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PREPARING PARENTS OF PEDIATRIC PALLIATIVE CARE PATIENTS FOR THE END-OF-LIFE-PROCESS: A REVIEW OF INTERNATIONAL PEDIATRIC END-OF-LIFE-CARE GUIDELINES

by
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ABSTRACT

OF THE PROJECT OF

Sarah Simon Al Ayass for Master of Science in Nursing
Major: Community and Public Health

Title: Preparing Parents of Pediatric Palliative Care Patient for the End-of-Life-Process: A Review of International Pediatric End-of-Life-Care Guidelines.

End of life care is part of palliative care and is provided for individuals at their last days of life. The main focus in end-of-life care is on symptom control and management to allow patients to die peacefully and comfortably, while taking into account the psychological status of patients and their caregivers. Pediatric end-of-life-care is a form of end-of-life-care provided to patients 18 years of age and younger. At end-of-life, there are many decisions that parents are forced to take that has to do with artificial nutrition and hydration, code status, and treating new infections. Often those decisions are uninformed. Without specific guidance from the interdisciplinary teams composed of oncologists, palliative care teams, and registered nurses caring for the pediatric patients, parents will not be able to take the right decisions that is in their children's best interest.

At AUBMC, pediatric hematology/oncology nurses are not equipped with the appropriate knowledge to provide care for end-of-life patients and there are no guidelines for end-of-life care. Hence, this project is meant to help nurses prepare parents to deal with decisions related to the end-of-life process.

Method: Content analysis of three international guidelines related to end-of-life care was conducted including: The European Society for Medical Oncology (ESMO) guidelines, the National Institute for health and Care Excellence (NICE) guidelines, and the American Academy of Pediatrics (AAP) guidelines. The content of the three international guidelines were analyzed and tabulated for the purpose of developing an evidence-based, customized one that fits the Lebanese culture.

Results: Six constructs were extrapolated from the three guidelines that will help improve the quality of end-of-life-care, to include: (1) communicating with the child and parents regarding disease prognosis, (2) integrating parents and the child in the decision-making process, (3) identifying the signs of a dying child, (4) designing an individualized advanced plan of care, (5) developing a treatment plan at the end-of-life, and (6) managing symptoms.

Conclusion: Adapting the developed guidelines will increase the nurse's knowledge with regards to end-of-life-care that would eventually empower parents to take decisions at end-of-life that has to do with their child's code status, artificial nutrition and hydration, and many more, that would have a positive impact on the child's quality of care at end-of-life.

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CHAPTER I

INTRODUCTION

Pediatric palliative care is a specialized care for children aged zero to 18 years living with chronic and serious illnesses. The main focus of palliative care is to provide relief from symptoms that individuals go through secondary to the disease or the treatment plan itself; it can be provided in conjunction with curative treatment and can be initiated at any stage of the illness (Aidoo & Rajapakse, 2018).

Pediatric end of life care is part of palliative care. It is estimated that 20 percent of pediatric oncology patients will die despite advancement in treatment protocols (Saad et al., 2011). End-of-life care focuses on symptom management, while providing psychological support to both the patient and family members.

The most important component of end-of-life care is advanced care planning that consists of designing an individualized treatment plan for the child (Orkin et al., 2020). Parents of pediatric palliative care patients reported that they were not prepared for the emerging health problems that the child might face at end-of-life and were not informed of available treatment plans (Wiener et al., 2019). The uninformed decisions add to their physical and psychological stressors prior to the child's death can complicate the grieving process following death (Wiener et al., 2019). Hence, it is important to have a guideline on how to provide end-of-life-care to the pediatric palliative care patient. The guideline is meant to provide enough information and guidance to parents facing this unfortunate situation.

In the Children's Cancer Center in Lebanon at the American University of Beirut Medical Center (AUBMC), parents of pediatric palliative care patients (31%) reported lack of communication by the health care providers, specifically oncologists and nurses, about the end-of-life process (Saad et al., 2011). The information about the emerging health problems that children go through at end-of-life and available treatment options is only given when the palliative care team at AUBMC is consulted that is because at AUBMC we don't have a palliative care unit and thus RNs caring for pediatric palliative care patients are not trained to provide end-of-life-care. The palliative care team includes one palliative care nurse, one pain nurse, and one advanced pediatric palliative care clinical nurse specialist. The latter oversees both pediatric and adult palliative care and end-of-life-care patients. Given the high demand for its services, many patients miss on receiving the consultation on time.

Moreover, AUBMC does not have advanced care planning directives. It is the role of the pediatric hematology/oncology nurse to educate parents about the end-of-life process and collaborate with the palliative team to come up with an individualized treatment plan as part of an advanced care plan for each patient at end-of-life. Doing so would reflect positively on the quality of life at end-of-life as reported by bereaved parents of pediatric palliative care patients at Children's Cancer Center in Lebanon (Saad et al., 2011). One of the reasons why parents are not prepared for the end-of-life process is due to the absence of pediatric end-of-life guideline at AUBMC. This guideline should provide nurses working at pediatric hematology/oncology units with the required knowledge to provide end-of-life-care for pediatric patients and would allow nurses to provide the required education and guidance for parents at end-of-life. By doing so, parents will be empowered to take the right decisions at end-of-life and would ultimately prepare them for the end-of-life process.

Based on that, three goals have guided this project: (1) to compile and design a guideline for registered nurses working in the pediatric hematology/oncology units at AUBMC on how to provide end-of-life care, to ease parental preparation for the end-of-life process; (2) to pilot and qualitatively evaluate the feasibility and acceptability of this guideline; and (3) to identify the facilitators and barriers for the implementation.

CHAPTER II

LITERATURE REVIEW

Despite improvement in pediatric cancer treatment protocols, malignant neoplasms are the leading cause of death, contributing to 9% of total deaths among the pediatric population (Wiener et al., 2019). At the end of their lives, patients face myriad physical and psychological symptoms, including pain, nausea, fatigue, shortness of breath, depression, and anxiety. Often, parents are the ones to deal with this situation, over and above the fact they are losing their children (Woo et al., 2006). Parents are also the decision makers for their children, and they need to be equipped with the right knowledge to take right decisions, more often parents are not informed of available treatment plan at end-of-life, that itself affects the quality of care that their child receives at end-of-life (Srivastava & Srivastava, 2022). Those who reported not being prepared for the end-of-life process were more likely to perceive the suffering of their child, because they were not able to make decisions that would serve their child's best interest at end of life (Wiener et al., 2019). Thus, parental preparation for what they may expect will allow better identification and control of the physical and psychological symptoms (Srivastava & Srivastava, 2022).

Parental preparation for the end-of-life process consists of informing parents on available treatment options at end-of-life to come up with an individualized advanced care plan on their child, and proper discharge planning if the patient's will be to die at home (Benzar et al., 2011). Often nurses play this important role as they provide parents with proper education needed about the end-of-life process and support them in decreasing complicated grief after the child's death (Orkin et al., 2020). However, the three main principles that guide the following preparation, is having an advanced care plan on the child. The three main principles of pediatric advanced care planning are: time to initiate the discussion, person-centered, and shared decision-making (Wiener et al., 2019). Most often, advanced care planning discussions occur late because health care providers tend to avoid discussing end-of-life early so as not to add further burden on parents with the idea that death is approaching (Lotz et al., 2016). In principle, a transparent and open communication needs to occur when the child is still in the acute phase, no matter how distressing such information may be (Lotz et al., 2016). Sensitive and gradual approach to open end-of-life discussion is recommended. Healthcare providers need to gently introduce advanced care planning and repeatedly offer such conversations without pressuring parents (Lotz et al., 2016).

