Questions to consider when caring for a child with a high risk of dying before adulthood

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The present article describes a fictional scenario depicting a patient requiring paediatric palliative care. Martin, a three-year-old boy, has a fatal progressive neurodegenerative disease. Martin lives with his two parents and five-year-old sister. He was diagnosed at two years of age during an investigation for psychomotor regression and balance problems. Martin's condition has deteriorated since that time; he has progressive hypotonia, spasticity in his lower limbs and major loss of his abilities. He is also increasingly choking on his food. He was recently hospitalized for aspiration pneumonia with severe respiratory distress. He was given intravenous antibiotics and a gastrostomy tube was inserted. Although his convalescence was long, Martin has finally been able to return home. Before he left the hospital, a palliative care team met with him. The team also communicated with the community paediatrician to ensure that Martin would receive follow-up in his region and that resources would be available for him at home.

Meeting with a child with an incurable progressive disease and their family brings up many issues. Over the course of several meetings, a relationship of trust is formed, and a special connection with the family is often established. The first meetings may be challenging for all because it is early in the relationship. To help clinicians better prepare for these meetings, a group of paediatric care experts developed a list of questions for clinicians about to meet with such children and families (Table 1). The order, or priority, of the questions may change depending on when the meeting takes place in the course of the child's illness (eg, whether at diagnosis, when stable or experiencing complications, or at end of life). While there are many potential subjects to be covered in these meetings, it is not always possible to cover them all in only one session. In addition, the clinician and the parents will need to decide whether or how the child will participate in discussions. It is important to acknowledge that many children, even minors, want to be a part of discussions concerning their care and have the capacity to do so (1).

At the outset of the meeting, it is helpful for clinicians to ask general open-ended questions about the child and about their understanding of the medical condition. Open-ended questions are also a way to help form a relationship with the family, to gather information about the child and, crucially, to give the parents the opportunity and the time to express what they are going through without interruptions from the clinican. As the parent(s) (or child) speaks, the clinician has the opportunity to listen to what is being said, to notice the choice of words and also to think about what is not being said; this helps the clinician ask the right questions and to adapt to the family's communication style.

Additionally, it is important to explore the communication styles preferred by the family (eg, direct or indirect styles). This is a respectful way to demonstrate (even if it remains unspoken) that the clinician will strive to care for the patient and their family in a way that is best suited to their particular needs.

The question about hopes and goals may be difficult for parents, who may feel that "there is no hope left". This is an opportune time to review their short-term hopes and goals, which are more attainable (eg, being at home as much as possible). Although the child and their family may clearly understand the nature of the illness and the poor prognosis, hope nonetheless often remains until the very end of life. Hope itself may, however, change over the course of the disease: the hope of recovery may become the hope of not experiencing complications, followed by the further hope for a peaceful end of life. As the end of life approaches, the short-term objectives become more important: spending an entire day without pain, sleeping soundly through the night, and having a moment's rest during the day become increasingly salient.

Assessing physical symptoms may serve to bring the conversation to a more emotionally neutral place. At each meeting, it is essential to review all the patient's symptoms listed in question 5. Assessing symptoms in a very young child can be very difficult. In fact, pain is the only symptom for which validated assessment scales exist for this age group. It is even more difficult, but nonetheless important, to assess other symptoms such as dyspnea.

The question about concerns and fears may serve to deepen the conversation. This question is often addressed with careful attention to timing. It should be asked late enough to ensure that a relationship has been established, but early enough that parents still have time to talk about their fears. It is common for parents to cry or turn silent at this point in the interview. Crying should not be seen as a negative outcome, but rather as an opportunity to express sadness that reflects their love.

It is also important to assess the impact on the siblings of the ill child – ie, to review with parents (if the siblings will not be met face to face) what unmet brothers and sisters are going through, talk about their needs and reactions, and consider separate meetings and/or appropriate referrals, as the situation dictates.

Financial issues and resources available to the family at home should also be reviewed at this time. Depending on local resources, a social worker may be very helpful in assisting in these areas and to ensure that the family obtains the resources they need.

When clinicians do not address the child's and parents beliefs related to religion, culture and spirituality, an important opportunity may be lost to convey the message that "What's important to you is important to me as your clinician".

