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Goals of care conversations and advance care planning for paediatric patients living with serious illness

Developed by Sahaj Puri for PedsCases.com.
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Introduction:

Hi everyone and welcome to this PedsCases podcast reviewing the CPS position statement on "Goals of care conversations and advance care planning for paediatric patients living with serious illness".[1] My name is Sahaj Puri and I'm a second year medical student at McMaster University. This podcast was developed in collaboration with Dr. Humphreys, a palliative care pediatrician from McMaster University.

The purpose of this podcast is to review the importance of goals of care and advance care planning conversations within the pediatric population. As medical advances continue to evolve, children living with complex life-limiting conditions have many medical comorbidities. As a result, families are presented with increasingly difficult decisions about interventions and treatments. As health care providers, we must counsel families making these tough choices and acknowledge the balance between prolonging a child's survival and compromising their quality of life. A general aim for providers involved in these complex cases is to "add life to the child's years, not simply years to the child's life".[2] These conversations can be difficult, as society often has a bias towards prolonging a child's life since we expect them to live longer than their parents. There can be a tendency to avoid having these difficult discussions, which is why practicing effective communication is crucial to ensure healthcare providers and families reach an agreement on appropriate interventions to address their goals.

Learning Objectives:

By the end of this podcast, the listener should be able to:

- Define advance care planning and goals of care conversations and the ways in which they may differ.
- Describe the importance of having advance care planning and goals of care discussions with pediatric patients and their caregivers, despite barriers that may exist.

- Recognize the responsibility of health care providers to initiate advance care planning and goals of care conversations with families, instead of waiting for them to share their preferences on their own.
- Recognize the value of an interdisciplinary approach to advance care planning conversations and the critical benefits of involving palliative care teams.
- Understand the CPS recommendations which aim to facilitate effective advance care planning and goals of care conversations among pediatric populations.

Clinical Case:

To guide our learning today, let's introduce a clinical case:

You are working in an inpatient service on your pediatrics rotation. Your preceptor introduces you to Melissa, a 13 year old girl admitted for a cystic fibrosis exacerbation, who is accompanied by her mother. She presented to the emergency department yesterday with a fever, increased mucus production and difficulty breathing.

Despite keeping up with her medications and chest physiotherapy, Melissa has had many severe cystic fibrosis exacerbations in the last year leading to increased time in hospital. She was recently admitted to the pediatric intensive care unit on two occasions for respiratory support. In the emergency department today, Melissa is started on antibiotics and admitted for monitoring to ensure her infection clears enough for her to be stable to return home.

During your encounter with Melissa today, you see her turn to her mother and ask "What happens if my lungs keep getting worse?". Melissa's mother has recently expressed to their social worker that she is worried about what will happen if her daughter's condition continues to worsen.

You recognize that Melissa and her family may benefit from a conversation about her goals of care. Keep this case in mind as we discuss having these conversations through the rest of the podcast.

Defining Advance Care Planning and Goals of Care

Let's start off by defining what advance care planning is. Advance care planning is an extension of the usual discussions we have with patients and families about their future care. They are needed when a child has a serious illness. Advanced care planning conversations encompass the short and long term goals for health and medical treatments. In addition to establishing goals of care, these conversations support patients and caregivers in their understanding of what may lie ahead. We use these conversations to identify what matters most to the patient and family regarding the child's medical care, which is rooted in their personal values. This allows clinicians to provide treatment plans that best align with their wishes.

Advance care planning conversations begin with discussing "goals of care". To establish goals of care, we can think of 3 main steps:
Step 1: Ensure understanding
Step 2: Identify "what matters most?"
Step 3: Recommend treatment

As we approach these conversations, we must assess our patient's and their caregiver's understanding of the illness so far, as well as what they would like to know moving forward. Once we have established a baseline, it is the responsibility of health care providers to share relevant information with patients and their families in a compassionate and clear manner. We want to accurately describe the medical situation and the relevant prognosis to avoid decisions being made upon false assumptions. Depending on the age and capacity of the child, these conversations may involve the patient as well. Once an understanding of the situation is established, the patient and family can take time to consider what matters most to them. For example, some patients or families may say they want to maximize their time at home. After the family has shared their priorities, the medical providers can use that information to delineate realistic goals of care. All three steps are critical, as clinicians that are unsure of the values of their patients will likely find it challenging to make treatment plans that meet the patient and families preferences.

