Promote relaxation	• Promote a calm and quiet environment

Encourage the family to:

- Provide the child with gentle reassurance
- Use gentle touch and a soothing voice
- Do not discipline or argue with the child
- Play familiar music that the child likes
- For younger children, read them their favorite story and keep familiar objects such a special blanket or teddy bear near them

Pharmacological Management

- Identify and treat reversible underlying causes

See table below for common medications used to manage delirium[2]:

Medication	Route	Comments
Risperidone	PO	• Antipsychotic (generally avoided as there is a lack of evidence of benefit without harm) • Sedating, expect drowsiness • May cause prolonged QT wave, avoid use in children with known dysrhythmia • Titrate every 1-2 days as needed
Olanzapine	PO	• Antipsychotic (generally avoided as there is a lack of evidence of benefit without harm) • Sedating, expect drowsiness • Children may be more sensitive to increased appetite and weight gain • Increase weekly if needed
Quetiapine	PO	• Increase daily as needed
Benzodiazepines (Lorazepam, Clonazepam)	PO, Buccal, IV, Subcutaneous	• Use only for alcohol or sedative drug withdrawal • Sedating, expect drowsiness • May have an opposite effect on children causing agitation, shaking, hallucinations
Haloperidol	PO, IV, Subcutaneous	• Antipsychotic • Less sedating than Midazolam • Use when delirium is moderate to severe, and patient is at risk of harming themselves/others or is causing distress to the family • Can be administered as continuous infusion • May cause prolonged QT wave, avoid use in children with known dysrhythmia
Midazolam	Buccal, PO, Intranasal, IV	• Extremely sedating • Use when delirium is moderate to severe, and patient is at risk of harming themselves/others or is causing distress to the family • Can be administered as a continuous infusion

Note: Some children may sense the presence of deceased loved ones, angels, or spirits. Allow the family to interpret this as they wish, as it may be related to spiritual or cultural beliefs and may comfort the family[2].

Reflection Exercise

Think of a patient you cared for recently who was experiencing delirium. Were they experiencing hyperactive, hypoactive or mixed subtypes? Did you implement any pharmacological or non-pharmacological interventions? Were they helpful? Why or why not?

Diarrhea

Definition

Diarrhea is an increase in frequency and wateriness of the stool. Typically, a child is considered to be having diarrhea if they are passing more than three watery stools a day[3].

Causes[3]

- Infection such as rotavirus or *Clostridum difficile*
- Intermittent bowel obstruction
- Fecal impaction
- Chemotherapy
- Medication side effects (antibiotics)
- Malabsorption

Patients at Risk

Diarrhea is not common in palliative care[2]. However, children receiving chemotherapy or antibiotics are at risk.

Assessment

The nurse should:

- Monitor the child's intake and output every shift
- Monitor the child's stools for color, odor, consistency and any mucous or blood
- Keep a stool chart
- Assess the child for signs of dehydration
- Perform an abdominal assessment at least once a shift monitoring for abdominal distension, tenderness, or diminished bowel sounds
- Notify the physician of any abnormal findings or concerns you may have

Note: The nurse should pay extra attention to the hygiene and skin care of the peri-anal area in a child experiencing diarrhea.

Non-Pharmacological Management

Non-pharmacological strategies to manage diarrhea include[3]:

Strategy	Nursing Role
Hydration	• Encourage oral rehydration solutions such as Gatorade or Pedialyte • Discuss parenteral hydration with the physician
High carb diet	• Encourage BRAT diet: banana, rice, applesauce, toast • If receiving enteral feeds, discuss changing regimen or reducing feed volume with the physician

Pharmacological Management[1]

- Discontinue any laxatives

Medication	Route	Comments
Loperamide	PO	• Well tolerated and effective
Octreotide	IV, Subcutaneous	• Last resort for intractable diarrhea
Morphine	PO, Subcutaneous	• See pain module

Dyspnea

Definition

Dyspnea is defined as the uncomfortable feeling of being short of breath which may or may not be associated with hypoxia[2].

Causes

There are many causes of dyspnea in a palliative care child[2]:

- Pulmonary: airway obstruction, asthma, damage from chemotherapy, radiation or surgery, emboli, fibrosis, effusion, primary or metastatic tumor
- Cardiac: congenital heart failure, arrhythmias, pericardial effusion
- Neuromuscular conditions which cause problems with the muscles for breathing
- Other: Anxiety, fatigue, weakness, pain, severe anemia, infection, peritoneal effusion

Patients at Risk

- Children with tumors on the lungs or pushing on the diaphragm
- Children with lung disease
- Children with neuromuscular conditions

Assessment

The nurse should:

- Perform a respiratory system assessment at least once a shift auscultating the lungs, noting any adventitious sounds (e.g., wheeze, crackle, rhonchi)
- Monitor respiratory rate and oxygen saturation every time the vital signs are checked

- Ask the child and/or their parents if they are having any trouble breathing or shortness of breath
- Notify the physician of any abnormal findings or concerns you have

Note: Dyspnea can cause much anxiety for the child and their parents / caregivers. The nurse should react in a calm and reassuring manner to help reduce anxiety.

For general prevention and management[2]:

Strategy	Nursing Role
Reduce pressure on the diaphragm	Encourage small frequent meals
Positioning	Encourage the child to sit upright supported by pillows If child must lay down, keep the head of bed elevated 15-45 degrees with arms elevated on pillows
Relaxation	In older children/teens, teach relaxation techniques and breath control methods such as, pursed lips and diaphragmatic breathing
Humidification	Use a humidifier in the room or humidified air via blowby

During an acute episode of dyspnea[2]:

- Maintain a calm environment
- Place a fan on the child's face to increase air movement
- Suction secretions if indicated
- Do not leave the child alone
- Oxygen is only helpful for hypoxic children, medical air via mask or nasal prongs may be helpful for non-hypoxic children

Pharmacological Management

See the table below for common medications used to treat dyspnea in children[1]:

Medication	Route	Comments
Salbutamol	MDI or nebulized	• Bronchodilator • Useful if bronchospasms are present or the child has a history of asthma
Methylprednisolone	Inhaled or IV	• Corticosteroid • Useful if the child has bronchial hyper-activity • Prolonged use not recommended
Morphine	PO, IV, SC, or nebulized	• Opioid • First line of pharmacological treatment • Moderates reflexive drive to breathe • Decreases awareness of dyspnea

		• Lower dose required than for pain • At end-of-life often combined with midazolam in IV infusion
Diazepam Midazolam Lorazepam	PO or IV	• Benzodiazepine • Dyspnea can be very frightening / anxiety provoking • Helps to reduce anxiety, agitation, and distress

Case Study

Answer the following questions related to the case study below. Answers can be found in Appendix B at the end of the module.

Andrew is a nine-year-old boy with a rare form of muscular dystrophy. Recently he has been experiencing dyspnea due to muscle weakness. You are doing a respiratory assessment on Andrew when he experiences an episode of dyspnea. His chest sounds are clear with good air entry bilaterally. His oxygen saturation is 92% on room air. Andrew begins hyperventilating and grabbing at his chest/throat saying “I can’t breathe! I need oxygen!”.

1. Which non-pharmacological interventions would you consider for Andrew?
2. Would you administer oxygen to Andrew via nasal prongs?
3. Would you administer any PRN medications? If so, which ones?

Insomnia

Definition

Insomnia is defined as the inability to sleep.

Causes

There are often many factors contributing to insomnia such as:

- Pain
- Discomfort
- Depression
- Anxiety
- Neurologic conditions
- Environmental factors

Patients at Risk

Sleep disturbances are common in palliative children. Those experiencing any of the causes listed above are particularly at risk.

