

Survey shows parents lack understanding of teens' with cancer preferred time to talk about end-of-life issues

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The findings of a survey of adolescent cancer patients and their families at four tertiary care U.S. pediatric hospitals showed that parents had a poor understanding of their teens' preferences for the best time to bring up end-of-life decisions, dying a natural death, and being taken off life support. The findings, published this week in *JAMA Network Open*, suggest that family-centered pediatric advance care planning interventions are needed to close this gap.

Families wanted to know their child's treatment preferences, but did not know how to "break the ice." As one parent reported, "I'm glad we said yes to being in the study. Some things we 'know,' but we don't really know for certain and aren't quite sure how to bring them up, so having someone to do that has been really nice."

Having those conversations ahead of time may minimize the misunderstandings that can take place when an adolescent is close to death—misunderstandings that can lead to ineffective communication, increased hospitalization, poor quality of life, and legal actions.

"Advance care planning interventions are needed to improve families' awareness and understanding of their teens' end-of-life choices," says Maureen E. Lyon, Ph.D., Children's National Hospital clinical psychologist and principal investigator on the study.

"Teens need to have a voice in their care and families are eager to know what their teens want, but those conversations can be difficult," says Dr. Lyon. Advance care planning interventions for parents and adolescents "create a space where they can ask questions and be honest with each other" before death is imminent.

The survey—which enrolled the largest sample of teens with cancer and their families to date—builds on earlier work by Dr. Lyon and her research colleagues. The findings are detailed in the article "Congruence Gaps Between Adolescents With Cancer and Their Families Regarding Values, Goals, and Beliefs About End-of-Life Care" published Wednesday, May 20, in *JAMA Network Open*.

The survey showed that family members' understanding of their adolescents' beliefs about the best time to bring up end-of-[life decisions](#) was poor. Among the teens, 86% wanted early timing (before getting sick, while healthy, when first sick from a life-threatening illness, when first diagnosed, or all of these), but only 39% of families knew that.

Families' understanding of what was important to their adolescents when dealing with their own dying was excellent when it came to wanting honest answers from their physician and understanding treatment choices. But their understanding was poor when it came to dying a natural death and being off [life-support](#) machines.

The study was conducted between July 16, 2016, and April 30, 2019, and included a 3-session intervention. The trial involved 80 adolescent-[family](#) dyads who were recruited from Akron Children's Hospital, Akron, Ohio; St Jude Children's Research Hospital, Memphis, Tennessee; University of Minnesota Masonic Children's Hospital, Minneapolis, Minnesota; and Children's National Hospital, Washington, D.C.

Family-centered pediatric [advance care](#) planning interventions offer a structured process that creates a safe space to contain the strong emotions that such conversations elicit. One parent said about the study, "Thinking about this makes me sad, but it's good to talk about them so we know what he wants."

The COVID-19 pandemic has led to a dramatic increase in advance care planning and the creation of advance directives, also known as living wills, in the United States. Now is the time to start having these conversations. People can use what's happening in the news as a trigger to begin the process of advance care planning. As one parent stated, "Everybody should talk about these topics, whether you are a teen or elderly or at any age."

More information: Sarah Friebert et al, Congruence Gaps Between Adolescents With Cancer and Their Families Regarding Values, Goals, and Beliefs About End-of-Life Care, *JAMA Network Open* (2020). [DOI: 10.1001/jamanetworkopen.2020.5424](https://doi.org/10.1001/jamanetworkopen.2020.5424)

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