The benefits of early pediatric advanced care planning, as reported by parents in Mitchell et al.'s work (2019), were multiple. It empowered them to make good decisions for their child from the beginning of the crisis. It gave them a sense of control and security by preparing them for what will come, and it made them feel that they did not fail the child (Mitchell et al., 2019).

Person-centered and shared decision-making are closely linked. Parents know their child more than anyone else. They know the preferences and they have significant knowledge and experience with their child's illness, which make them best positioned to decide the treatment plan they believe is best for their child (Mitchell et al., 2019). Hence, parents need to be integrated into the decision-making process to yield positive outcomes at the end of their child's life.

Shared decision-making is one of the most important components of advanced care planning. One of the pillars of shared decision-making is the trusting relationship between parents and health care providers (Mitchell et al., 2019). It is important that parents feel empowered because they believe that they receive the right information from their health care provider that will help them make important decisions (Mitchell et al., 2019). It is well-known that physicians are primarily responsible for making decisions about end-of-life treatments. However, nurses play a significant indirect role in the decision-making process at end-of-life. Nurses need to advocate for their patients and provide guidance for caregivers to take the right decisions (Lotz et al., 2016). For example, caregivers are confronted with end-of-life decisions, such as withholding artificial food or fluids, oxygen therapy, treating new infections, etc. Nurses play a major role in assessing the benefits of withholding or continuing life prolonging treatments (Lotz et al., 2016). Thus, they need to be prepared to deliver such advanced care planning decisions. They need guidelines for the kind of information that can be provided to parents at end-of-life, to make way for advanced care planning and ultimately impacting the quality of care provided to their children (Michelson et al., 2008).

There are many organizations that have compiled different guidelines to provide pediatric end-of-life-care. However, the most common organizations that were used by hospitals abroad were the National Institute of Care and Excellence (NICE), the European Society of Medical Oncology (ESMO), and the American Academy of Pediatrics (APP). When using the guidelines of those three organizations, the quality-of-life at end-of-life improved for pediatric patients (Bergstraesser, 2012).

CHAPTER III

METHODS

When trying to develop an end-of-life-care guideline that could be implemented at AUBMC, the literature was searched to know what other hospitals outside Lebanon use. Many hospitals rely on international organizations that have worked to provide evidence-based recommendations on how to provide pediatric end-of-life-care, as those recommendations reflected positively on the quality of care of pediatric patients at end-of-life. The three most common organizations that were used by other institutions to guide their end-of-life-care practices were: The National Institute of Care and Excellence (NICE), the European Society of Medical Oncology (ESMO), and the American Academy of Pediatrics (AAP). The three models were used to compile a customized pediatric end-of-life-care guideline that would fit the cultural norms and suit the local needs of the Lebanese population.

Initially, the criteria of the three disseminated guidelines were assessed, and resources present at AUBMC were identified to be addressed in the customized guideline. Fortunately, at AUBMC all of the required resources from pain team, to palliative care team, to pharmacy are present, since all play a significant role in the provision of pediatric end-of-life-care as per international guidelines. However, an important factor that the international guidelines focus on is preparing the child for death, and not just parents and family members. Preparation is usually done by the pediatric palliative care and end-of-life-care clinical nurse specialist through educational resources in collaboration with the pediatric nurse caring for the patient. At AUBMC there is lack of such educational resources, and the pediatric nurses are not trained enough to carry the role. Moreover, parents tend to hide the idea that death is approaching their child. This being a cultural norm, change in perspective would be difficult as it needs time and required resources, and thus the customized model took this into consideration. Another important factor that the customized guideline took into account is that at AUBMC we don’t have a palliative care unit and thus the RNs that are caring for pediatric palliative patients are not trained to provide pediatric end-of-life-care, thus the customized guideline had to be more detailed in explaining how to provide such care.

At AUBMC, we only have three pediatric units that include the children’s cancer center inpatient unit, the regular pediatric unit, and the pediatric intensive care unit. After customizing the guideline, a total of 10 registered nurses (RNs), working at three different pediatric units at AUBMC, were approached and asked to answer a compiled list of questions that assess the feasibility of applying the customized guideline. Four of the RNs work at the children’s cancer center inpatient unit, four at the regular pediatric unit, and two at the pediatric intensive care unit. All were approached while on duty, were given the customized guideline, and given the questions regarding feasibility. They were then asked to read the guideline and answer the designed questions.

Out of the ten RNs who were approached to complete questions on customizing the guideline, only 4 who worked at the children’s cancer center inpatient unit responded. This will act as a bias since all answers regarding feasibility are based on one unit of the nurses’ practice.

Questions regarding the feasibility of applying the guideline are based on the availability of resources, such as adequate staffing, the presence of medications that are used at end-of-life, and the availability of specialized pediatric palliative care and end-of-life care personnel that would guide the nurse’s practice. Nurses were asked to grade their choices on the availability of resources using a likert scale. This was followed by providing a justification for their choices.

Table 1: Guideline Feasibility-Related Questions

Do we have the required resources at AUBMC to provide end-of-life care?	
YOUR APPRAISAL	PROBING QUESTION
1. No 2. Probably not 3. Probably yes 4. Yes 5. Varies 6. Don't know	Please provide a justification for your choices:
Do we have the required staff to provide end-of-life care?	
YOUR APPRAISAL	PROBING QUESTION
1. No 2. Probably not 3. Probably yes 4. Yes 5. Varies 6. Don't know	Please provide a justification for your choices:
Do we have the required bereavement support needed to provide end-of-life care?	
YOUR APPRAISAL	PROBING QUESTION
1. No 2. Probably not 3. Probably yes 4. Yes 5. Varies 6. Don't know	Please provide a justification for your choices:
Do we have the required end-of-life information and guidance to provide end-of-life-cre?	
YOUR APPRAISAL	PROBING QUESTION

1. No 2. Probably not 3. Probably yes 4. Yes 5. Varies 6. Don't know	Please provide a justification for your choices:

Three steps guided the process of developing a customized guideline for providing the end-of-life care. In step 1, three existing guidelines regarding pediatric end-of-life-care were reviewed: NICE (see Appendix A), ESMO (see Appendix B), and AAP (see Appendix C). The different principles addressed by the three international guidelines were compiled and tabulated. Step 2 marked the establishment of a customized guideline through the customized adaptation model. As for step 3, the compiled recommendations concerning the feasibility of applying the customized guideline were shared for feedback by the participating nurses.

CHAPTER IV

RESULTS

The results are presented in three different sections, with each section representing the various steps taken to reach the final customized guideline that could be applied at AUBMC. In section 1, a summary of all areas covered by the three different associations and the main guideline principles were tabulated (see Table 2). A compiled list of recommendations, after being customized to fit the Lebanese cultural norms, formed section 2 of the guideline development process. Section 3 solicits the final recommendations emerging from the responses of the nurses who participated in the guideline development process at the children's cancer center inpatient unit at AUBMC. A detailed description of each section is included in this chapter.

Section 1: Common Principles by the Three International Guidelines

The three international guidelines have many principles in common. However, six main principles surfaced from the review process, to include: (1) shared decision-making process between the family members and the pediatric palliative care team; (2) training pediatric nurses on how to communicate with the pediatric palliative care patients and their family members; (3) having an advanced care plan that would provide pediatric nurses with an overview of the agreed treatment plan at the child's end-of-life; (4) managing the patient's end-of-life symptoms; (5) recognizing signs of an imminently dying patient; and (6) training pediatric nurses on bereavement care. Table 2 includes a detailed description of the principles.