Assessment

The nurse should always ask the patient and/or their parents/caregivers how the child is sleeping. During night shifts the nurse should notice the child's sleeping patterns whenever entering the room.

Non-Pharmacological Management

Strategy	Nursing Role
Promote an environment conductive to sleep	• Cluster the child's care • Reduce light and noise as much as possible • Play relaxing music • Stick to the child's bedtime routine as much as possible

Pharmacological Management

See the table below for common medications used to manage insomnia in children[1]:

Medication	Route	Comments
Melatonin	PO	• Give before bed
Clonidine	PO	• Give before bed • Increase slowly as needed
Trazodone	PO	• Give before bed • Increase every 1-2 weeks as needed
Zolpidem	PO	• Give before bed • Children may experience dizziness and hallucinations

Reflection Exercise

Have you ever experienced insomnia? If so, which factors were contributing to your inability to sleep? Did you try any non-pharmacological strategies to help you fall asleep? Were they helpful? Is there something else you could have tried?

Nausea and vomiting

Definition

Nausea is defined as an unpleasant sensation of needing to vomit[2]. *Vomiting* is defined as the forceful ejection of gastric contents through the mouth and/or nose[2]. Nausea and vomiting are common symptoms experienced by palliative care children often impairing quality of life.

Causes

There are many reasons why a palliative care child can become nauseated or vomit. Common causes include[1]:

- Opioids and other drugs

- Chemotherapy
- Gastro-intestinal inflammation
- Raised intracranial pressure (ICP)
- Metabolic disturbances
- Constipation
- Infection

Patients at Risk[1]

- Children taking opioids
- Children receiving chemotherapy
- Children with brain tumors (increased ICP)
- Children with metabolic disturbances
- Children with infections

Assessment

The nurse should:

- Perform an abdominal assessment on all patients at least once a shift monitoring for abdominal distension, tenderness, diminished or hyperactive bowel sounds
- Discuss any abnormal findings with the physician

If the child begins to experience nausea and/or vomiting:

- Monitor for signs of dehydration (e.g., absence of tears during crying, dry mucous membranes, sunken fontanelles in newborns)
- Monitor for signs of infection (e.g., fever)
- Monitor for signs of drug toxicity
- Monitor for signs of raised ICP (headache, cranial nerve signs especially in the morning, vomiting without nausea)
- Discuss any concerns with the physician

Non-Pharmacological Management[1]:

Strategy	Nursing Role
Prevent dehydration	• Promote sips of water, juice or flat soft drinks • Encourage foods with lots of water such as soup, ice chips and Jell-O • Discuss enteral hydration with the physician
Reduce nausea	• Suggest aromatherapy such as ginger and peppermint • Encourage the child to chew ginger pieces
Manage nutrition	• Offer bland foods or salty foods/snacks • If the child is receiving enteral nutrition, discuss altering feed rates with the physician (e.g. slow continuous feed instead of bolus feeds)

Pharmacological Management:

- In order to medically treat nausea and vomiting the cause should first be determined
- Antiemetic drugs target different brain receptor sites therefore the medication chosen should depend upon the most likely reason for the nausea or vomiting
- Vomiting caused by severe constipation should be relieved with adequate constipation treatment

See the table below for common medications used to manage nausea and vomiting in children[1,2]:

Medication	Route	Indication	Comments
Ondansetron	PO, IV	• Drugs (steroids, opioids, chemotherapy) • Metabolic disturbances (e.g. hypercalcemia) • Toxins (e.g. infection)	• QTc prolongation risk • Avoid IV ondansetron when using IV metoclopramide
Dimenhydrinate	PO, IV	• Drugs (steroids, opioids, chemotherapy) • Metabolic disturbances (e.g. hypercalcemia) • Toxins (e.g. infection) • Raised intracranial pressure (ICP) • Bowel obstruction • Severe constipation	• Sedating, expect drowsiness
Metoclopramide	IV	• Drugs (steroids, opioids, chemotherapy) • Metabolic disturbances (e.g. hypercalcemia) • Toxins (e.g. infection)	• Avoid IV ondansetron when using IV metoclopramide
Lorazepam	Sublingual	• Anxiety • Pain • Emotional factors	• Anxiolytic • Sedating, expect drowsiness • May have an opposite effect on children causing agitation, shaking, hallucinations

Medication	Route	Indication	Comments
Dexamethasone	PO, IV	- Raised ICP	- Long-term use associated with weight gain, behavioral changes, fragile skin, eventually steroid resistance
Omeprazole	PO	- GI inflammation (secondary to NSAIDs, steroids)	- May interact with certain chemotherapy drugs
Ranitidine	PO, IV	- GI inflammation (secondary to NSAIDs, steroids)	- Administer in the evening

Note: Children with a possible gut obstruction should avoid stimulant agents such as metoclopramide as they can aggravate the obstruction resulting in increased pain.

Pruritis

Definition

Pruritis is defined as an intense cutaneous discomfort creating the urge to scratch[2].

Causes

There are many different causes for pruritis in a palliative child such as:

- Skin conditions
- Systemic disease
- Neurologic conditions
- Uremia
- Biliary obstruction
- Medication side effects
- Psychological factors

Assessment

The nurse should:

- Monitor all patients for any scratching or itchiness
- Monitor all patients for any skin rashes
- Ask the child and/or the parents if the child has been itchy and/or if they have been scratching

Non-Pharmacological Management:

If a child is experiencing itchiness[1]:

Strategy	Nursing Role
Keep skin hydrated	• Moisturize skin with a fragrance-free cream-based emollient
Avoid scratching	• Instruct the child and/or parents to avoid scratching • Keep fingernails and toenails short to avoid scratching • Use cotton gloves to cover the hands in young children with a strong urge to scratch
Keep skin clean and dry	• Encourage short baths with lukewarm water, mild or low pH soaps, and the addition of sodium bicarbonate to the bath water • Inform parents to dry the child's skin gently by patting with a soft towel • Maintain a cool room temperature and avoid rapid temperature changes • Encourage the child to wear loose cotton clothing • Use cotton bedding

Pharmacological Management:

- Gabapentin has been found effective in reducing pruritis due to cancer, opioids and burns

See the table below for common medications used to manage pruritis in children[2]:

Medication	Route	Indication	Comments
Promethazine hydrochloride	PO	• Histamine reaction	• Antihistamine • Sedating, expect the child to be drowsy
Trimeprazine	PO	• Eczema • Medication reactions • Chickenpox	• Antihistamine • Sedating, expect the child to be drowsy
Cetirizine	PO	• Histamine reaction	• Antihistamine • Non-sedating
Loratadine	PO	• Histamine reaction	• Antihistamine • Non-sedating
Doxepin	PO	• Cholestasis • Psychogenic	• Tricyclic anti-depressant • Can cause dry mouth (xerostomia) • Sedating, expect the child to be drowsy

Medication	Route	Indication	Comments
			• More effective than hydroxyzine or diphenhydramine • QTc prolongation if dose over 100 mg per day
Paroxetine	PO	• Cholestasis • Solid tumors • Paraneoplastic disorders • Opioid-induced	• Selective serotonin uptake inhibitor • Nausea, vomiting and drowsiness • Lower dosing required in severe renal or hepatic impairment • Use caution in seizure disorder patients • Avoid abrupt discontinuation • Antipruritic effect may disappear after 2-3 months of use
Gabapentin	PO	• Lymphoma • Opioid-induced • Uremia • Burns • Failure of other treatments	• Drowsiness, dizziness, fatigue, ataxia, peripheral edema, visual disturbances, unsteadiness • Adjust dose for reduced renal function • Very few drug interactions
Topical corticosteroid	Topical	• Atopic dermatitis	

Reflection Exercise

Think of a patient you cared for recently who was experiencing pruritis. What was the cause? Did you implement any non-pharmacologic interventions? If so, did they work? Did you implement any pharmacologic interventions? Were they effective? Is there anything else you could have tried?