Discussions concerning advance care planning and end-of-life care options may be challenging and cannot always take place during the first interview. However, failure to discuss these fundamental issues can have serious and unintended harmful outcomes. One approach is to explain why it is important to talk about these issues: "I understand it's difficult to talk about what might happen if your child's condition deteriorates, but it is important to have this discussion so that I know what your wishes are. If we don't make these decisions together and an emergency situation arises, care might be given or not given to

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TABLE 1
List of questions to consider when caring for a child* with a high risk of dying before adulthood

*The clinician should evaluate whether the child, depending on his maturity, could be present at the interview and whether some questions can be addressed directly to him/her

1. Can you tell me a bit about your child?
    a. What does he/she like/makes him/her happy?
    b. What doesn't he/she like?
2. What is your (and/or your child's) understanding about his/her medical condition?
3. What are some important things (eg, how you and your family best communicate) for us to know in talking with you, your child and other family members?
4. What are some of your hopes and also specific goals over the:
    a. Short term (today and for the next few days)?
    b. Medium term (next few weeks)?
    c. Long term?
5. Are there important symptoms that are bothersome, specifically pain, headache, nausea, vomiting, diarrhea, constipation, poor appetite, difficulty feeding, sleep problems, itching, fatigue or difficulty breathing?
6. What is your biggest concern or fear right now (and for the immediate future)?
7. What do your other children understand about [child's name]'s condition and what is happening now? Do you have any questions or concerns about any of their behaviors (eg, crying, acting out, poor sleep) or interactions (eg, school refusal)?
    Possibly add: Would you like to know what may be helpful in involving siblings in age-appropriate ways at any stage of their brother's or sister's illness?
8. Are there financial problems that we should know about and possibly help address?
    Possibly add: Do you know about the compassionate care leave benefit?
9. Who do you have in place for support at home now? For example, home care, home housekeeping, home nursing, pharmacy access, access to family respite?
10. Are there issues of faith, religion or culture that are important for us to know about?
11. Given some of your concerns and hopes, it is important to know what your preferences are about medical care and treatment if things do not go well in the future (even as we all continue to hope they do).The kind of things that are important to talk about are:
    a. Level of resuscitation status in the event of a sudden deterioration (cardiopulmonary resuscitation, ventilation, intubation), as well as treatments that should be administered to your child (analgesia, antibiotics, anticonvulsants, transfusions).
        i. Advance care planning may or may not be appropriate to begin to discuss here depending on the child, parents, illness and setting.
    b. Have you thought about if you prefer care to be more in your home or in the hospital (or in hospice if available) as your child becomes sicker (and closer to possibly dying)?
    c. Would you like to know more about what the end of life may look like?
    d. Let's figure out together who might be the best professional for you to call for help or advice once you are not in the hospital. Let's discuss when to call 911 and what to say when you call 911.
12. Is there anything that I have not asked about you, your child or your family that you think we should discuss?

This list of questions was compiled with input from Canadian paediatric palliative care clinicians from Vancouver to Halifax in response to the question Dr Andrew Lynk (past president of the CPS) asked Dr Stephen Liben (paediatric palliative care) at a meeting: "Is there a list of the top 10 or so issues an MD should think about and consider bringing up with the child/family when seeing a child with a significant chance of dying?". With special thanks to Dr Lynk and Canadian paediatric palliative care clinicians who co-created this list.

your child without their and your wishes being taken into account". In addition to discussing do-not-resuscitate status and invasive care (intubation, mechanical ventilation, amines), this is a good time to discuss the specific kinds of care that could be used if the child's condition deteriorates (antibiotics, transfusions, etc) and comfort care (2). This conversation also allows for entry into the delicate issue of possible end-of-life scenarios. How will dying look at the very end? Will my child suffer? What can I do to help? Parents may find it helpful to have a protocol in place in the home to manage distressing symptoms in case of acute need. Discussions about location of care preferences helps clinicians to better understand whether the family wishes to stay at home for as long as possible or whether they would prefer to return to the hospital (or palliative care centre, as the case may be) if the child's condition deteriorates. Do the parents know who to call in case of deterioration? Do they have the appropriate forms for emergency services (do-not-resuscitate order and advance care planning)?

Before ending each conversation, it is often helpful to ask whether there are any issues that have not been discussed or any further questions the patient or family would like to ask. This gives them the chance to express any remaining fears or bring up other difficult issues.

You have now known Martin and his family for a year. His condition has deteriorated rapidly in the last few months, and his parents have decided not to return to the hospital but rather to provide as much care as possible in their home. Through previous meetings, an advance care plan is in place and the decision has been agreed upon that if Martin's condition deteriorates, he will receive comfort care but no cardiorespiratory resuscitation. A home care nurse visits the family regularly. Martin receives morphine through his gastrostomy tube when he is in pain or experiences dyspnea. The parents have a home distress protocol in case they need it. They know who to call in case of serious deterioration. They plan to stay at home with their son until his death, but they know that they nonetheless could return to the hospital at any time if needed. Martin's sister has received guidance from her parents and is doing well for the time being. The parents know that after the death, the care team will continue to be available for bereavement follow-up.

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