

PedsCases Podcast Scripts

This is a text version of a podcast from PedsCases.com on “**Pediatric Palliative Care.**” These podcasts are designed to give medical students an overview of key topics in pediatrics. The audio versions are accessible on iTunes or at www.pedsCases.com/podcasts.

Pediatric Palliative Care

Developed by Cailey Turner and Dr. Cheryl Mack for PedsCases.com.
July 9, 2018

Introduction:

Hello, my name is Cailey Turner, I’m a second-year medical student at the University of Alberta. This podcast was developed with the help of Doctor Cheryl Mack, a Cardiac Anesthesiologist and part of the ASSIST pediatric palliative care team at the Stollery Children’s Hospital in Edmonton, Alberta. I would also like to give a big thanks to Carmen Victor a grief counselor at the Stollery Children’s Hospital, as well as a bereaved mother who provided invaluable insight on this topic. This podcast will be an overview of pediatric palliative care and give generalized information on this subject.

Case:

Let me begin with a clinical case to put everything into context. You are a third-year pediatric resident going into your first rotation in pediatric palliative care. The first patient you see is an eight-year-old girl with end-stage neuroblastoma. You are introduced to her parents and two younger sisters. In discussion with their health care team, the family has decided to not pursue further treatment. Your preceptor asks you to explain what pediatric palliative care is and how your team will care for and support their child. What are important symptoms to manage for this eight-year-old child? What is unique about pediatric palliative care versus adult palliative care? And lastly, what are the best ways to discuss death and sickness to both the child with neuroblastoma as well as her two younger siblings?

Objectives:

In this podcast we are going to look at four main learning objectives:

- 1) Examine the guiding principles of palliative care
- 2) Contrast and compare pediatric versus adult palliative care
- 3) Review key symptoms to consider when managing a child at the end of life
- 4) Discuss the ways to explain death to children and their siblings

What is Palliative Care?

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To start this podcast lets first understand what palliative care is all about. Palliative care includes the control of pain and other symptoms and addresses the psychological, social, or spiritual problems of patients living with life threatening or terminal conditions. It seeks to enhance the quality of life by relieving symptoms and conditions that would otherwise deter from the patient's enjoyment of life. This includes symptom management, such as pain or nausea, but also includes a broader assessment of a patient's context, including social supports and isolation.

In palliative care, there is a delicate balance between doing all treatments possible and solely focusing on comfort care. The team must take into account the values and beliefs of the patient and family to establish the goals of care. Some treatments may only offer the slimmest chance of improvement and result in increased pain, isolation, and fear for the patient and the family. Continuing with unsuccessful treatment can move the family further from integrating the reality of a probable death. On the other hand, a treatment plan solely focusing on comfort care may deprive the family of any hope and may fail to prevent an avoidable disability or death. Therefore, treatment plans must be individualized to the child and be monitored continuously to ensure the treatment changes with the child's condition. In cases when we cannot cure a patient's illness, the key is to focus on the type of care that can improve both the length and quality of life. Quality of life for a child and a family can look very different for different families. Palliative care tries to explore the unique needs of each patient and family.

Pediatric palliative care is needed for a wide range of diseases. These often differ from adult diseases, as they are often rare and familial. Four large groups of life-limiting diseases have been identified in children, all of these can benefit from the specialized care offered by the pediatric palliative service. The first is diseases where a curative treatment may be feasible, but may fail, for example cancer. The second is diseases where premature death is anticipated, but treatment can prolong a good quality of life, for example in cystic fibrosis. The third category is progressive diseases where treatment is exclusively palliative, for example a child with spinal muscular dystrophy. The last category is conditions with severe neurological disability that is not progressive, but can cause complications leading to premature death, for example severe cerebral palsy. In all four groups of patients, early involvement of palliative care can ensure adequate managements of symptoms, and help support decision-making in the best interest of patients and families

Unique Aspects of Pediatric Palliative Care

Now we are going to discuss a number of aspects that are unique to pediatric palliative care.

The first unique aspect is the type and amount of family support in pediatric palliative care. Losing a child is one of the most difficult things a person may go through in their

life and therefore, this support is vital for the family. Families need continuous support from the time of diagnosis, throughout the illnesses trajectory, and after the time of death. The support a family should receive requires an interdisciplinary approach and may involve the physicians, nurses, social workers, a grief counselor, etc. The family of a child that has an inherited disease can have additional difficulties. They may have additional feelings of guilt and blame and the healthcare team must ensure the family receives adequate support.

The second unique aspect of pediatric palliative care is the limited number of cases and expertise in this field. The number of terminal pediatric cases is limited compared to the number of adult cases. On top of this, there are a limited number of physicians with the proper expertise in dealing with terminal illness in children. Therefore, physicians specialized in this area often assist in the care of children over a very large area. For example, the pediatric palliative care team at the Stollery Children's Hospital provides assistance to patients throughout Northern Alberta, all three Territories, Northern British Columbia, and Northern Saskatchewan. Therefore, compared to adult palliative care pediatric palliative care can be challenging to ensure each patient gets the proper care and requires an immense amount of organizational skills.

The third unique aspect of pediatric palliative care we are going to talk about today is the decision making process. In adult palliative care this process is directly through the patient. If the adult patient is competent they have complete autonomy over their care. However, in children there are varying degrees of this decision making process; ranging from infants whose guardians make all the decisions to adolescents who should be as fully involved in the process as possible. Parents and guardians are entrusted with making decisions that promotes their child's best interests. Sometimes disagreements can arise with the healthcare team over what constitutes best interests. When disputes arise over clearly beneficial treatments, such as giving chemotherapy for acute lymphoblastic leukemia, the physician must act as an advocate for the patient and devote sufficient time to educating the guardians. If the parents continue to refuse treatment the ethics committee can be consulted to help resolve the disputes. As a last step, legal action may need to be taken, which can decide what the best interest is for the child and who will make the decisions. Thankfully, this very rarely happens.