Respiratory Congestion

Definition

The term respiratory congestion describes the noise produced by the movement of excessive secretions in the upper airway of a dying person. The excessive secretions are produced by the salivary glands when the person is unable to swallow due to a reduced level of consciousness or extreme weakness[2].

Respiratory congestion has also been referred to as:

- Noisy respirations
- Noisy breathing
- Respiratory tract secretions
- Excess secretions
- Death rattle

Note: Respiratory congestion has been reported to predict death in 75% of palliative patients, often within 48 hours of onset[2].

Although excess respiratory secretions are not associated with respiratory distress, they may cause anxiety and fear in a child that is alert. The child's family may also find the sound upsetting and fear that their child is drowning.

Note: Avoid using the term *death rattle* with patients and families.

Causes

Excessive oropharyngeal secretions plus a weak gag/cough reflex causes pooling of secretions and saliva in the airway[2].

Patients at Risk

Excess secretions are a common and expected symptom at the end-of-life stage. Children especially at risk include those with[2]:

- Cystic fibrosis
- Neurodegenerative diseases
- Tumors in the brain or lungs
- Prolonged dying phase
- Pneumonia
- Superior vena cava syndrome

Assessment

The nurse should:

- Perform a respiratory system assessment at least once a shift auscultating the lungs, noting any adventitious sounds (e.g., wheeze, crackle, rhonchi)
- Monitor respiratory rate and oxygen saturation every time the vital signs are checked
- Notify the physician of any abnormal findings or concerns you have

Non-Pharmacological Management[2]

Strategy	Nursing Role
Positioning	• Position the child upright with the head of the bed raised 30-45 degrees and turn head to the side to allow secretions to drain
Mouth care	• Gentle oral-pharyngeal suctioning for the presence of copious secretions in the oropharynx as needed (avoid suction below the oropharynx as it is more distressing than helpful) • Provide regular mouth care as needed
	• Keep air in the room well humidified • Discuss decreasing fluid intake with the physician
Provide reassurance	• Reassure the family that respiratory congestion or noisy breathing is expected and is a normal part of the dying process

Note: Oxygen is not beneficial for noisy breathing.

Pharmacological Management[1]

Pharmacological management is usually always required for respiratory congestion. As soon as respiratory congestion begins the child should be medicated to avoid distress for the family. See the table below for medications commonly used to manage respiratory secretions in children.

Medication	Route	Comments
Hyoscine hydrobromide	Subcutaneous	• First choice drug • May be sedating
Glycopyrrolate	Subcutaneous, IV	• Selective and prolonged effect on salivary/sweat gland secretions • Consider use if hyoscine ineffective
Atropine	Subcutaneous, IV, Sublingual	• May be stimulating • May cause tachycardia

Seizure

Definition

A seizure is a sudden surge of electrical activity in the brain[4]. Seizures vary in intensity and type and may cause an absent stare, muscle rigidity, cyanosis and an altered state of consciousness lasting from 1-4 minutes[2].

Status epilepticus is the term given to a seizure lasting 5 minutes or longer, or repeated seizures without regaining consciousness between them[2].

Causes

- Seizure disorder (epilepsy)
- Brain tumor or increased ICP
- Electrolyte imbalances (hypoglycemia, hyponatremia, hypercalcemia)
- Fever
- Infection / Sepsis

Patients at Risk

Many palliative care children are at risk for seizures, such as children with:

- Brain tumors
- Raised ICP
- Intracranial hemorrhage
- Metabolic disturbances (hypoglycaemia, hyponatraemia, hypocalcaemia, hepatic encephalopathy)
- Infection and fever
- History of seizures or a known seizure disorder
- History of recreational drug or alcohol use (teens)

Assessment

The nurse should monitor the patient for any signs of seizure activity, such as:

- Absent staring
- Eye rolling
- Repetitive blinking
- Repetitive hand movements
- Muscle rigidity
- Jerking of limbs
- Cyanosis
- Altered state of consciousness

As soon as the nurse is alerted or notices that the patient is having a seizure, he/she should begin timing the seizure. It is important to know how long the seizure lasts.

> **Note:** Witnessing a seizure can be very upsetting for parents and caregivers. Provide support to parents as appropriate.

Non-Pharmacological Management

During a seizure the nurse should:

Strategy	Nursing Role
Monitor	• Begin to time the seizure as soon as you notice it
Ensure comfort	• Do not attempt to restrain the child • Do not force anything into the child's mouth • Loosen any tight clothing around the child's neck
Maintain airway	• Ensure oxygen and suction are readily available at the bedside • Apply oxygen if patient is not actively dying • When the seizure has stopped turn the patient on to their side until they are fully alert

Pharmacological Management

- Children with a history of a seizure disorder will typically be on regular anticonvulsants and these should be continued
- Control of seizures may be lost if the child becomes unable to tolerate their medication[1]
- During a seizure, emergency medications such as sublingual or intranasal Midazolam or Lorazepam should be administered
- If a child is prone to seizures or the physician believes the child will experience one, emergency medications should be ordered and readily available
- If it is likely that a child will experience seizures, regular anticonvulsants as maintenance treatment should be discussed with the physician[1]

See the table below for common medications used to control/manage seizures in children[1]:

Medication	Treatment Type	Route	Comments
Phenytoin	Maintenance	PO	• Used for prevention of tonic-clonic and focal seizures and focal seizures • May cause dizziness or drowsiness
Phenobarbitone	Maintenance	PO	• Used to control tonic-clonic and simple partial seizures • May cause dizziness or drowsiness • Often causes excitement instead of drowsiness in young children

Medication	Treatment Type	Route	Comments
Carbamazepine	Maintenance	PO	• Used for treating complex partial seizures, generalized tonic-clonic seizures and simple partial seizures • May cause dizziness or drowsiness
Diazepam	Emergency	IV, PR	• May give q15 mins x 3 doses
Clonazepam	Emergency	PO, IV, Subcut, PR	• Sedating, expect drowsiness
Midazolam	Emergency	IV, Subcut, SL, Intranasal	• Extremely sedating, expect drowsiness
Lorazepam	Emergency	IV, Subcut, SL, PR	• Sedating, expect drowsiness • May give q15 mins x 2

Seizure at End-Of-Life

Status epilepticus should be controlled even in the unconscious patient near death due to the distress that seizures cause to the patient's family[2].

Reflection Exercise

Think of the first time you witnessed a seizure. Were you surprised? How did you feel? Consider how a parent may feel the first time they witness their child have a seizure. How could you help them?

Terminal Hemorrhage

Definition

A terminal, catastrophic, or massive hemorrhage is rapid, massive blood loss which leads to the death of a patient within minutes[5]. Although rare, terminal hemorrhages are a palliative care emergency. A massive hemorrhage is extremely distressing for the patient, their family, and the nurse[5].

Causes

A massive hemorrhage is caused by either[5]:

1. Local insult to a major blood vessel as a result of surgery, radiotherapy, or tumor invasion
2. A systemic process such as coagulopathy, thrombocytopenia, disseminated intravascular coagulation (DIC), or coagulopathy.