Generally, the goals of care for children with serious illnesses fall into 1 of 3 categories.

- Category 1 is to prolong life. In these cases, children should have access to all medical treatments, including resuscitative measures, as long as they are in their best interest.
- Category 2 is to prioritize as much good time as possible. Here, patients and families will consider life-prolonging treatment in the context of maintaining a quality of life that they have defined as acceptable. Any care that may not restore the patient's quality of life, such as resuscitative measures, may not be pursued.
- Category 3 is to focus on comfort. Although it is always important to maximize patient comfort, this is viewed as the top priority for patients in this category. Treatments that prolong an unacceptable quality of life, as defined by the patient or their decision makers, may be discontinued or declined.

Now that we've talked a bit about advance care planning and goals of care, it's important to ensure we can describe how they relate to each other. Goals of care are used to guide treatment in the present, while advance care planning encourages us to think about how we can apply goals of care to future medical scenarios. They both prioritize the values and wishes of patients and their families. It is important to recognize that while some families may be open to discussing goals of care to guide current treatment, they may be hesitant to engage in advance care planning decisions.[3] If the patient and family are not yet ready, respecting and supporting their autonomy while deferring the decision making to another time is crucial. It is important to recognize that even if decisions are not actively made within the conversation, initiating advance care planning discussions allows families to process information and reflect on decisions that they may need to make in the future.

Importance of Advance Care Planning Discussions

Sometimes, parents can overestimate how positive a child's prognosis may be.[4] Other times, health care providers may overlook how receptive parents are to discussions about life-prolonging interventions.[5] In cases where early death is acknowledged as a possibility, health care providers may assume that the patient and family would want to prioritize prolonging life; however, acting based on this assumption does not allow for treatment preferences to be shared. It is especially critical to have these discussions for patients with chronic conditions, where timing of death or decline is likely uncertain.

Though initiating a conversation about advance care planning can be challenging, it is most often appreciated by patients and their families as it promotes open dialogue, mutual respect and transparency. In a study of adolescents followed in an outpatient cardiac clinic, 92% wanted to be informed if their condition was terminal and 91% wanted to engage in conversations about their care at the end of life.[6] In another study looking at children with cancer, 87% of parents wanted as much prognostic information as possible.[7] While 36% of parents found the information "very" or "extremely" upsetting, they were just as likely to share that receiving the information was important and helped them with their decision making.[7] Some researchers have also found that parents can feel more prepared to advocate for their child through advance care planning.[8] Opportunities to discuss advance care planning can allow for meaningful adjustments to be made at the end of life, such as involving palliative and home care.

Initiating Advance Care Planning Discussions

Goals of care and advance care planning discussions for children are often initiated at times where there is a need for critical intervention. Although this is understandable, evidence suggests that we should begin these conversations earlier on in the disease course, as this allows for patients and families to reflect on these difficult topics when the possibility of death or decline is less imminent.[9, 10] Even if a child is stable, if they have a risk of deteriorating, these conversations are important to ensure they don't first occur when the child is seriously unwell.

Goals of care should be discussed at multiple points throughout the patient's medical journey, as families may and often do alter their wishes as circumstances change. The goals that a family expresses at the start of the illness may differ substantially from what they believe matters to them as time goes on and the clinical circumstances change. When approaching these conversations, it is best to explain that the purpose is to ensure optimal care is provided if and when the medical situation changes. If these conversations are instead perceived as attempts to alter decisions about care, families may be more reluctant to engage.

Families have acknowledged that they feel a need to be “ready” for advance care planning conversations, but recognize that there is never a “good” time for them. Nevertheless, it is the responsibility of the clinician to initiate discussions about advance care planning instead of leaving it to the family to bring up. Signs that a family may be open to discuss advance care planning include an expression of worry and concerns about quality of life. For example, a patient may ask “What if this new treatment doesn’t work?”. In response, we can ask open-ended questions to get a better understanding of the patient’s preferences. For example, we may ask “Are there aspects of your or your child’s health that worry you? What’s most important to you as things start to change?”. A helpful guide to follow is the pediatric “Serious Illness Conversation Guide - PEDS” which outlines using terminology such as “I wish…, I worry… and I wonder…”.[11]

While the primary health care provider responsible for the care of the child should be involved in the conversation, including other specialists such as palliative or critical care teams can be beneficial. Pediatric patients should be offered the opportunity to be involved in the discussions, even if they may not have the full capacity to make decisions about their care. We can observe signs from the child such as their voice, body language and behaviours to help inform decision making. Involving extended family, spiritual leads, language interpreters and other community members into the conversation is also valued.