Symptom Management

Now that we know what palliative care is, let's talk about important symptoms to consider in pediatric palliative care. Good symptom control, especially in the last few weeks of life, can have a lasting positive impact on the family. However, failure to control symptoms is associated with increased grief and bereavement. A child's report of symptoms is the 'gold standard', however if the patient isn't old enough to communicate the parental report, physiologic indicators, and behavioral indicators are alternate assessments to be used.

The first symptom we are going to talk about and the one most people probably think about when talking about palliative care is pain. For a good basic overview of pain management in children, please check out our PedsCases podcast on pediatric pain, however we will discuss a few points specific to palliative care. Pain management includes both pharmacologic and non-pharmacological methods. Medications include Tylenol, non-steroidal anti-inflammatory drugs, or NSAIDs, as well as use of strong opioid medications. Physicians often lack experience in administering analgesics, such as strong opioids to children, which can lead to inadequate recognition and management of pediatric pain. There are guidelines available on this topic and we strongly encourage you to check them out if you feel uneasy about administering opioids to young children. It is important to be pro-active in managing the side effects of opioids including constipation, pruritus, and sedation. All children prescribed opioids should be managed with regular laxatives along with PRN antihistamines for itching. The child initially will become sleepy from the sedating effects of opioids and parents should be warned about this so they do not fear that their child's disease has suddenly progressed.

The next area we are going to discuss is difficulty with nutrition and feeding. Children with life-limiting illness often have a number of nutritional problems including difficulty with oral-motor skills of feeding, feeding intolerance, and decreased appetite due to side effects of medications and chemotherapy. This can be managed with appetite stimulating medications, or such interventions as nasogastric tubes or surgically placed feeding tubes. Nutritional goals need to take into account the child and their particularly needs. Sometimes, nutritional goals are secondary to comfort and enjoyment. Good palliative care assesses ongoing needs and helps make decisions regarding the appropriateness of invasive interventions.

Next let's discuss respiratory symptoms. Dyspnea is one of the most common respiratory symptoms in children at the end stage of life. The treatment for dyspnea requires an inter-disciplinary approach, which includes relaxation techniques, deep breathing, and/or distraction. First line medication for non-specific dyspnea is scheduled opioids. Benzodiazepines can also be used to treat dyspnea and can be especially helpful if there is associated anxiety and agitation. It is also important to educate the family on end of life changes in respiratory patterns like apnea, noisy breathing, and irregular breathing, to help alleviate distress in the parents.

The last symptom we are going to discuss is nausea and vomiting. Nausea can be secondary to the direct effects of an illness, such as chronic kidney disease or increased intracranial pressure, or a side effect of medication or chemotherapy. Management of these symptoms is often related to the direct cause and antiemetic should be administered according to the presumed cause of the nausea. If the antiemetic chosen does not relieve nausea and vomiting, a second antiemetic with a different mechanism of action should either be added or substituted to the current

regime. Common agents include dimenhydrinate or Gravol, ondansetron or Zofran, or metoclopramide or Maxeran.

Discussing Death With Children and Siblings

It can be extremely difficult to discuss death with a child, and physicians often struggle with how to most appropriately approach the topic. We recommend approaching the subject directly, giving time over multiple encounters for the child to absorb the information and ask questions. When discussing death with children you always want to first ask the child what they know and understand. This allows you to gauge how much the child already grasps, the language they use, and potentially how much information they may want to know. A child's understanding of illness, death, and dying can be drastically different than an adult's understanding. Therefore, it's important to use a language that the child will comprehend. For example, a young child may not understand the concept of death so using the words 'heaven' and 'angels' may help the child understand better. As well, it is important to ask the child what their fears are of dying, often times the discussion alone will help ease some of these fears and can lead to more open conversations in the future. However, it is also important that not every conversation centers on death and their illness. It is still important that the child can still be a child.

These concepts are also important when talking to a patient's siblings. Often younger siblings will feel guilty and may feel at fault for their sibling's sickness. Therefore, it is important to have a discussion with them to talk through these feelings. The timing of disclosure varies with the age and maturity of the siblings. For younger siblings, it may be important to not tell them immediately that their sister or brother is dying because young children often act as the town crier and will begin telling everyone that so and so is going to die. In these cases it may be more appropriate to wait until the time is near and then have the discussion with them. On the other hand, with older siblings it is a good idea to have the talk with them earlier on. That way you can help prepare the siblings and ensure they have the appropriate time with their brother or sister. It is a good idea to ask them what they would like to do with their brother and sister before the time comes and anything that would like to be said. As well, you can ask the siblings how involved they would like to be in the care of their brother or sister and assure them that there is no right or wrong answer to this question.

Summary of Learning Objectives

This sums up our podcast, but first lets due a quick review of the learning objectives we discussed today. Palliative care seeks to improve the quality of life and symptoms in individuals suffering from a life-threatening illness or terminal condition. Although adult

and pediatric palliative care overlap in many aspects pediatric palliative care has some unique aspects. These include more involved family support, a limited number of cases and specialized physicians over a wide area, and a different decision making process. There are many symptoms to consider when dealing with palliative care. The four symptoms we talked about today were pain, feeding, respiratory symptoms, and nausea and vomiting. Lastly, when talking about death and illness to a child ensure you are using age appropriate language, ask them what they already know, and try and make them as comfortable as possible.

This brings us to the end of this PedCases podcast on pediatric palliative care. I also recommend listening to 'Medically Assisted Dying: A Pediatric Perspective' for more information on this topic, found on www.PedsCases.com. Thank you for listening!

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