Patients at increased risk for a terminal hemorrhage[5]:

- Children with head and neck tumors
- Children with hematological malignancies (cancers of the blood i.e. leukemia)
- Children with fungating tumors (when a tumor under the skin breaks through the skin)
- Children with GI tumors with previous bleeding
- Children with tumors close to major blood vessels
- Children with hematologic complications such as thrombocytopenia, DIC, or coagulopathy
- Children taking anti-coagulants, NSAIDS or steroids
- Children with thrombocytopenia (low platelets)

Warning Signs:
Terminal hemorrhages are difficult to predict, and some patients may not have any predisposing signs or symptoms. However, there are some warning signs to watch for which may indicate an impending terminal bleed[5]:

- Any bleeding at all regardless of how minimal
- Ballooning or visible pulsing arteries

Assessment

The nurse should:

- Monitor the patient for any bleeding at all. Common sites for bleeding are the mouth/gums, eyes, nose, and anus
- Monitor the patient for any signs of internal bleeding such as bruising and petechiae
- Monitor the patient for any ballooning or visible pulsing arteries
- Notify the physician of any bleeding or concerns you may have

Non-Pharmacological Management[2,5]:

Although bleeding is not painful for the child, it can be a very frightening event for the child and anyone who witnesses it. A terminal bleed can have a lasting impact on the family's experience at the time of death and can affect their grief and bereavement. Special care must be taken by the nurse to make the event as least traumatizing as possible for the child and their family[2].

Strategy	Nursing Role
Be present	• Do not leave the patient; this is considered the most important intervention
Provide reassurance	• Remain calm; do not panic • Speak reassuringly to the child letting them know you are with them and will not leave

	• Reassure the family that the child is not in pain and that the event was anticipated
Keep the child comfortable	• Keep the child's face clean with cool wet clothes
Minimize trauma	• Use dark towels and blankets to reduce visibility of the blood

Pharmacological Management:

If the child is alert, sedation should be administered as quickly as possible to reduce distress[1]. See the table below for information on commonly administered sedative medications.

Medication	Route	Comments
Midazolam	IV, IM, Subcutaneous	• Can be administered as a continuous infusion • Will sedate the child
Lorazepam	IV, Subcutaneous	• Can be administered as a continuous infusion • Will sedate the child

Platelet transfusion.

During curative treatment platelet transfusions are given to children when their platelet count drops below a defined level. However, in palliative care platelet transfusions are usually only given for significant bleeding such as nosebleeds, bleeding gums or gastrointestinal bleeding[1].

Note: Deciding whether to transfuse the child with platelets should always be discussed with the parents/caregivers.

Other Bleeding

Other types of bleeding may also occur in a palliative care child. Although a terminal hemorrhage is the most distressing, any active bleeding at all can be frightening for the child and their parents/caregivers. The nurse should monitor the child for[1]:

- Subconjunctival hemorrhages (blood in the eyes:) although distressing, the nurse should reassure the child and their parents/caregivers that these bleeds are not life threatening, do not impair vision, and no treatment is necessary.
- Epistaxis (nosebleed): apply gentle pressure on the bridge of the nose, or an ice pack on the back of the neck to stop the bleeding.
- Bleeding gums
- Bloody stools
- Hematuria (blood in the urine)

Documentation

Every time any symptom assessment is conducted the nurse must document it in the progress note.

Data:

- Include in quotations any words that the patient (or their parent) used to describe their symptom
- Include any physical findings that you observe

Action:

- Document any symptom management intervention(s) you implemented (both pharmacological and non-pharmacological)

Response:

- Document the patient's response to the intervention by re-assessing them for the symptom after the intervention is implemented
- Compare their symptom pre and post intervention to determine intervention efficacy
- Continue to monitor as necessary

Test your Knowledge

Identify each statement as true or false. Answers can be found in Appendix C at the end of the module.

1. Not telling a school age child their treatment/management plan will help reduce their anxiety. ___
2. A child who had a watery stool is experiencing diarrhea. ___
3. Children with brain tumors have an increased risk for nausea and vomiting. ___
4. Respiratory congestion often predicts that death will occur within 48 hours. ___
5. The first thing you should do if your patient experiences a terminal hemorrhage is to go and get help. ___
6. You should encourage caloric intake in a child by offering them high in calories and their favorite foods. ___
7. No intervention is required for status epilepticus in a child near death. ___
8. A cold drink of water can be helpful to prevent coughing spasms. ___
9. Encouraging small frequent meals can help prevent dyspnea. ___
10. Gabapentin can be used to reduce pruritis. ___

Test Your Knowledge

Complete the following short answer questions. Answers can be found in Appendix D at the end of the module.

1. Define respiratory congestion.
2. What are the possible causes of delirium in a palliative care child?
3. Which medications should be used to treat nausea in a child with raised ICP?
4. Which non-pharmacological interventions should you implement for a child with insomnia?
5. Which medication should be administered to a child experiencing a terminal hemorrhage?
6. How should you assess a child for anorexia?
7. What non-pharmacological interventions should you implement during an acute episode of dyspnea?
8. Which seizure medications should be used for emergency management?
9. Which medication is first-choice for relieving constipation in children? If it does not provide relief what should be given next?
10. Which medications are used for dyspnea?

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Appendix A: Answers to Case Study Questions on Page 191

1. Yes, it is likely that Susan is constipated. Although her father stated that she had "a little bit of diarrhea" she could have been experiencing overflow.

2. You could offer Susan small frequent meals or her favorite foods instead of the chicken meal her mother made at home. You could encourage her to have a nutrition support drinks such as Boost or Ensure. You could also consult a dietician for recommendations or discuss starting NG feeds or TPN with the physician.

3. Data: include in quotations any words that the patient (or their parent) used to describe their symptom. Include any physical findings that you observe.
   For example: *"Abdomen tight and slightly distended. Hypoactive bowel sounds x 4 quadrants. Vitals stable. Susan is refusing to eat today. No food intake thus far. Father reports Susan had "a little bit of diarrhea today."*

   Action: document any symptom management intervention(s) you implemented (both pharmacological and non-pharmacological).
   For example: *"Susan offered chocolate flavored Boost drink. Father encouraged to offer Susan small frequent meals instead of large meals at once, and her favorite foods."*

   Response: document Susan's response to the intervention(s) by re-assessing after the intervention is implemented.
   For example: *"Susan drank 100 mls of Boost. Will continue to encourage her to drink."*

Appendix B: Answer to Case Study Questions on Page 198

1. Appropriate non-pharmacological interventions for Andrew would be relaxation techniques, breath control methods, positioning upright supported by pillows, maintain a calm environment, medical air via mask or nasal prongs may be helpful for non-hypoxic children, place a fan on his face. Most importantly, do not leave Andrew alone.

2. No, Andrew is not hypoxic therefore oxygen would not be beneficial. Instead, you could administer medical air via nasal prongs or a mask for comfort.

3. Yes, you could administer PRN medications such as an opioid (first line of pharmacological treatment) and a benzodiazepine such as lorazepam for his anxiety/panic.

Appendix C: Answers to Test your Knowledge Questions

Answers to true or false questions on page 213

1. False. Clear communication between the healthcare team and the child/family will help reduce anxiety. See page 187.

2. False. A child is considered to be having diarrhea if they are passing more than three watery stools a day. See page 195.

3. True. See page 200.

4. True. See page 205.

5. False. The most important intervention for a terminal hemorrhage is to stay with the patient. See page 210.

6. True. See page 185.

7. False. See page 209.

8. False. See page 192.

9. True. See page 197.

10. True. See page 213.

Appendix D: Answers to Test your Knowledge Questions

Answers to short answer questions on page 214

1. Respiratory congestion is the noise produced by the movement of excessive secretions in the upper airway of a dying person. See page 204.