Table 2: Compiled List of Principles of the Three Associations

Item	**NICE**	**ESMO**	**AAP**
Principles	Children and parents play a vital role in the decision-making process supported by a multi-disciplinary team to provide them with different treatment options plans.	Sharing the decision with family member, while observing individuals' preferences (i.e. person-centered), supported by a multidisciplinary team.	The multidisciplinary team to consult with the palliative care team to provide person-centered care based on shared decision-making
Communication	When providing information, health care providers need to take into account the child's age and level of understanding and use different channels to convey the message such as play, art and music activities, while observing their religious and cultural preferences. It is important to provide up-to-date and specific information related to the child's condition.	Person-centered approach. It is important to assess the readiness to receive information before providing it. Include information on treatment options and goals of care, place of care, and place of death. Nurses role include managing physical deterioration of the body, supporting family members and setting goals.	The importance of communicating with the child and family members the disease prognosis and treatment plans while taking into consideration the family' s cultural believes. The importance of providing information that the family members want to know.
Advanced care planning			
Symptom management	The importance of managing distressing symptoms at end-of-life such as pain, nausea, agitation, shortness of breath, and managing hydration and nutrition.	The importance of rationalizing treatment to focus on symptom management and discontinuing treatments that are of no benefit, and the importance of not initiating artificial nutrition and hydration at end-of-life.	The importance of providing adequate symptom management with regards to pain, nausea and vomiting, delirium, shortness of breath, and artificial nutrition and hydration.

Recognizing that the child is dying	The importance of recognizing the signs and symptoms that the child will face at end-of-life for better symptom management.	The importance of recognizing the prognostic factors in advanced cancer.	none
Bereavement care	The importance of providing psychological support for both the child and family members and to continue providing such support for the family after the child's death.	The importance of providing psychological support for the patient and family members and continue providing such support to family members after the death of the patient.	The importance of providing bereavement support for the child and family members.

Section 2: Compiled List of Recommendations

After reading the three different recommendations disseminated from the previously mentioned associations, a customized guideline was established based on Lebanon's cultural norms and available resources at the AUBMC. The following is the customized guideline divided into sections based on the principles mentioned in table 2.

1- General Principles

- Recognize that children and their parents play a vital role in the decision-making process at end of life.
- Discuss and constantly review with the child and the parents how they want to be involved in making decisions about the end-of-life care.
- Parents and their child need to be provided with different treatment option plans at end of life known as parallel planning and need to be given the required time to take such difficult decisions.

- Be aware that all family members including the parents and the child’s siblings, and other members of the child’s household need to be provided with psychological support at end of life.

2- Communication

- When providing information about the child’s disease, prognosis, and when engaging in end-of-life conversations, health care providers need to take into account the child’s age and level of understanding, the healthcare provider can use play, art, and music activities.
- When communicating with the child and their parents, healthcare providers need to play special consideration to the patient’s religious, spiritual, and cultural beliefs.
- When providing information to parents and the child, it is important that healthcare providers give information that are up-to-date, consistent, clearly explained, and specific to the child’s condition. It is also important that the following information to be provided both verbally and in writing.
- Be aware that some parents may be anxious about receiving information about the child’s condition. Based on that, it is important to ask parents how they would like to discuss the child’s condition, the topic that they feel is important to them and want further details on, how would they want their child to be involved and the kind of information that they would want their child to know.
- Provide the family with advanced care planning.

2- Advanced Care Planning

- The advanced care planning needs to include an up-to-date demographic information about the child and family members.
- The detailed outline of the treatment plan that has been agreed on.
- The code status of the child.
- The education material to the child and family members.
- Preferred place of care and death.
- Funeral arrangement.
- A copy of the advance care plan needs to be given to the family and a copy needs to be kept in the child’s file.
- The advanced care plan is subject to change and is put based on the child’s/family’s goals and objectives

4- Symptom Management

Table 3: Signs and Symptoms at End-of-Life and Related Management

Sign or Symptom	Examples of Anticipatory Guidance	Potential Approaches
Decreased appetite	The child may not be probably hungry or thirsty and this will not bother the child.	- Swabs or moisturizers for dry lips and mouth. - Decreasing or turning off any artificial nutrition or hydration the child is receiving.
Decreased alertness	The child may sleep a lot especially in the last days of life.	You can still talk to the child and he can still hear you even if eyes closed.

Changes in breathing: slow, fast, apnea	The child may have changes in breathing that are generally not uncomfortable, if we are worried about comfort, there are medications that could be given to help make the child comfortable.	Distressing respiratory symptoms may improve with intermittent or scheduled opioids.
Noisy breathing because of oral secretions.	The child will swallow less and the saliva in the back of the throat may make a sound that may sound uncomfortable to us.	The first step is to position the child to promote drainage, if this is ineffective an anticholinergic is effective in reducing secretions.
Skin changes	The child will begin to feel cooler and may start to appear pale and blue in color.	Keep monitoring for signs of distress and provide reassurance that these signs are not uncomfortable to the child.
Cardiac insufficiency	The child will have slower and weaker pulse and sometimes irregular heart rate.	Keep monitoring for signs of distress and provide reassurance that these signs are not uncomfortable to the child.
Loss of bowel and bladder control	The child may lose control of his/her urine and stools at end-of-life which may require the use of diapers.	Prepare supplies such as towels, diapers, pads…

5- Managing Hydration and Nutrition

- If a child with a life limiting condition and is actively dying, encourage them to drink if they are fully conscious and are able to.
- If the child is not conscious and is unable to drink or eat, discuss with the caregivers whether starting continuous enteral tube or intravenous fluids and hydration is of the best interest of the child. Inform parents that the following may have a significant effect on care, may be a burden to the child, and may mean that the place of care and death need to be in the hospital.

- Continuously review with the parents if they want to continue with administering hydration depending on the child condition. The child may develop edema, congestion in the lungs, infection around the peg tube if a tube is placed, abdominal distension, that might affect the child's quality of life at end of life.
- Continue providing lip and mouth care to the child.

6- Routes of Drug Administration

- At end-of-life the oral route is considered unsuitable when there is generalized weakness, swallowing dysfunction, altered consciousness, nausea and vomiting, or bowel obstruction.
- Intermittent or continuous administration of medications either intravenously or subcutaneously is effective.
- Gastrostomy or nasogastric tube should not be initiated at end-of-life.
- If the gastrostomy tube is dislodged, or the intravenous central access is lost, reinsertion may be inappropriate at end-of-life.
- Placement of subcutaneous access and transdermal patches on the trunk or abdomen may ensure more effective absorption of medication.
- Transdermal delivery system may be continued, but initiation or increase in dose of transdermal treatment is not recommended because efficacy may be unpredictable due to decreasing peripheral perfusion, sweating…

7- Recognizing Child Likely to Die Within Hours or Days

- The following signs are common in the last hours or days of life such as a change in breathing patterns, impaired peripheral perfusion, loss of interest or inability to drink or eat, an unexplained fall in urine output, an altered level of consciousness, intractable seizures that keep occurring even with optimal management, increasing pain and need for analgesia.

- Allow caregivers to express their concerns openly during the last days of life.
- Provide the care as specified in the advance care plan during the last days of life.
- Discuss with caregiver's invasive intervention and whether they can be of benefit to the child, and any intervention that the child is currently receiving and can be discontinued because it is no longer an interest to the child.
- Ensure that caregivers are left to spend the last hours with their child the way they would like to, give them privacy when needed.

