Communications about Cancer Prognosis: Parent Preferences and Considerations

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Learning Objectives

After reviewing this Guide you will be able to:

- Understand the language that oncology teams use to discuss prognosis
- Consider reasons that prognostic information might be helpful
- Find ways to ask about prognosis

Introduction

When clinicians talk about prognosis, they are talking about the future and what might occur. Often they are talking about the chances of cure or the expected length of life (life expectancy). Some aspects of prognosis include:

- Whether a cure is possible
- How likely it is that the child will be cured
- If cure is not likely, how long the child might have to live
- What life might be like for the child in the future; for example, how the child might feel and what daily life might be like

Learning Your Child's Prognosis: Pros and Cons

Sometimes physicians will offer information about prognosis around the time of diagnosis, or at important decision points. But physicians are also sometimes worried about causing parents stress by addressing this topic. As a result, they may wait for parents to ask for this information. If the physician does not offer prognostic information, you may wish to ask for it.

Why might you want prognostic information? Many parents of children with cancer feel better when they have received information about their child's prognosis, even if the news is not what they hoped for. Some want to understand the chances of cure or their child's life expectancy. They believe that once they know what is expected, they can begin to deal with that reality.

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Hearing about prognosis might help them feel prepared to do their best for the child, to make the best possible decisions. It may also affirm for them that the medical team will help them by communicating with honesty and transparency. Even if information is hard to hear, they don't want to feel that information is being withheld from them.

In fact, research has shown that parents who receive more prognostic information tend to have greater peace of mind and trust in the medical team. Many parents also report greater hope and less distress after receiving this information, even if the prognosis is poor.

However, some parents simply prefer not to receive prognostic information, and even parents who want the information may want it on their own timeline. Parents who prefer not to have prognostic information may fear that the information will be difficult to hear. In addition, hearing about chances of cure does not tell parents for certain what will happen to their own individual child. Some parents feel that the child's future will be decided by fate or a higher power, so a medical prediction is not as useful. Some parents fear that asking about prognosis indicates negativity or a lack of hope. Others believe that it's possible to learn what research says while also committing to hope for their child's outcome.

When Parenting Partners Have Different Preferences

Sometimes one parent wants to know about prognosis, and one parent does not. There might also be other people in your family or your life who have different wishes for information. When needs for information differ within your family or support system, you may have questions about how to move forward.

It can be helpful to talk with the other parent or family member openly about the different needs. You can think together about different possibilities. You might ask yourself and each other:

- What would it be like for one parent to know about prognosis, and for the other not to know?
- What would it be like to decide together to both get the information, even though one parent might not want it?
- What would it be like to decide together that neither parent should get the information, at least initially?

These conversations are not always easy, and they can be even more difficult if there are other challenges in the relationship, as when parents are not living together, divorced or separated. But the conversation can also give parents or families a chance to find ways to work together, considering one another's feelings and perspectives.

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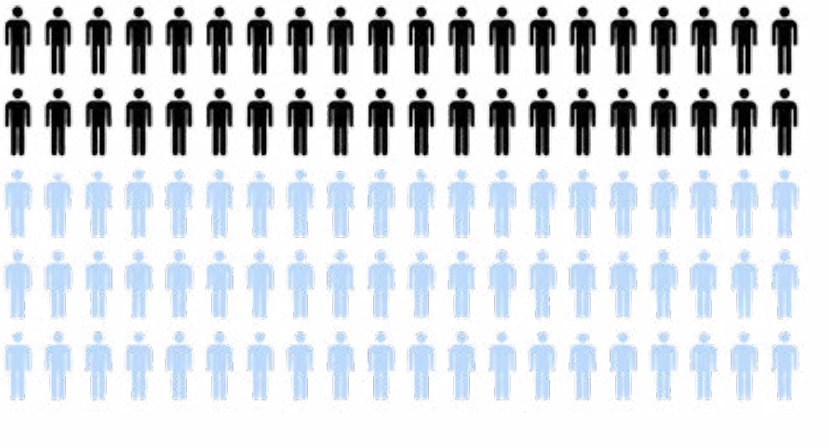
How Clinicians Communicate about Prognosis

Your child's prognosis is based on a variety of factors, including their diagnosis, the severity of the disease, and the availability of treatment options. Clinicians compare this information with research to determine an estimate for prognosis. Some conditions are well researched and have clear data about prognosis; other cancers occur less frequently and there may be less data about prognosis.

Prognosis can be expressed in different ways. Sometimes prognosis is expressed numerically. For example, a clinician might describe a percent likelihood of cure, the chance of surviving to five years after treatment, or an approximate amount of time that a child might have to live. Sometimes clinicians describe median survival, which is the length of time after which half of the patients are still alive and half have died (for example, if median survival is about six months, this means that about half of children will live less than six months, and about half will live more than six months). However, an individual's prognosis depends on a lot of factors and so it's difficult for medical teams to be completely certain. This is why some physicians avoid numbers and express prognosis with words; for example, that a child has a good chance of cure. Or, they might give a range of numbers to help describe the different possibilities. They can also give information about the best case scenario and the worst case scenario, with guidance about what they feel is likely.

Sometimes a visual representation of the prognosis statistic can be helpful. In this example, the image below shows 100 people. The people in blue represent 60, or 60%, of the people in the group. This could represent that 60% of people respond well to the proposed treatment.