2. Infection, metabolic disturbances, hypoxia, pain, sleep deprivation, constipation, dehydration, and organ failure can all cause delirium. See pages 192-193.

3. Dimenhydrinate and dexamethasone are used to treat nausea caused by raised ICP. See page 201-202.

4. Cluster the child's care, reduce light and noise as much as possible, play relaxing music, stick to the child's home bedtime ritual as much as possible for example, bath and bedtime story before bed. See page 199.

5. Sedate the child as quickly as possible to reduce distress using midazolam or lorazepam. See page 211.

6. Ask the patient and/or their family how the child's intake has been, monitor the child's intake by filling out a caloric intake record daily, monitor the patient's weight by measuring and charting daily. See page 185.

7. Maintain a calm environment, place a fan on the child's face to increase air movement, suction secretions if indicated, do not leave the child alone, apply oxygen if the child is hypoxic, otherwise apply medical air via mask or nasal prongs. See page 197.

8. Diazepam, Clonazepam, Midazolam and Lorazepam. See page 209.

9. Polyethylene Glycol is the first-choice medication for relief of constipation in children as it has no taste and does not cause cramping or bowel spasms. If an oral laxative is unsuccessful in relieving the child's constipation, a glycerin tip suppository is then administered. Enemas are generally used as a last resort. See page 190.

10. Opioids, bronchodilators, corticosteroids, and benzodiazepines. See page 197.

Learning Resource for Pediatric Palliative Care

Module 4: End-Of-Life

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Module 4: End-Of-Life

The purpose of this module is to provide information about end-of-life (EOL) care for pediatric patients. This module can be used by registered nurses (RNs), licensed practical nurses (LPNs), and any other healthcare professionals who care for children at EOL. This module may also be beneficial for anyone who simply wants to learn more on this topic.

This module contains information, reflection exercises, case studies, documentation tips, tools for practice, and self-tests.

Learning Objectives:

Upon completion of this module, you will be able to:

1. Recognize the physical signs that death is near;
2. Identify appropriate nursing interventions for various physical symptoms of the dying process;
3. Provide parents and families with emotional support during their child's dying process;
4. Provide post-mortem care according to the guidelines at the Janeway;
5. Recognize normal responses to grief and identify appropriate interventions;
6. Implement strategies to prevent staff burnout; and
7. Document appropriately and accurately the death of a patient.

Table of Contents

End-Of-Life

End-of-life (EOL) is defined as the final days and hours of a person's life. During the dying process major organ functions are progressively impaired as the body begins to shut down. This is usually a series of physical changes that do not require invasive interventions[1]. The goal for EOL care is to keep the patient as comfortable as possible.

End-Of-Life Physical Symptoms

It is impossible to predict the exact time of a child's death, however there are some recognizable physical changes that indicate death is getting closer.

Note: Remind the parents that these physical changes are an expected part of the dying process.

Confusion and Mental Changes

The child may become drowsy, restless, easily confused, or irritable. They may withdraw and not want to talk, or they may talk about seeing or hearing things that others cannot see or hear. Hearing is often the last sense lost, so even though the child may not be able to respond, this does not mean that they cannot hear[2].

Loss of awareness is common, however some children will remain alert and responsive until the moment of death, while others will become semiconscious or unconscious for days to hours before[1].

The nurse should[2]:

- Keep the atmosphere quiet and calm
- Speak to the patient in soothing tones
- Hold the patient's hand and remind them that you are there
- Share the names of people in the room with them
- Do not correct what they may see or hear
- Encourage the family to talk to the child
- Play the child's favorite music, or read them their favorite story

If the child becomes extremely restless or agitated, the nurse should discuss pharmacological management with the physician. Medications such as midazolam or clonazepam may be required[1].

Note: A continuous parenteral infusion of morphine and midazolam in a syringe pump is commonly administered at EOL to control pain, agitation and restlessness[1]. The goal is not to hasten death, but to sedate the child so that he/she is not feeling intolerable symptoms.

Eating and Drinking

It is normal for the child not to want to eat or drink very much, or even at all. The child may also have trouble swallowing. Trying to force a child to eat or drink at the EOL phase can cause them much distress and discomfort. They may also feel upset that they are not able to eat or drink when their parents want them to[2]. Enteral and parenteral feeding and hydration have been shown to cause discomfort to patients during the end-of-life phase and should be avoided.

The nurse should[2]:

- Try encouraging intake by giving the child small portions of soft food, and sips of drink, popsicles, or ice chips if they are requesting food or drink
- Educate the parents not to force the child to eat or drink if they do not want to
- Moisturize the lips and keep mouth moist with damp sponge swabs

Eye Changes and Vision

The child may experience reduced or blurry vision. The pupils of a child at EOL may become fixed and dilated, and their eyes may become sunken or bulging[1].

The nurse should:

- Use soft or dim lighting such as a small lamp or night light
- Apply a small damp dressing over a bulging eye to provide comfort
- Remove any eye secretions with a warm damp cloth

Hearing

The child's hearing may seem overactive and the child may experience extra sensitivity to sound[2].

The nurse should[2]:

- Avoid loud noises
- Avoid turning on the TV
- Play soothing music that the child enjoys

Circulatory Changes

The child's hands, feet, and face may feel cold to touch, and appear pale or even a blue-purple color due to a decrease in the circulation of blood to the extremities. This does not necessarily mean that the child is cold. The child may also sweat and feel damp.

The nurse should[1]:

- Place an extra blanket on the child if it does not cause distress. However, avoid putting too many blankets on at a time
- Change the child's clothes if they become damp
- Explain to the family that this is a normal and expected part of the dying process

Incontinence

The child will likely experience incontinence of both stool and urine at end-of-life as the muscles of the gastrointestinal and urinary tracts begin to relax[2]. As oral intake decreases and the kidneys stop working, the child's urine output will decrease[2].

The nurse should:

- Discuss catheterization with the physician and the parents
- Use diapers/incontinence pads and disposable draw sheets
- Keep the perianal area clean and dry
- Inform the parents that when death occurs the child will likely be incontinent and there may be oozing of bodily fluids from the mouth and nose[1]. If unaware of these possibilities, parents may become distressed if this occurs[1].

Note: Parents are sometimes reluctant for a catheter to be inserted to drain urine and may prefer to use incontinence pads or disposable draw sheets.

Temperature and Heart Rate

The child's body may feel hot[2]. Their heart rate may speed up or slow down[2]. These are all normal signs of the dying process.

The nurse should[2]:

- Adjust blankets to keep the patient at a comfortable temperature
- Wipe the patient's face with a cool cloth
- Turn a fan on directed toward the patient
- Consider acetaminophen if the patient has a fever and is uncomfortable

Pain

See module 2 on pain assessment and management. No child should experience a painful death.

Respiratory Changes

Respirations may become rapid, irregular and shallow or they may also slow and the child may experience Cheyne-Stokes breathing, which is periods of apnea[1]. Cheyne-Stokes breathing is common in the last days and hours of life and may go on for some time[1]. Gasping is a reflex that happens when the child is unconscious. This reflex is not suppressed by medication and is a normal sign of impending death. Gasping and Cheyne-Stokes can be distressing for parents to witness.