8- Rationalizing Discontinuation of Treatments

- Discontinuation of treatments must be individualized and influenced by patient and family preferences, goals of care, patient prognosis, and risk-benefit assessment of the treating physician.
- Anticancer therapies in the last month of life is associated with adverse outcomes including poor quality of care, cardiopulmonary resuscitation, mechanical ventilation, and with dying in an intensive care unit.
- Radiotherapy offers limited benefits for patients with poor performance scale and is not recommended in the last month of life.
- Single-fraction RT may provide effective symptomatic relief for metastatic bone pain within 2 weeks, and tumor-related bleeding within 2 days.

- Use of immunotherapy at end-of-life is associated with increased risk of dying in hospital and for significant financial hardship. Immune checkpoint inhibitors should not be used at end-of-life.

9- Bereavement Care

- Nurses need education about grief and loss to be able to recognize background factors that pre-disposes caregivers to poor outcome in bereavement.
- Provide information to the parents and the child about the emotional and psychological support available and how to access it.
- Regularly discuss the emotional and psychological wellbeing of children and their parents particularly at times when the child clinically deteriorates, personal circumstances change, changes in the treatment plan of the child.
- Make sure that upon discharge the family members are provided with the right resources and tools to provide care at home.
- Health care providers need to constantly assess the family's preparedness for death and try to target their concerns through proper communication.
- Individuals who are at risk for complicated and prolonged grief need to be referred to a specialist.
- Families need to be contacted in the post death period to make sure that caregivers are coping relatively fine.

Section 3: Final Recommendations for Adaptation by AUBMC

After designing the customized guideline, four nurses working at children's cancer center inpatient unit read the compiled guideline and answered the questions stated previously regarding feasibility, the following is a summary of their answers.

Table 4: Summary of Nurses' responses Regarding Guideline Feasibility

Do we have the required resources at AUBMC to provide end-of-life care?	
YOUR APPRAISAL	PROBING QUESTION
1. No 2. Probably not 3. Probably yes 4. Yes 5. [✓ Varies] 6. Don't know	End-of-life-care is not only about pain management, At AUBMC, we tend to focus on pain and forget about the psychosocial and spiritual aspects.
Do we have the required staff to provide end-of-life care?	
YOUR APPRAISAL	PROBING QUESTION
1. No 2. Probably not 3. [✓ Probably yes] 4. Yes 5. Varies 6. Don't know	At AUBMC, we are currently in shortage of RNs and the RN to patient ratio is high which doesn't leave enough room for the RN to provide the best quality of end-of-life care for the patient.
Do we have the required bereavement support needed to provide end-of-life care?	
YOUR APPRAISAL	PROBING QUESTION
1. [✓ No] 2. Probably not 3. Probably yes 4. Yes 5. Varies 6. Don't know	This is only provided by the palliative care team and the child life services at Children's Cancer Center. However, The RNs are not trained to provide bereavement support for family members.
Do we have the required end-of-life information and guidance to provide end-of-life-cre?	
YOUR APPRAISAL	PROBING QUESTION
1. [✓ No] 2. Probably not 3. Probably yes 4. Yes 5. Varies 6. Don't know	Sometimes families do not receive the required information regarding end-of-life-care. Nurses also experience a certain level of ethical dilemma with regards to providing or stopping certain treatments at end-of-life.

After sharing with the participating nurses the compiled recommendations for the guideline, there were no further modifications made. We concluded that nurses working at CCCL are not empowered with knowledge and skills to provide end-of-life care. They also don't know the material that they need to educate the parents about the end-of-life. Therefore, the proposed guideline is necessary to guide their practice in caring for pediatric end-of-life patients, increase their understanding with regards to the end-of-life process, and allow them to provide parents with the required education at end-of-life.

CHAPTER V

DISCUSSION AND CONCLUSION

In Lebanon, and at AUBMC, there is no pediatric-end-of-life-care guideline. More often RNs working at pediatric floors find it difficult to provide care for pediatric end-of-life patients because they do not have the proper knowledge and guidance to provide such care. The NICE, ESMO, AAP organizations were the most common organizations that institutions refer to for guidance.

In this project, we compiled three different end-of-life-care guidelines and provided recommendations on how to provide end-of-life-care. A summary of principles derived from the three different organizations was established to come with an evidence-based pediatric end-of-life-care guideline that could be applied in Lebanon, and more specifically at AUBMC.

There are many facilitators and challenges to implementing pediatric end-of-life guideline. Khraisat et al. (2017) reported that nurses are stressed when delivering this service as they are insufficiently prepared for this task. Accordingly, nurses encounter the challenge of dealing with families. If the family is accepting the fact that their child is dying, then they facilitate the nurse's role, otherwise it becomes a challenge (Khraisat et al., 2017). This project promotes the role of the nurse as an informational broker between the treating team and the family. Given the daily contact with the patient, the nurse can recognize changes in symptoms, facilitate communication with the treating physician, and coordinate the needed services (Adistie et al., 2020). Hence, the role of the nurse encompasses the following: a communicator, counselor, collaborator, advocator, educator and care provider (Adistie et al., 2020). The nurse communicates with the family what the doctor has explained in a simple language. As a counselor, the nurse eases the anxiety of both patients and families, communicates with empathy the bad news. The nurse advocates so as the parents make the best decision that fits their child's preferences and collaborate with the health care team to ensure that the needed services are delivered (Mehta et al., 2017).

In light of the above, it is important to train nurses on how to assess the parent's readiness to engage in end-of-life conversations and how to communicate with parents about end-of-life matters (Adistie et al., 2020). This is in contrast with the nurse's present involvement which is a complete absence from the discussion with the advanced palliative care nurse. It is important for nurses to be involved in the goals of care discussion to know how to approach the family members and the kind of educational material that should be provided.

Another challenge that needs to be taken into consideration is the parent's spirituality and religious background. More often, the parent's decision to withhold or continue a certain treatment is influenced by their religious figure. Globally, Fang et al. (2016) conducted a scoping review to identify the cultural and spiritual end-of-life practices, as few studies have explored the different cultural and spiritual experiences at end-of-life. Regionally, the few studies that discussed end-of-life and spiritually discussed the beliefs of the Islamic faith towards the decision-making at the end-of-life. Generally, discussing end-of-life matters are considered a taboo in the Middle Eastern Countries, especially in the Islamic Faith (Fang et al., 2016). However, Islam is also against delaying an individual's death with futile treatment, and withdrawal from life support is encouraged (Chamsi-Pasha & Albar, 2016). More often, at AUBMC parents often tend to ask religious figures on their input about the matter. It is important therefore for all healthcare providers to conduct spiritual screening and discuss with a spiritual leader the matter, to ease the anxiety of parents when these life decisions are taken (Chamsi-Pasha & Albar, 2016).

At an institutional level, one challenge that nurses spoke about was the issue of understaffing at AUBMC. Nurses fear that they don’t have time to provide the best quality of care for their end-of-life patients because they are loaded with regular patient care. AUBMC needs to work on a contingency plan to hire new RNs and train them on how to provide end-of-life care.

At a national level, legally speaking, nurses are not allowed to initiate end-of-life discussions, only physicians are allowed to do so. However, nurses are allowed to engage in such discussions as they need to advocate for their patients and be present when the physician initiates end-of-life discussions so that they can continue to engage in such discussion even when the physician is not present. When providing nurses with a brief educational session to teach them on means of communication and how to engage in end-of-life conversations, nurses reported feeling more comfortable to engage in such conversations and ultimately advocate for their patients (Mehta et al., 2018).