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Asking for Prognostic Information

If you decide to ask for prognostic information, you might consider what it is you would like to know, and why. Is it most important for you to understand what your child's future life might be like? Whether the cancer is curable? The chances of cure? Understanding what you want to know can help you and the clinicians have meaningful discussions about your child's and family's future. Some questions you might ask are:

- What is the likely outcome of my child's cancer?
- Can they be cured?
- What are the chances of cure?
- (For times when cure is not expected or likely) How long might my child have to live
- What can you tell me about what my child's life will be like over the next several months? How will my child feel? How will their life be affected day to day–what changes might there be to their social or school life?
- What can you tell me about what my child's life will be like in the future, after treatment is finished? Will they have symptoms?
- What do you see as the range of possible outcomes for my child, the best case and worst case? What do you think is most likely to happen?

You may have other questions that you want to ask, or other ways to ask them. There is not a right or wrong way to ask; what's most important is that you get the information you need. Some parents find it helpful to write their questions down to make it easier to remember. Some parents also like to send questions to their health care team, such as through a patient portal, ahead of a visit. Think about what is comfortable for you.

You might also think about when to ask about prognosis. For example, you might want to ask during a visit where you have support from a family member or friend. You might also want to ask early enough in the visit that there is time for this discussion; if you ask as the physician is finishing the visit, there may not be time for a full conversation. If you do not get all of the information you need in one appointment or meeting, you can revisit your questions at a future appointment.

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When the Prognosis is Uncertain

Sometimes physicians or other health care team members offer less information than you want. They might tell you that it's hard to know, or that there is a lot of uncertainty. Even if there is uncertainty, though, it may be possible for them to share a range of possibilities; for example, the best case and worst case, or what they see as most likely. You can ask for that information if you would find it helpful.

There are also times when a child's cancer is very rare, and there is limited data to help your child's medical team formulate a prognosis. Uncertainty can be hard, but sometimes it is the reality. You may find it helpful to learn more about how the medical team thinks about the prognosis. You might ask, for example, what might change in the future to make them think things are going well, or not well? If a child has a good response to treatment based on initial radiology scans, would they think that the prognosis is more favorable? What might make them concerned that prognosis is more difficult? The answers to these questions might help you to understand the clinician's thought process, even if definitive information is not available.

Understand that prognosis almost always comes with some degree of uncertainty. Even if a cancer has a 95% chance of cure, some children will not be cured, and your child's future is hard to predict with certainty. Living with a child's cancer diagnosis sometimes means accepting that some things are unknown, and many things are out of anyone's direct control.

Using the Information You Receive

Parents may have different reactions to learning their child's prognosis. Sometimes they feel relief that the prognosis is better than they expected; other times the information might feel frightening. They might also feel both some relief and some fear. They may also feel pleased that they were able to have an open conversation with the medical team about this important topic. There is no right way to feel or respond.

There may be moments in your child's cancer journey when information about their prognosis would be important to have. This is especially true of times when you are asked to make medical decisions. For example, a new treatment may be offered for you to consider, perhaps a clinical trial. You may want to understand whether this treatment offers a chance for cure or prolonging life before deciding whether to use this treatment or to pursue a clinical trial. Many considerations go into these hard decisions, and there is often not just one best path. Understanding the possibilities for your child's future is one piece of information that can help a parent who is making important choices.

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Tending to your own emotions, and your other family members' emotions, is an important part of caring for your child. Some parents decide to put the information aside and not dwell on it. Caring for a child with cancer comes with many tasks and responsibilities, and some parents may find it helpful to focus on the present moment as much as possible. Other parents may prefer to think and plan according to the information they have received. If the information is overwhelming or on your mind so often that it gets in the way of daily life, you might consider talking with a trusted person, either someone in your personal life or from your child's cancer care team.

You may have found different, or other, resources for cancer information. Many families turn to online sources as a resource. Online sources can be useful, but it can be hard to be sure it is accurate or to know whether it applies to your child. You might also hear information from other parents or from family members and others in your life. Again, some of this information can be useful and helpful. But the best and most accurate information about your child's specific situation comes from your child's medical team, especially the oncologist who is in charge of your child's care.

Sharing Prognosis Information with Your Child

The answer to this question is individual, and depends on your feelings as well as your child's desire and readiness for this information. Many children have questions about the future, just as their parents do. Sometimes, when issues are not addressed openly, they fear the worst. In addition, they may assume that they aren't supposed to talk about their worries, and they may even choose not to share these questions and concerns because they want to protect their parents from difficult topics. So whether or not to share prognosis information with your child is individual, and depends on your feelings as well as your child's desire and readiness for this information.

Oftentimes,for adolescents, learning about prognosis is associated with less distress, more hope, and greater peace of mind, just as it is for parents. In many cases, allowing open conversation helps to address fears about the future and gives children a way to seek support for their deepest worries. You can find additional guidance to help with this question here: https://courageousparentsnetwork.org/guides/guide-to-speaking-with-your-child-about-prognosis/.

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Prognosis May Change Over Time

Your child's prognosis may change over time, depending on circumstances. Throughout the child's life, understanding prognosis may remain important to you, even as the answers may change. At diagnosis, it might be helpful to know whether cure is possible, or the chances of cure. If your child's cancer does not respond well to treatment, it may be helpful to ask about prognosis again, or to know their expected length of life if cure is not possible.

There might also be times when something has changed about your child's cancer. For example, maybe there has been good news about a test result, or difficult news about the cancer returning or responding poorly to treatment. Maybe treatment has been adjusted because of side effects. Any of these situations may cause a parent to wonder if the child's prognosis has changed.

Finally, parents may have times when they feel especially ready for prognostic information, even if they did not want it at the time of diagnosis. There is no wrong time to ask for this information, and it's most certainly okay to ask to revisit these topics with your child's health care team over the course of your child's care.