The nurse should:

- Turn a fan on directed towards the patient's face to help relieve any sensation of air hunger
- Reposition the child as necessary to avoid lying flat
- Raise the head of the bed as necessary

- Reassure the parents that Cheyne-Stokes breathing is an expected part of the dying process and that the child is likely unaware at this point

Respiratory Congestion

The child may experience respiratory congestion. Respiratory congestion often sounds like moaning, rattling, or gurgling. These sounds can be distressing for the parents/caregivers however they should be reminded that the child is usually unaware and is not experiencing any discomfort[2]. Use of suction is often more distressing than helpful[2].

The nurse should:

- Reposition the child on their side or with their head slightly tilted down to allow drainage[1]
- Discuss pharmacological management with the physician and administer medications as needed/ordered[2]

Reflection Exercise

Think of a patient you cared for recently at EOL. Did they experience any physical signs of impending death? If so, which signs did they experience? Which nursing interventions did you implement? Were they effective in keeping the patient comfortable? Could you have done something different?

Case Study

Answer the following questions related to the case study below. Answers can be found in Appendix A at the end of the module.

John is an 8-year-old boy with a brain tumor at EOL. During your day shift you notice that he has been sleeping a lot more than usual, he has not taken any food or fluids by mouth, and his hands and feet appear mottled and are cold to touch. His mother is concerned that he has been sleeping more of the day and hasn't taken anything by mouth. She is trying to wake him up to get him to drink something. After multiple attempts to wake him and get him to drink she asks you "how much longer does he have?"

1. Which physical signs of impending death is John displaying?
2. Which nursing interventions could you implement?
3. How would you respond to John's mother?

Preparing for Death

Prior to the child's death a member of the healthcare team who the family is familiar with should have a conversation with the parents to prepare them for what will happen. It is important to reassure the parents that it is reasonable to be prepared and to know what to expect[1]. The parents should be informed of the legal requirements that must take place after their child's death. A physician will assess the child, confirm death, and complete the required documentation (e.g., death certificate, authorization for autopsy if one is to be conducted). Assure the parents that there is no urgency for this, and that they are welcome to take as much time as they need to be with the child after they have passed.

Note: The death of a child is an emotionally painful experience for families and no amount of preparation can ever prepare them entirely.

Final Hours

Remember that even though the child may not be able to talk to you they may still able to hear you. Speak to them if it does not bring them discomfort or restlessness.

The family may wish to have pastoral care or clergy visit at this time. Always check with the family to see what their wishes are. To know more about their spiritual beliefs and practices you can ask "Is there anything we should know about your religious beliefs so that we can help support you?"

Let the family know they will not be abandoned; reassure them that you will be present. You can offer to be present in the room or suggest that you will return on a regular basis.

Nursing interventions around the time of death:

- Be calm and courteous, don't speak too loudly
- Look at people when you talk to them, sit down
- Use the child's name when you speak about them
- Do not avoid the words "death" and "dying"

At the very end the child's breathing and heart beat will stop. Breathing may be followed by a few long-spaced breaths or one long final deep breath. You will know death has occurred when there is no breathing, no pulse, and the child's eyes are fixed in one direction, either opened or closed. Their mouth may fall or remain open as the jaw relaxes. Skin will become pale and waxy looking.

Time of Death

Once you believe the child has died you should call the physician if they are not already present to pronounce the time of death.

Give the family members and any other visitors a quiet place to gather such as the family room. Determine if the parents wish to be present or assist with the care of the body.

Contact a support person (nurse, spiritual care, social worker) to stay with any family members who will not be assisting with care of the body.

Post-Mortem Care

Once the death has been pronounced by a physician and you have checked with the parents to see if they would like to be present or help assist with the care, you may begin the post mortem care:

- Remove any tubing and invasive measures from the child's body such as a Foley catheter, cardiac monitor, electrodes, saturation probe, or nasogastric tube
- Disconnect any IV tubing but keep IV in place (do not remove peripheral IV)
- Close the child's eyes by gently pulling eyelids over eyes
- Wash the child's body
- Remove any soiled dressings and replace with clean dressings using paper tape
- Place an absorbent pad under the buttocks
- Dress the child in a gown or pair of pajamas
- Brush or comb the child's hair
- If family members have requested to view the child, place a clean sheet over the body up to the chin with the arms outside the covers[1]
- Remove unneeded medical equipment from the room[1]
- Provide soft lighting and chairs for family members[2]

Allow the family private time to say their goodbyes to the child and perform any religious or cultural rituals such as[1]:

- Washing and dressing the child for the last time
- Taking photos (infants)
- Praying
- Touching and cuddling the child
- Talking to the child
- Taking handprints/footprints
- Cutting a lock of hair (with parental consent)

If the family would like to hold the child's body, allow them to do this. Every family will have a different level of comfort with this; some families may want to spend hours with their child's body while others may not want to spend any time at all. The nurse should ask the family their preference and honor their choice[3].

It is important for hospital staff to respect the family's privacy but also be available to provide support. It may be necessary for the nurse to advocate for the family to ensure they have sufficient time to say goodbye to the child[1].

Communication with Parents

Nurses often struggle with what to say to the family at the time of death, and often fear they will say the wrong thing. Oftentimes there is no need to say anything; giving a hug or placing your hand on their shoulder may be enough. See the table below for tips on what to say and do at the time of death[4].

What to say and do	What NOT to say or do
Use simple and straightforward language	Do not use medical jargon
Be comfortable in showing emotions	"It's best this way"
Listen to the parents and touch the child	"It could be worse"
"I'm sorry"	"You can have more children"
"I wish things would have ended differently"	"Time will heal"
"I don't know what to say"	"Jesus needed him/her"
"Do you have any questions?"	Do not argue with parents
"We can talk again later"	Do not avoid questions

Once the family has finished saying their goodbyes:

- Remove linens and gown/pajamas
- Place the child's body in a shroud provided by the hospital
- Place an identification label on the outside of the shroud
- Transport the body to the morgue

Parents often find it extremely distressing and painful not taking their child home from the hospital[1]. Some parents may arrange for a funeral director to take their child's body directly to the funeral home rather than going to the hospital's morgue. Some parents may want to walk with their child's body as it is brought to the funeral director's vehicle or the morgue[1]. In this case the nurse should walk with the family and be there to provide support when they leave their child's body[1]. The nurse should consider who will be nearby and ensure that the way is clear of other families and staff before removing the child's body from their room[1].

Reflection Exercise

Have you ever been present at the time of death for a pediatric patient? If so, did you participate in the post-mortem care? Did the parents wish to be involved in the post-mortem care? Did the parents spend time with the child's body after they had passed? How did you provide emotional support to the parents? Is there anything you could have done differently?

Documentation

You must document the child's death in the progress notes. Include the following:

Data:

- A brief description of the events surrounding the child's death
- Time of death
- Name of the physician certifying the death
- Who was present
- The parents' reaction

Action:

- Post-mortem care
- Your interventions with the family
- Time the body was transferred to the morgue
- Location of body identification tags

A Pediatric Bereavement Checklist must also be completed and placed on the patient's chart. The checklist can be found in the filing cabinet on the unit and includes "child/family information" (diagnosis, age, date of death, parents' names, etc.), "at time of death" checklist (were parents present, was chaplain present, did parents hold/touch child, etc.) and "persons to be contacted" (family doctor, chaplain, social worker, etc.). The Pediatric Bereavement Checklist is a multipart form. The white copy is placed on the patient's chart, the yellow copy is sent to social work and the pink copy is sent to pastoral care. The patient care coordinator is responsible for ensuring copies get to social work and pastoral care.

Bereavement of Family

Grief is defined as the thoughts, behaviors, and emotions related to a loss[1]. Anticipatory grief is the grief associated with an impending loss[1]. Grief is a natural process by which people adapt to the changes in their lives as a result of a loss[1].