Let’s spend a couple of minutes delving a bit deeper into the role of palliative care in advance care planning discussions. The goal of palliative care is to improve quality of life, reduce patient suffering and support patients goals of care (such as providing comfort measures when needed).[12] Families may resist the idea of integrating palliative care early on in the disease course as it was originally perceived as being synonymous with end-of-life care. However, pediatric palliative care is focused on supporting a child while they are living just as much as supporting the dying process. Palliative care teams may not need to be present at full capacity through all stages of a child’s illness, and instead, measures may be introduced intermittently alongside potentially life-prolonging treatments. Palliative teams may aid with the patient’s access to other supports such as community supports, nursing care and ensuring accurate documentation of goals of care and advanced directives.

Barriers to Implementing Advance Care Plans

Since we are working with a pediatric population, there are barriers that may arise when we attempt to implement advance care plans. Advance directives are legal documents that highlight care-related preferences and substitute decision makers as indicated by the patient. However, most Canadian jurisdictions don’t grant legal validity to advance directives created by capable mature minors. The stipulated legal age for advance directives is 16 years old in Ontario, New Brunswick, Prince Edward Island, Newfoundland and Labrador and Saskatchewan. Additionally, advance directives can only be made by a patient for themselves. When substitute decision makers, or parents, work with health care providers to create these documents for a child who is incapable of doing so themselves, consent for the plan of care is still required in the moment. This differs from what we see in adult care, where physicians are expected to abide by the advance directives of a previously capable adult. Despite these challenges, written documents that share the wishes of a pediatric patient are still valued by providers to guide care.

CPS Recommendations

Through reviewing advance care planning and goals of care conversations, the CPS has made the following recommendations:

1. Health care providers should initiate conversations about goals of care and advance care planning.
2. Conversations should start early in the disease course for children living with serious illnesses, especially for those who may have a shortened lifespan. 3. Health care providers should assess patient and/or parent readiness to engage in advance care planning. Signs of readiness may be verbal (e.g., “I don’t ever want to go back to the ICU again”; “Something’s different … he’s lost that spark”) or non-verbal (e.g., the patient can no longer do the things that they loved to do).
4. Unless urgent decisions are needed, health care providers should respect a family’s wish to delay conversations about the future, but with an agreement to check in again at a later time.
5. A health care provider who has a trusting relationship with the child and family should be continuously involved in these discussions, whenever possible. 6. Health care providers should emphasize that the primary goal of these discussions is to engage patients and families in thoughtful conversations about what matters most to them. Decisions regarding future care or the drafting of advanced directives may or may not be an outcome.
7. Specialist pediatric palliative care teams are available and should be accessed to facilitate goals of care discussions and advance care planning for children within their jurisdiction, when needed. These conversations can be conducted using virtual care technologies.

Back to Clinical Case

Let’s go back to our case. You recognize the signs that Melissa and her family may be ready for a conversation about her current goals of care and advance care planning. This is not a conversation for a medical student to have on their own, and you recognize the importance of involving various team members in the discussion. You return to your preceptor and share your thoughts about initiating a more serious discussion about what Melissa’s future care could look like. You want to get a better understanding of her preferences in the case that her lung function continues to decline. You refer to the pediatric Serious Illness Conversation Guide and think about how you would approach this conversation. After your preceptor checks with Melissa and her family, they ask you to consult the palliative care team. Together, you plan to explore how Melissa and her family feel about her quality of life and what wishes they have for her future care.

Conclusion

Thank you for listening to this podcast about goals of care conversations and advance care planning for pediatric patients living with serious illness! We hope you learned something new and gained an appreciation for the role of these serious conversations in complex medical cases. Stay tuned for more podcasts from PedsCases!

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