Limitations

The following project had a total of three limitations. One limitation is that when trying to ask nurses working in pediatric floors to read the proposed guideline and give their opinion on the matter, many did not want to read it, complaining that they don’t have time and are very loaded with patient care. Only 10 RNs were approached to share their opinion on the subject under discussion. Moreover, when asking the nurses to give their answers with regards to feasibility, only 4 RNs responded, all of which work at children's cancer center in-patient unit.

Another limitation is that when trying to find the benchmarking organizations for the pediatric end-of-life-care guidelines, only two organizations, the NICE and the APP were available. The ESMO disseminated adult end-of-life-care guidelines; however, due to similarities it was also used as a reference. Therefore, there were limited organizations that dealt with pediatric end-of-life-care. The third limitation is when trying to customize the guidelines from the 3 different organizations, a lot of modifications were made on it to fit our cultural norms and way of practice, and it was established based on available resources at AUBMC.

Strengths

The following project may be submitted to the CPDC at AUBMC to use the recommendations, to provide the best quality of care for pediatric end-of-life patients. Moreover, the following guideline can be integrated in the curriculum of nursing students to increase their knowledge about the end-of-life-process and provide them with the right skills to provide the best quality pediatric end-of-life-care. For future plan, more research needs to be done after implementing the following guideline at AUBMC to see whether it has improved the quality of care provided to pediatric end-of-life patients, and whether it has increased the nurses' understanding about the end-of-life process, the type of educational material that needs to provide to the patient and family members, and the skills needed to provide pediatric end-of-life-care.

We conclude that nurses working at CCCL are not empowered with knowledge and skills to provide end-of-life care. Therefore, adapting the developed guidelines will increase the nurse's knowledge about end-of-life-care that would eventually empower parents to take decisions at end-of-life that has to do with their child's code status, artificial nutrition and hydration, and many more, that would have a positive impact on the child's quality of care at end-of-life.

APPENDIX A

National Institute of Care and Excellence (NICE) Guidelines for Pediatric End-of-Life Care

The following guideline covers the planning and management of end-of-life pediatric population aged 0 to 18 years old, its main purpose is to involve children, and their families in decisions about their end-of-life care and improve the support that needs to be provided to them at end of life (Villanueva et.al,2016).

The following guideline is intended to health care providers and social workers, as well as for the primary care givers and the patients living with life threatening diseases.

This guideline includes recommendation on the following:

1- General principles:

The following are general principles that health care providers need to know before providing end of life care for pediatric patients:

- Recognize that children and their parents play a vital role in the decision-making process at end of life.
- Discuss and constantly review with the child and the parents how they want to be involved in making decisions about the end-of-life care.

- Explain to the patient and the parents that their contribution to the decision-making process is important, however, they don’t need to take decisions purely on their own and the multi-disciplinary team is present to guide them.
- Parents and their child need to be provided with different treatment option plans at end of life known as parallel planning and need to be given the required time to take such difficult decisions.
- Be aware that all family members including the parents and the child’s siblings, and other members of the child’s household need to be provided with psychological support at end of life.
- Ask the child and their parents if there are other people that are important to the child that they want to be involved in the care, and how they would like them to be involved.

2- Communication:

- When providing information about the child’s disease, prognosis, and when engaging in end-of-life conversations, health care providers need to take into account the child’s age and level of understanding, the following activities can be used to ease this discussion:

Play, art and music activities.

Written materials and pictures.

Social media.

- When communicating with the child and their parents, healthcare providers need to take into account:

  Their religious, spiritual, and cultural beliefs and values.

  Their personal and family situation.

3- Providing information:

- When providing information to the parents and the child, it is important that healthcare providers give information that are up-to-date, consistent, clearly explained, and specific to the child's condition. It is also important that the following information to be provided both verbally and in writing.
- Be aware that some parents may be anxious about receiving information about the child's condition. Based on that it is important to ask parents how they would like to discuss the child's condition, the topic that they feel is important to them and want further details on, how would they want their child to be involved and the kind of information that they would want their child to know.
- Always review with the parents and the child if there is additional information that they would like to discuss because they will need different information at different times depending on the circumstances.
- Provide the parents and the child with an advance care plan.
- It is important to provide consistent care from preferably the same professional at end of life. The following team is responsible to lead and coordinate the child's care.

4- Advance care planning:

Health care providers need to develop and record an advance care plan at an appropriate time for the current and future care of each child with a life limiting condition. The following plan should include:

- Demographic information about the child and their family.
- Up-to-date contact information for the child parent's, or caregivers, and key professionals involved in the care of the child.
- Statement about who has the responsibility for giving consent.
- A brief summary of the life limiting condition of the child.
- An agreed approach on how to communicate and provide the required information to the child and their caregivers.
- A detailed outline of the child's life ambitions and wishes that has to do with:

  Family relationships.

  Social activities and participation.

  Education.

  Incorporating their religious, spiritual, and cultural beliefs into the care.

- A record of discussions held with the child and their parents.
- The treatment plans and objectives that were agreed upon.
- The education plan that was provided to the child and their parents.
- A record of important decisions on important topics at end of life such as:

Preferred place of care and death.

Organ and tissue donation.

Resuscitation and life support.

Funeral arrangement and care of body.

- The following advance care plan needs to be kept in the child's chart and a copy needs to be distributed to the child and his/her caregivers.
- The following plan needs to be regularly reviewed and changes can be made depending on the child's condition.
- An advance care plan is individualized and should be developed depending on the beliefs and values of the child and the parents.
- The benefits of advance care plan should be explained to the child and the parents that are the following:

Helping parents be involved in planning for their child's care.

Helping parents understand their child's life limiting condition and its management.

- The advance care plan needs to include the nature, consequences, and prognosis of the child's disease, and the expected benefits and possible harm of treatment options available at end of life.

5- Emotional and psychological support and interventions:

- Be aware that the child and the parents may have emotional and psychological distress and crises, relationship difficulties, and mental health problems.
- Be aware that sometimes parents and their child need support from psychologist to receive psychological interventions to help them cope with the distress. The following psychologist needs to be always on board.
- Provide information to the parents and the child about the emotional and psychological support available and how to access it.
- Regularly discuss the emotional and psychological wellbeing of children and their parents particularly at times when the child clinically deteriorates, personal circumstances change, changes in the treatment plan of the child.

6- Social and practical support:

- Parents and their children need to be given material support such as oxygen tanks, equipment used for drug infusion, ets…
- Parents need to be trained upon discharge home on how to administer drug infusion at home.
- Financial support if applicable.
- Educational support such as hospital school services.

7- Care of the child who is approaching end of life:

Managing distressing symptoms:

Managing pain:

- when assessing and managing pain, be aware that several factors can contribute to it including biological, environmental, psychological, and social (religious, spirituality).
- When assessing pain in children use age-appropriate scales such as r-flacc for children from 0 to 3 years of age, wrong baker's faces from 4 to 7 years of age, verbal descriptive scale from 8 to 11 years of age, and numerical rating scale from 12 to 18 years of age. When the patient is sedated or anxious, behavioral pain scale or r-flacc can be used.
- Think about non-pharmacological interventions such as music, physical contact, hot or cold applications on the source of pain.
- When tailoring a treatment plan for pain management, inform parents on the benefits of the pain treatment plan, possible side effects of the medication administered, it is important to note that the most common side effects of opioids are sedation, reduced mobility, and constipation.
- The choice of analgesia should be based on the patient's pain score and comfort score.
- The following are off label use: oral paracetamol for children under 2 month of age, intravenous paracetamol for preterm infants, concentrated liquid paracetamol (500mg/5ml) for children under 16 years of age, ibuprofen for children under 3 month or weighing under 5 kg, oramorph liquids for children under 1 year.
- If treatment with a specific opioid does not give adequate pain relief or it causes severe side effects, an alternative opioid need to be given.