Parents

When a child is diagnosed with a life-threatening illness most parents will experience grief related to the loss of normal family life, and the loss of their hopes and dreams for their child's future. Parents facing an imminent bereavement often feel that there is a general avoidance of them or their child, leaving them to feel isolated.

It can be difficult to know how to communicate with a family facing an imminent bereavement. Here are some tips[1]:

- Remember that it is not your job to eliminate the family's emotional pain. This would be impossible and any attempt to do so would only deny the reality of the family's experiences.

- Families need recognition and validation of their experience. This can be achieved by being available to listen to their feelings and their search for meaning.
- Attempting to give general advice to the family is never helpful. Each family will grieve differently and require flexible support from staff.
- Listening is often more healing than talking.
- Avoid phrases such as "moving on," "closure," and "we know how you feel."

The nurse must remember not to judge a family's expressions of grief. Grief is a unique experience and people express their grief in many different ways. The nurse may believe that a family is in denial about the seriousness of their child's illness, however this may be the family's way of coping that allows them to live day to day[1].

Note: There is no set timeline for how long the intense pain of grief will last, as grieving is unique to each individual[3].

Sick Child

The sick child will also experience their own grief as they experience the losses related to their illness such as, loss of normal life and their routine activities. Adolescents particularly may grieve over the loss of their hopes and dreams for their future.

Siblings

It is important to include siblings in conversations about the dying child to allow them to express their own concerns and emotions.

Children's expressions of grief after their sibling has died can often seem less intense than adults. However, they often need to revisit their understanding of their brother or sister's death and the emotional impact it has on them as they grow older[1]. When discussing their sibling's death, children can often be blunt and matter-of-fact. They may ask for details, for example, what will happen to the body? Some children's response may be to change the subject or request to go play. The nurse should reassure parents that this is normal and encourage the child to talk about their fears and concerns[3].

Children of all ages experience grief. The extent of their understanding of death depends on their age and developmental maturity. See the table below outlining children's common responses to grief according to age[3].

Age	Understanding	Behaviors	Interventions
0-3 years	• Does not comprehend death • Aware that someone is missing in the home	• Altered eating and sleeping patterns • Irritable • Clings to others	• Maintain routines • Choose familiar caregivers • Acknowledge feelings by naming them and giving

Age	Understanding	Behaviors	Interventions
			permission to express them • Give hugs when needed
3-5 years	• Sees death as temporary • Continually asks if person will return	• Concerned about own wellbeing • May use imaginative play • Withdraws • Irritable • Regresses	• Reinforce that when people are sad, they cry • Provide materials for child to draw pictures • Expect misbehavior as child struggles with confusing feelings • May benefit from knowing that the person is no longer breathing, unable to talk or other physical indicators that person is not alive
6-9 years	• Begins to understand concept of death • May be uncomfortable in expressing feelings • Worries that other important people will die	• May seem outwardly uncaring • May use denial to cope • May act out in school or home • May play death games	• Listen to determine what information the child is seeking • Work on identifying more sophisticated feelings (e.g., frustration, confusion) • Encourage creative outlets for feelings (e.g., drawing, painting, clay) • May benefit from knowing that the person is no longer breathing, unable to talk, or other physical indicators that person is not alive
10-12 years	• Accepts death as final • Has personal fear of death • May be morbidly interested in skeletons, gruesome details of violent deaths	• May appear tough or funny • May express and demonstrate anger or sadness • May act like adult, but regress to earlier stage of emotional response	• Encourage creative expressions of feelings • Explore support group/peer-to-peer connection • Establish family traditions and memorials • Incorporate children into rituals, not just at time of death, but at important

Age	Understanding	Behaviors	Interventions
			anniversaries (e.g., Christmas, birthdays)
Adolescents	• Has adult concept of death, but ability to deal with loss is based on experience and developmental factors • Experiences thrill of recklessness • Focuses on present • Questions existence of an afterlife	• Increased reliance on peers instead of family • Moodiness and irritability • May engage in risk-taking behaviors, appear rebellious and tests limits • May act impulsively	• Allow for informed participation • Encourage peer support • Suggest individualized and group expressions of grief • Recommend creative outlets, (i.e., writing, art, and music)

Reflection Exercise

Think of a child you have had contact with in your personal life or at work who was grieving the loss of a family member. Did they display any behaviors which surprised you? Were the behaviors appropriate for their age? How did you handle the child's behavior? Are there any other interventions you could have implemented?

Case Study

Answer the following questions related to the case study below. Answers can be found in Appendix B at the end of the module.

Jessica is a 15-year-old girl with leukemia at EOL. She has been non-responsive for the last two days and you predict that death is near. During your day shift her parents have been sitting quietly at her bedside, holding her hand and talking to her. Her mother has been crying off and on but has not said much to you. You notice Jessica's 11-year-old brother has been goofing around and making jokes to his parents throughout the day. Jessica's father comes out to the nursing desk and tells you he is worried that Jessica's brother is not taking the situation seriously.

1. How can you provide emotional support to Jessica's family?
2. Are you concerned about Jessica's brother's behavior?
3. How would you respond to Jessica's father?
4. What are some interventions you could suggest to help Jessica's brother grieve?

Bereavement of Staff

Prevention of Staff Burnout

Nurses develop relationships with their patients and their families. The death of a child can have both a professional and personal impact on the nurse. Nurses who face continued exposure to the death of children without acknowledging the impact can suffer from burnout.

Burnout is defined as the accumulated experience of working in a setting that impacts your emotional wellbeing. Signs of burnout include[1]:

- Strong emotions such as anger, helplessness, and sadness
- Problems with memory and concentration
- Irritability
- Social withdrawal
- Self-medication

There are many different strategies which nurses can employ to help reduce burnout and manage their grief after the loss of a patient. See the table below[3].

Strategy	Explanation
Recognize inevitability of the child's death	You may wonder if something more could have been done to prevent the child's death. Focusing on providing the child with a comfortable and dignified death can bring you comfort. Recognize that you did all that was possible to do. Avoid self-blame for situations which you have no control over.
Develop knowledge and apply it	Increasing your personal knowledge about providing care in death, dying, and grief can assist you to feel more confident about the care you provide. From each death you gain knowledge and understanding which you will bring to the next.
Identify ways the work setting can provide support	Requesting to change your patient assignment, taking some time off, accessing employee assistance programs, and participating in multidisciplinary team debriefings are ways in which you can seek support from the work setting.
Briefing	Nurses informing each other of what is happening with a terminal patient can help each other anticipate and prepare for the death. You may want to be informed when a child dies, instead of coming to work and learning of the death by viewing the child's empty bed.
Debriefing	It can be helpful for you to discuss the death, your feelings, and to share your experience with your colleagues during group debriefings led by a skilled facilitator.
Find meaning	You may find it helpful to find meaning in the child's death. For example, how has your life been changed in a positive

Strategy	Explanation
	way by knowing the child and their family? What has the experience taught you?
Separate work and personal life	It can be helpful for you to develop a habit of leaving work behind when you go home, compartmentalizing your work and home life.
Practice self-care	Ensure you are getting proper exercise, nutrition, rest, and sleep. Make time for yourself to do things you enjoy and develop a balance between work and personal life. Learn strategies to manage stress.
Say goodbye	Find a way to say goodbye to the child, such as attending the funeral or writing a note to the family to produce closure to the relationship.

