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Deeper Conversations Need Not Wait Until the End

Lori Wiener,

National Cancer Institute, Bethesda, MD

Chris Feudtner,

The Children's Hospital of Philadelphia, Philadelphia, PA

Pamela Hinds,

Children's National Health System and George Washington University, Washington, DC

Joanne Wolfe, and

Dana-Farber Cancer Institute and Boston Children's Hospital, Boston, MA

Jennifer Mack

Dana-Farber Cancer Institute and Boston Children's Hospital, Boston, MA

To the Editor

In the April 10, 2015, issue of *Journal of Clinical Oncology*, Eaton Russell and Bouffet¹ poignantly describe communication challenges of nonverbal children at the end of life. The authors described the helplessness families experience and the energy devoted to trying to capture the child's voice, and they recognized that something important was missing from computer tools developed for this purpose. The authors also noted that, in the end, it was the emotional connection that was needed most, because that connection, not the tool, is what parents will remember when their child is no longer alive.

Interestingly and importantly, data suggest that deepening conversations early in the cancer trajectory can prevent the urgency to feel connected when life expectancy seems short.^{2,3} Early engagement of parents about what it means to them to be a good parent to their ill children can facilitate the need for connection that the authors described so well.⁴ Similarly, instruments such as My Wishes or Voicing My Choices were not designed to be a tool per se

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Lori Wiener

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Chris Feudtner

No relationship to disclose

Pamela Hinds

No relationship to disclose

Joanne Wolfe

No relationship to disclose

Jennifer Mack

No relationship to disclose

but, rather, a way to avoid a pause in the sense of being heard or being deeply emotionally connected in the living and dying experience.^{5,6} In this sense, communication and connection are seamlessly synonymous.

In talking about the child who was giving away her prized possessions, the authors seem to allude to the silence about the unfortunate and continued taboo nature of these discussions. If children are to have their voices heard, verbally or nonverbally, then waiting until their abilities begin to change is too late—their voices are silenced. Children and parents need to communicate about these emotional connections before changes in the child's medical status make such connections more difficult.

Initiation of conversations early means that, at times, discussions occur before the terminal nature of a child's illness is known definitively, and clinicians may be uncomfortable raising such issues in the setting of prognostic uncertainty. However, early conversations also can be an opportunity to explore values, hopes, and fears as they relate to the future, before the pressure of decision making about end-of-life care is high.^{7,8} However, even when conversations occur late in care, children report benefits and no harms to them from being included in conversations about the end of curative treatments.⁹

Back et al¹⁰ offer one way to allow patients and families to prepare for potential difficult outcomes while also hoping that things may be different. One might ask parents and children, for example, "What would you want if things don't go as you hope?" Asking any child, or any parent, what they expect is ahead, what they are hoping for, and what they are worried about can offer important information, no matter what is ahead for that child. Such questions also remind children and their parents that we value them and wish to know them as people. Finally, as clinicians, we can model these conversations as a way to open these difficult, highly personal topics within the family.

Parents need to be assured that they are doing everything possible to comfort their children, and children need to be assured that they will be remembered. It is then that the connection about which Eaton Russell and Bouffet¹ eloquently spoke is solidified and children can find peace in being able to say goodbye.

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