- Titrate treatment to provide continuous analgesia for the patient and have prn orders for breakthrough pain.
- Consider giving anticipatory doses of analgesia for children when performing certain procedures that might contribute to the child’s pain such as changing dressings, positioning…).
- Opioid calculation for children is based on weight rather age.
- When suspecting neuropathic pain and standard analgesia is not helping, consider adding the following medications:

Gabapentin.

A low dose tricyclic antidepressant.

Anti- NMDA agent such as ketamine.

Managing Agitation:

-Children with life limiting conditions at end of life may become agitated and that is shown by restlessness, irritability, aggressive behavior, and crying.

- Children can also show signs of delirium such as confusion, disrupted attention, disordered speech and hallucinations.

- It is important to make sure that the child is free from physical injury when experiencing these agitations.

- The following medical conditions places the child at a higher risk of becoming agitated, such as pain, hypoxia, anemia, dehydration, urinary retention, or constipation. Moreover, adverse effects of medications such as opioids can cause agitation.

-For children with a neurological disability who are approaching end of life, signs and symptoms of agitation can be mistaken for symptoms of seizures or dystonia.

-Before giving medication for children for their agitation, it is important to identify and treat any medical or psychological condition that may be contributing to it, think about non-pharmacological interventions such as calm speaking, reassurance, providing the child with a calm environment, relaxing music.

- If the following measures did not work, think of pharmacological interventions such as benzodiazepines (midazolam, diazepam, lorazepam), and neuroleptics (haloperidol, levomepromazine).

Managing seizures

- If a child is approaching end of life and has seizure, look for and treat any potential cause such as fever, electrolyte imbalance, drug reactions, pain, excessive environmental stimulation, and sleep deprivation.
- If a child is known to have a history of seizure, seizure management should be included in the advance care plan.
- Children approaching end of life have abnormal movements such as dystonic spasms, the following might be mistaken for seizures.
- Explain to the parents what they might notice if a seizure happens, and how they should manage it if they were at home.
- Explain to parents upon discharge how to give anticonvulsant medications.

Managing respiratory distress

- If the child approaching end of life has respiratory distress, breathlessness, or noisy breathing, think of contributing factors that might be causing this respiratory distress such as anxiety, physical discomfort, accumulated airway secretions.
- If the child is known to have a medical condition such as pneumonia, heart failure, sepsis, or acidosis, the following interventions can be used such as bronchodilators, nebulized saline, opioids, and oxygen supplementation.
- For children placed under DNI/DNR, consider giving oxygen through a nasal canula or facemask.

Managing hydration and nutrition

- If a child with a life limiting condition and is actively dying, encourage them to drink if they are fully conscious and are able to.
- If the child is not conscious and is unable to drink or eat, discuss with the caregivers whether starting continuous enteral tube or intravenous fluids and hydration is of the best interest of the child. Inform parents that the following may have a significant effect on care, may be a burden to the child, and may mean that the place of care and death need to be in the hospital.
- Continuously review with the parents if they want to continue with administering hydration depending on the child condition. The child may develop edema, congestion in the lungs, infection around the peg tube if a tube is placed, abdominal distension, that might affect the child’s quality of life at end of life.

- Continue providing lip and mouth care to the child.

8- Recognizing that the child is likely to die within hours or days:

- The following signs are common in the last hours or days of life such as a change in breathing patterns, impaired peripheral perfusion, loss of interest or inability to drink or eat, an unexplained fall in urine output, an altered level of consciousness, intractable seizures that keep occurring even with optimal management, increasing pain and need for analgesia.
- Allow caregivers to express their concerns openly during the last days of life.
- Provide the care as specified in the advance care plan during the last days of life.
- Discuss with caregiver's invasive intervention and whether they can be of benefit to the child, and any intervention that the child is currently receiving and can be discontinued because it is no longer an interest to the child.
- Ensure that caregivers are left to spend the last hours with their child the way they would like to, give them privacy when needed.

APPENDIX B

European Society of Medical Oncology (ESMO) Guidelines for End-of-Life Care

The available ESMO is for adult cancer patients, however, due to similarities between adult and pediatric patients at end of life, the following guideline can be used (Crawford et al., 2021).

1-Communication and the family:

- It is recommended that family member to be involved in the decision-making process.
- When communicating with the patient about their disease and prognosis, it is important to assess at first the patient’s level of knowledge of their diagnosis, their wishes around disclosure, and what they would like to disclose to family members.
- The multidisciplinary team should engage in end-of-life conversations that should include treatment options and goals of care, place of care, and place of death.
- Advance care planning is important at end- of- life and plays as a protective factor against later distress.

2-Nursing considerations:

- Core nursing roles include managing physical deterioration of the body that includes managing tissue viability, oral, bowel, and bladder care.
- Supporting family members in the adjustment to the process of dying.

- Nurses have a role in advising on changing goals and settings of care.
- The ability to appropriately diagnose dying since it helps to guide family members from the point of deterioration to death.

3-Prognostic factors in advanced cancer:

- Prognostic estimates are important and allows patient to plan their goals of care, unfinished business, and preferences about the type of end-of-life care.
- Objective factors associated with short prognosis includes deteriorating performance status, dyspnea, dysphagia, anorexia, and cognitive impairments.
- Laboratory findings associated with short prognosis includes elevated c-reactive protein levels, reduced albumin levels, and leukocytosis.
- The following documents are proven to be valid to predict survival: the palliative performance scale, the palliative prognostic score, the palliative prognostic index, and the Glasgow prognostic score.
- Signs predictive of the last weeks and days of life may include reduced conscious state, palliative performance scale less than 20%, not tolerating food and fluids.
- Signs predictive of like hood of death within 3 days include non -reactive pupils, decreased urine output to less than 100 ml in 12 hours, Cheyne-strokes respiration and grunting.

4-Rationalizing treatments:

- Discontinuation of treatments must be individualized and influenced by patient and family preferences, goals of care, patient prognosis, and risk-benefit assessment of the treating physician.
- Anticancer therapies in the last month of life is associated with adverse outcomes including poor quality of care, cardiopulmonary resuscitation, mechanical ventilation, and with dying in an intensive care unit.
- Radiotherapy offers limited benefits for patients with poor performance scale and is not recommended in the last month of life.
- Single-fraction RT may provide effective symptomatic relief for metastatic bone pain within 2 weeks, and tumor-related bleeding within 2 days.
- Use of immunotherapy at end-of-life is associated with increased risk of dying in hospital and for significant financial hardship. Immune checkpoint inhibitors should not be used at end-of-life.

5- Routes of drug administration

- At end-of-life the oral route is considered unsuitable when there is generalized weakness, swallowing dysfunction, altered consciousness, nausea and vomiting, or bowel obstruction.
- Intermittent or continuous administration of medications either intravenously or subcutaneously is effective.
- Gastrostomy or nasogastric tube should not be initiated at end-of-life.
- If the gastrostomy tube is dislodged, or the I.V. central access is lost, reinsertion may be inappropriate at end-of-life.