Workplaces can offer support to nurses caring for dying children by[3]:

- Assigning one-to-one nursing care to allow the nurse to focus attention on the needs of the child and family, creating a sense of accomplishment in providing the family with the attention and care they need.
- Allow the nurse time away from the unit after the death to reflect on the experience and its personal significance.
- Provide nurses with the flexibility necessary to meet the child's and family's needs rather than enforcing strict hospital rules. For example, extending visitation hours, or arranging a visit from a pet.
- Allow nurses who had close relationships to the child time to attend funeral services.
- Encourage nurses to take their annual leave at regular intervals to reduce burnout.
- Encourage nurses to participate in group debriefing.
- Attend to nurses who show signs of complicated grief reactions and burnout, such as over-involvement with a child or family, spending personal time off caring for the family, or exaggerated emotional expressions of grief by referring them to Employee Assistance Program.

Reflection Exercise

Have you ever experienced any signs of burnout? If so, what were the signs and how did you handle them? What are some ways in which you practice self-care? Are you aware of any available supports to you should you feel like you are experiencing signs of burnout?

Test your Knowledge

Identify each statement as true or false. Answers can be found in Appendix C at the end of the module.

1. A child's hands and feet turning purple are a physical sign that death is near. __
2. If a child at EOL claims to see someone in the room who is not really there, the parents should correct them. __
3. When providing emotional support to the parents of a child who has just died, there is often no need to say anything. Your presence and a gentle touch are enough. __
4. It is inappropriate for the parents to wash the child's body themselves after he/she has died. __
5. A ten-year-old child becoming morbidly interested in skeletons after the death of his sister is a normal grief response. __
6. Following the death of a child the only documentation to be completed is the Pediatric Bereavement Checklist. __
7. Cheyne-Stokes breathing is more distressing for parents than the child, as the child is usually unaware that they are experiencing it. __
8. During a child's final hours of life, they may still be able to hear you despite being unable to talk. __
9. Children under the age of 3 are unaware when someone has died and usually do not display any behaviors related to grief. __
10. Nurses should practice self-care such as getting proper exercise, nutrition, rest, and sleep to avoid burnout. __

Test your Knowledge

Complete the following short answer questions. Answers can be found in Appendix D at the end of the module.

1. List three physical signs that death is near:
   ____
   ____
2. Suzy's father is upset that she has not eaten anything in two days. He states to you "I know she is dying but I don't want her to die hungry." How would you respond to Suzy's father?
   ____
   ____
3. List three things to say to a parent and three things not to say to a parent following the death of their child:
   ____
   ____
4. List the steps of preparing child's body for family viewing:
   ____
   ____
5. What are three supportive strategies for nurses following the death of their patient?
   ____
   ____
6. List the data that must be included in your progress note after the death of a child:
   ____
   ____

Test Your Knowledge

Match the intervention with the symptom. Answers can be found in Appendix E at the end of the module.

Symptom	Intervention
1. Respiratory congestion	a) Use soft or dim lighting
2. Overactive hearing	b) Change clothes if they become damp
3. Excessive sweating	c) Avoid turning on the TV
4. Reduced or blurry vision	d) Position child on their side with head tilted down
5. Urinary incontinence	e) Keep the perianal area clean and dry

References

1. Children's Health Queensland Hospital and Health Service. (2014). A practical guide to Palliative Care in Paediatrics. Retrieved from: www.health.qld.gov.au

2. Eastern Health. (2011). Towards an understanding of the final days of life. Retrieved from: www.easternhealth.ca

3. Texas Cancer Council. (2000). End-of-life care for children. Retrieved from: www.childendoflifecare.org

4. Proulx, M.C. (2011). Interventions for when a child is dying in the hospital.

Appendix A: Answers to Case Study on Page 227

1. John is displaying mental changes (increased sleeping), eating and drinking changes (decreased oral intake), and circulatory changes (decreased circulation to extremities).

2. For the changes in John's mental status (increased sleeping) encourage the family to talk to John, play John's favorite music, or read him his favorite story. For John's eating and drinking changes (decreased oral intake) educate the parents not to force John to eat or drink. For John's circulatory changes place an extra blanket on him if it does not cause distress. Explain to the family that these are all normal and expected parts of the dying process. See pages 224 and 225.

3. You should gently explain to John's mother that although he is displaying signs of impending death there is no way to know exactly how much longer he has. This should be communicated to John's mother in a supportive way. Use a soft tone, be calm and courteous, look at her when you talk to her, sit down, use John's name, do not avoid the words "death" or "dying" and reassure her that she will not be alone. See pages 224 and 228.

Appendix B: Answers to Case Study on Page 234

1. Do not attempt to eliminate the family's emotional pain, be available to listen to their feelings and their search for meaning, do not attempt to give general advice to the family. Remember that listening is often more healing than talking, avoid phrases such as "moving on," "closure," and "we know how you feel." See pages 229, 231 and 232.

2. No, his behavior is not concerning. A normal response to grief for children of his age is to attempt to be funny. See page 233.

3. Reassure Jessica's father that it can be a normal response to grief for children of his age to attempt to be funny. Offer referral to psychology and/or social work. Encourage Jessica's brother to talk about his feelings. See page 233.

4. Encourage creative expressions of feelings (drawing, writing, etc.), explore support group/peer-to-peer connection. See page 233.

Appendix C: Answers to Test your Knowledge Questions

Answers to true and false questions on page 237

1. True. See page 225.
2. False. You should not try to correct the child. See page 224.
3. True. See page 230.
4. False. You should always ask the parents if they would like to participate in washing their child's body, or if they would like you to do it. See page 229.
5. True. See page 233.
6. False. You must document in the progress note. See page 231.
7. True. See page 226.
8. True. See page 228.
9. False. Children under the age of 3 do not comprehend death however they are aware when someone is missing in their home. Normal behavioral responses to grief are altered eating and sleeping patterns, irritability, and clinginess. See page 232.
10. True. See page 236.

Appendix D: Answers to Test your Knowledge Questions

Answers to short answer questions on page 238

1. Physical signs that death is near: confusion and mental changes, decreased eating and drinking, decreased urinary output, vision changes, overactive hearing, cold and pale/blue-purple hands, feet, and face, incontinence, changes in heart rate, Cheyne-Stokes breathing, and respiratory congestion. See pages 224-227.

2. Explain to Suzy's father that not eating is a normal expected part of the dying process. Reassure him that Suzy is likely unaware and does not feel hungry. See page 225.

3. Things to say to a parent: "I'm sorry", "I wish things would have ended differently", "I don't know what to say", "Do you have any questions?", "We can talk again later." See page 230.

   Things not to say to a parent: "It's best this way", "It could be worse", "You can have more children", "Time will heal", "Jesus needed him/her." See page 230.

4. List the steps of preparing child's body for family viewing (post-mortem care): Remove any tubing and invasive measures from the child's body, close the child's eyes, wash the child's body, remove any soiled dressings and replace with clean dressings, place an absorbent pad under the buttocks, dress the child in a gown or pair of pajamas, brush the child's hair, place a clean sheet over the body up to the chin with the arms outside the covers, remove unneeded medical equipment from the room, provide soft lighting and chairs for family members. See page 229.

5. Supportive strategies for nurses following the death of their patient: recognize inevitability of the child's death, develop knowledge and apply it, identify ways the work setting can provide support, briefing, debriefing, find meaning, separate work and personal life, practice self-care, say goodbye. See pages 235-236.

6. Data that must be included in your progress note after the death of a child: description of the events surrounding the child's death, time of death, name of the physician certifying the death, who was present, the parents' reaction. See page 231.

Appendix E: Answers to Test your Knowledge Questions

Answers to matching questions on page 239

1. D. See page 227.
2. C. See page 225.
3. B. See page 226.
4. A. See page 225.
5. E. See page 226.