- Placement of subcutaneous access and transdermal patches on the trunk or abdomen may ensure more effective absorption of medication.
- Transdermal delivery system may be continued, but initiation or increase in dose of transdermal treatment is not recommended because efficacy may be unpredictable due to decreasing peripheral perfusion, sweating…

6- Nutrition and hydration

- In patients with an expected survival of less than a few months and not receiving anticancer treatment, nutritional interventions with low risks/burdens for the patient (counselling, oral nutritional supplements) are preferred.
- In patients with a survival of 1-to-4-month, supplemental parenteral nutrition or oral feeding does not improve quality of life or survival but increased adverse events.
- Patients with expected survival of days to weeks are unlikely to benefit from enteral and parenteral artificial nutrition.
- Before considering artificial nutrition, therapeutic goals need to be discussed with the patient and family members, the following decision requires intensive clinical and ethical consideration and discussion.
- If the patient is able to swallow, it is preferred that they take liquids and food by mouth using small- volume meals spaced throughout the day at the request of the patient, rather than large quantities of food at scheduled times.
- In the last weeks of life, nutritional interventions are rarely indicated, the focus of care needs to primarily target alleviation of hunger and thirst if verbalized by the patient. Artificial nutrition should not be initiated in the last weeks of life.

- Nutrition may be less important when approaching the last weeks and days of life, as reduced intake of food and liquids caused by anorexia-cachexia, dysphagia, delirium, and reduced desire for food is part of a natural process of dying.
- Artificial hydration given through IV or subcutaneous routes in the last days of life has not been demonstrated to prevent or relieve the symptoms of thirst.
- Hydration at end -of-life may worsen edema, ascites, and respiratory secretions. For these reasons, each clinical case must be carefully evaluated, and hydration tailored according to patient needs.
- Mouth care should be always provided to patients at end-of-life.

7-Symptom management:

- **Cancer related fatigue**
- Cancer related fatigue is defined as distressing, persistent, subjective sense of physical, emotional tiredness and exhaustion related to cancer or cancer treatment.
- The intensity of CRF increases in the last month and days of life.
- Most pharmacological treatments are not recommended expect for the short-term use of dexamethasone or methylprednisolone. However, the use of corticosteroids is contraindicated in patients with delirium or approaching imminent death.

- **Pain**

- Assessment of pain should be carried out regularly and consistently and it should include the quality, intensity, trigger, relieving factors, efficacy and tolerability of analgesics currently used.
- Standardized scales for assessment of pain intensity should be used (r-flacc wong baker faces, VDS, NRS). Behavioral scales should be used in the presence of lowered consciousness, delirium, and palliative sedation.
- It is recommended when death approached to use strong opioids such as morphine for pain management.
- In case of renal failure and decreased urine output, it is recommended to use fentanyl instead of morphine since it has an inactive metabolite and only small amount is excreted renally.
- If pain crises occur in the last few days of life, immediate release subcutaneous or IV opioids ensure faster pain control.
- In the last days of life, orally administered adjuvant drugs such as gabapentin, pregabalin, or serotonin-norepinephrine re-uptake inhibitors should be withdrawn.

- Nausea and vomiting

- At end-of-life the possible causes of nausea and vomiting could be emetogenic medications (opioids), recent chemotherapy or radiotherapy, psychological distress, increased intracranial pressure, ascites, gastroparesis, and malignant bowel obstruction.
- Treating reversible possible cause of nausea and vomiting should be considered.

- The drug of choice to manage nausea and vomiting in advanced cancer is metoclopramide. Alternative options include haloperidol, and levomepromazine.
- drugs with an antidopaminergic mode of action (e.g. haloperidol, metoclopramide) and serotonin 5-hydroxytryptamine (5-HT3) receptor antagonists (e.g. ondansetron, palonosetron) are not effective in patients with opioid-induced emesis.

-Breathlessness

- the gold standard for breathlessness assessment is based on patient self-report. In patients unable to self-report, vital signs may assist in diagnosis and treatment.
- Patients can rate their breathlessness by using the numerical rating scale.
- Oral and parental low dose opioid is the standard treatment option for breathlessness.
- Benzodiazepine is frequently used when breathlessness is associated with anxiety.
- Noisy breathing such as gurgling or rattling sounds often referred to as death rattles are the kind of breathing that occur at end-of-life. It is an indication of impeding death within the coming 3 days.
- Noisy breathing is unlikely to cause suffering on the patient since patients are usually unconscious when it occurs.
- The accumulation of tracheobronchial secretions leading to noisy breathing may be reduced by avoiding fluid overload. Evidence does not support oropharyngeal suction since it may exacerbate secretions.

- It is recommended to use hyoscine butyl bromide and glycopyrronium bromide to reduce tracheobronchial secretions and thus reducing noisy breathing.
- Antimuscarinic agents are not recommended since they may induce dry mouth, urinary retention, delirium, agitation, and excessive sedation. If antimuscarinic agents were started, it is recommended to continuously monitor for side effects, and stop them when such side effects persist.

-Delirium

- Delirium is often associated with short survival, it has an impact on functional decline, increased length of stay and medical cost, it also causes a significant distress on family members.
- Delirium is associated with disturbed consciousness, altered cognition, reduced attention.it occurs in 90% percent of patients towards end-of-life.

-Intractable (refractory) symptom management and palliative sedation

- Palliative sedation is considered a treatment of last resort for symptoms that are not well controlled by using all available treatment options (refractory symptoms).
- Refractory symptoms are defined when the only available treatment options would not adequately relieve distress, not provide relief in an appropriate time frame, and is associated with intolerable toxicity and adverse effects.
- The most common refractory symptoms experienced at end-of-life are pain, dyspnea, delirium, and psychological distress.

- The discission must be made after discussion with the patient and primary caregivers.
- An informed consent must be obtained and both parents needs to sign it, it should include the aim and process of sedation and predicted prognosis.

8-Psychological issues

- People with a previous history of psychiatrist disorder are more likely to develop psychological issues at end-of-life.
- Anxiety at end-of-life is better managed with an anti-depressant initially rather than benzodiazepines that are considered to be second line of treatment.
- Palliative sedation can be considered for persistent psychological symptoms at end-of-life.
- Spirituality should be addressed at end-of-life and is considered part of symptom management.
- Tool to assess spirituality includes the FICA tool that addressed faith, belief, meaning, important and influence of community.

9- Bereavement care

- Staff need education about grief and loss to be able to recognize background factors that pre-disposes caregivers to poor outcome in bereavement.
- Health care providers need to constantly assess the family’s preparedness for death and try to target their concerns through proper communication.
- Individuals who are at risk for complicated and prolonged grief need to be referred to a specialist.

- Families need to be contacted in the post death period to make sure that caregivers are coping relatively fine.

APPENDIX C

American Academy of Pediatrics (AAP) Guidelines

The following is the guideline published by the American Academy of Pediatrics, intended for health care providers (Linebarger et al., 2022).

1- Palliative care engagement

- The multidisciplinary team need to consult palliative care on patients suffering from life threatening diseases.
- The palliative team need to provide caregivers with straight forward information, they need to respect the relationship between the family and the child, need to give meaning to the faith and hope that the patient and family have, need to give time for family to ask questions, they need to be easily and readily accessible, and they need to provide the family members for resources outside the hospital setting that can provide home-based palliative care.
- It is important for the interdisciplinary team to involve the patient and primary caregivers in the decision-making process. The shared decision-making process includes exploring and understanding the patient and family’s values, providing medical information in an individualized way, and finally recommending a treatment plan that aligns with the patient and family members’ wishes and desires.
- It is important to note that shared decision making at end-of-life requires attention to the patient’s cultural and religious norms.

2-Advance Care Planning

- In an ideal situation advance care planning to be initiated before the occurrence of an acute emotional or clinical crisis.
- Advance care planning require that the primary health care givers review the natural course of the death, prognosis, quality of life, while exploring the patient and family's goals and objectives of care.
- Advance care planning need to be documented in the patient's record and a copy needs to be given to the patient.
- Advance care planning includes the decisions that need to be taken at end-of-life such as withholding life sustaining treatments (intubation, resuscitation, artificial nutrition and hydration…).
- Parents have reported that having an advance care plan early on allowed them to not have decisional regret and to plan for their child's care ahead of time. It is important here to understand the parent's concept of what it means to be a good parent.
- Advance care planning need to include all available treatment plans at end-of-life and the benefits and burden of each on the quality of life at end-of-life.

3- Code status documentation

- This includes the documentation of a written medical order that delineates whether cardiopulmonary resuscitation or intubation should be initiated in the event of pulselessness or absence of spontaneous reparations.
- In the past decade, most hospitals have adopted the POLST or MOLST form for more scenarios than pulselessness or absence of respiratory effort.

- The physician should document the discussion held with family members concerning resuscitative measures in the patient’s advance care plan.
- It is worth mentioning to primary caregivers that having a DNR/DNI order does not mean that the patient will not receive any further medical management.

4- As end of life nears

- As death nears, discussion considered the place of death need to be held with the patient and primary caregivers.
- Some parents would rather stay at hospital at end-of-life because of equipment availability at home, and the complex care that the child might require at end-of-life.
- When having the discussion of the place of death early on and before the child approaches death, the team will then be able to provide all the necessary resources for the child to die at home.

5- Role of the Interdisciplinary Team

- Distress and suffering can escalate for both the parents and the patient as death nears, this time period may be recalled by primary health care givers for years.
- The interdisciplinary team needs to address the physical, spiritual, and psychological needs of the patients and their family.
- The interdisciplinary team should consist of pediatric palliative care physicians along with nurses, social worker, psychologist, and bereavement specialists.

- The engagement of the interdisciplinary team should happen early and before acute deterioration, for the patient and family members to develop trust with the interdisciplinary team.

6- Providing Care in the Final Days

- Intensive supports are needed at end-of-life whether the child is placed in a hospital or home setting.
- Tasks that should be performed at end-of-life includes reviewing of all medical interventions being done on the child to limit or discontinue the unnecessary ones, preparing parents for the dying process, symptom management, and discussing postmortem care that usually includes questions about organ and tissue donation.

7- Plans for Life-Sustaining Medical Treatment

- Physicians needs to identify when life-sustaining medical treatment prolong the dying process and the suffering of the patient.
- Physicians need to be clear with the parents about their child prognosis, goal, and degree of pain and suffering.
- It is important for primary health care providers to use terms that does not include withdrawing care and support because they continue regardless of the child’s prognosis, they should use instead the term forgoing treatments and interventions that do not promote comfort.
- Primary health care providers need to discuss the goals of care and comfort care with the family members and they need to discuss that life-sustaining treatments

such as mechanical ventilator, artificial nutrition and hydration, vasoactive medications, may not provide comfort for the patient at end-of-life.

- According to the AAP policy statement on forgoing life-sustaining treatment, it is considered ethical when the burdens of treatment outweigh the benefits to the child. An important question that could guide the decision is: Are we doing this to the child, or for the child?
- Given cultural norms when it comes to artificial nutrition and hydration, it is important to explain to parents that the child is dying for the disease process and not from the lack of nutrition and hydration. However, the decision to forgo artificial nutrition and hydration should not preclude offering the child food or water for comfort and pleasure.

8- Preparing for the Dying Process

- Parents would like to be prepared for the physical and psychological changes that their child might face at end-of-life, and how the following symptoms will be managed.
- Older pediatric patients may also want to know about the dying process, and failure to address their concerns may lead to withdrawal.
- The approach to these conversations needs to be tailored to the patient’s and the family’s reediness to engage in end-of-life conversations, and to understand the type of information that they want to receive. Questions that might help are: What are you worried about? How much information do you want to know at this time? Do you want to talk about what may happen over the coming days?

- Primary health care providers need to understand the repeating the information provided to family members at end-of-life does not equate denial or misunderstanding and can be due to family distress.
- Primary health care providers need to understand that as death approaches, family member may verbalize statements such as Please do something to help my child, or Can’t you help my child more? The following does not necessary indicate that they want to alter the goals of care and can be due to distress. Primary health care providers need to to reassure family members that they are doing everything they can to ensure that the child is comfortable and in peace.

9- Symptom Management

- Children and young adults’ express distress in different ways depending on their age, ability to communicate, and their diagnosis. The assessment of symptoms at end-of-life should take all of the following factors into consideration.
- It is important to explain to family members the signs of the natural dying process such as moaning, restlessness, facial grimacing, and brow furrowing.
- Primary health care providers should also rely on the family members who are constantly present with the child to detect any sign of distress and make way for symptom management.

Table 5: Common signs and symptoms naturally occurring at end of life and their management

Sign or Symptom	Examples of Anticipatory Guidance	Potential Approaches
Decreased appetite	The child may be probably not be hungry or thirsty and this will not bother the child.	-Swabs or moisturizers for dry lips and mouth. -decreasing or turning off any artificial nutrition or hydration the child is receiving.
Decreased alertness	The child may sleep a lot especially in the last days of life.	You can still talk to the child and he can still hear you even if eyes closed.
Changes in breathing: slow, fast, apnea	The child may have changes in breathing that are generally not uncomfortable, if we are worried about comfort, there are medications that could be given to help make the child comfortable.	Distressing respiratory symptoms may improve with intermittent or scheduled opioids.
Noisy breathing because of oral secretions.	The child will swallow less and the saliva in the back of the throat may make a sound that may sound uncomfortable to us.	The first step is to position the child to promote drainage, if this is ineffective an anticholinergic is effective in reducing secretions.
Skin changes	The child will begin to feel cooler and may start to appear pale and blue in color.	Keep monitoring for signs of distress and provide reassurance that these signs are not uncomfortable to the child.
Cardiac insufficiency	The child will have slower and weaker pulse and sometimes irregular heart rate.	Keep monitoring for signs of distress and provide reassurance that these signs are not uncomfortable to the child.
Loss of bowel and bladder control	The child may lose control of his/her urine and stools at end-of-life which may require the use of diapers.	Prepare supplies such as towels, diapers, pads…

10-Most Common Symptoms Faced at End-of-Life:

- The most common symptoms are pain, dyspnea, anxiety, agitation, delirium, fatigue, nausea, and poor appetite.
- Opioids and benzodiazepines are useful classes of medications to address symptoms at end-of-life for children of all ages.
- The balance of adequate symptom control and sedation side effects of end-of-life medications should be routinely assessed and discussed in relation to the patient and family's goals of care.
- At times, the medication doses needed for symptom control may shorten the time to death because of their impact on sedation level and respiratory rate, such risk may be taken if it aligns with the goals of care. However, it is important to note that prescribing medication with the intent to hasten death in unethical and illegal.

10- Organ and Tissue Donation

- Family members need to contact their regional organ procurement organization. Death pronouncement:
- Clinicians need to be empathetic when announcing time of death because this may have a long-lasting impact on the family's grieving process.
- The examination to declare death should include auscultation to confirm the cessation of beathing and the absence of heart sounds and palpation to confirm loss of carotid and radial pulse.
- Once death is confirmed the clinician should mentally note the date and time and inform the family members of death.

11-Supporting Families:

- Sometimes the family’s needs are conflicting, where they would want privacy and some alone time with the child and at the same time support.
- Parents need to be given options for memory-making with the child such as: participating in bedside care, hand for footprints or molds, fingerprint charms, locks of har, artwork, videos, audio recording of doppler heartbeat, religious or cultural rituals, memory boxes with mementos.
- Nurses and primary health care providers are expected to provide bereavement care for family members and to refer caregivers who are at risk for complicated grief to a specialist such.

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