

# The Road to Readiness: Guiding Families of Children and Adolescents with Serious Illness Toward Meaningful Advance Care Planning Discussions

**Lori Wiener, PhD, DCSW**, National Cancer Institute; **Cynthia J. Bell, PhD, RN**, Wayne State University; **Jessica L. Spruit, DNP, CPNP-AC**, Wayne State University; **Meaghann S. Weaver, MD, MPH, FAAP**, University of Nebraska Medical Center, and National Center for Ethics in Health Care; and **Amanda L. Thompson, PhD**, Inova Schar Cancer Institute

August 2, 2021

Seriously ill children, adolescents, and young adults (C-AYA) live with a heavy symptom burden, uncertain or poor prognoses, and evolving expectations of their disease course that require health care professionals (HCPs) to facilitate and maintain meaningful conversations across clinical settings. Caring for C-AYA with life-threatening illnesses is complex for family caregivers and HCPs. Among the many responsibilities of HCPs attending to the needs of these young patients and their caregivers is engaging in early advance care planning (ACP) discussions. Such conversations can help in understanding values, goals, and preferences to promote alignment with the medical care being delivered including interventions at end of life and preference regarding place of death. Further, engaging in conversations that clarify the wishes of C-AYA patients and caregivers can guide the patient's care, promote a sense of shared decision making, and prevent enduring, detrimental experiences of regret [1]. Initiating and leading these conversations requires readiness. The purpose of this commentary is to promote awareness of the dynamic and multifactorial nature of readiness, the HCP's ability to assess their own and the family's readiness to engage, and the immediate and long-lasting impact these meaningful conversations can have on the lives of those in their care.

Readiness has been defined as both a state and a process. It is important for HCPs to identify the state of readiness of patients and their families and also to understand the dynamic process of readiness that influences these clinically important conversations. In a study involving adolescents with incurable cancer, readiness is described as a multidimensional con-

struct, consisting of awareness, acceptance, and willingness to engage in conversations and defined as a dynamic internal process influenced by the patient's physical condition and by other people present in the life of that patient [2]. Readiness is not a linear process—rather, it has alternating routes and pathways that stimulate cognitive or emotional discussions that are largely driven by the patient's awareness context. Conversations are critical in meeting the needs of patients and their families and provide opportunities for HCPs to build and establish rapport while facilitating this critical dialogue. For this commentary, the authors are building on the definition of readiness described in adolescents with incurable cancer to include not only the readiness of C-AYA patients, but also family caregivers and HCPs.

In clinical conversations within pediatric settings, HCPs often communicate with patients and their parent(s) or other family members advocating for the child's care. It is essential to recognize that within this triadic relationship (C-AYA, family caregiver, HCP), the patient's state of readiness may not be congruent with the family caregiver's or HCP's readiness to talk and that each member of this triad may be in a different state of readiness from day to day, or even moment to moment. As a result, the assessment of readiness requires the HCP to both evaluate their own readiness to initiate difficult conversations and to be aware of readiness discordance among individuals involved in difficult clinical conversations. Oftentimes, the perception of readiness may hinder the readiness of other members in the triad and interfere with the opportunity to have meaningful conversations. For example, the fam-

ily caregiver or HCP may feel the C-AYA is not “ready” to engage in these conversations and may avoid difficult topics. To the contrary, C-AYA have reported a sense of responsibility to “protect” their devoted family caregivers and focus on treatment-related discussions while avoiding topics such as end-of-life care.

**What the Evidence Tells Us**

While readiness can constitute a significant barrier to initiating important ACP conversations, to date, only a handful of papers have reported on ACP readiness [3]. These include studies with populations across the life span: pediatric and adolescent patients with chronic medical conditions, adults with advanced disease processes, and older adults living in care facilities.

**Pediatric Populations**

ACP has been associated with improved parent-reported end-of-life outcomes for C-AYA with complex chronic conditions [4]. To address the disconnect between the perceived benefits of early ACP discussions with what occurs in pediatric practice, Orkin and colleagues conducted semi-structured interviews with parents of children living with a chronic health condition and HCPs of various disciplines [3]. Enhancers to ACP discussions emerged from the data, including “partnerships in shared decision making, a supportive setting, early and ongoing conversations, consistent language and practice, family readiness, provider expertise in ACP discussions, and provider comfort (and readiness) in ACP discussions” [3].

HCPs also spoke about the need to assess family readiness for ACP discussions and to follow the family’s lead [3]. Parents emphasized that HCPs should respect their feelings, especially when they make it clear that they are not ready to engage in ACP conversations. Other HCPs acknowledged that families might never feel ready to engage in ACP conversations, which can be challenging in planning for end-of-life care. The importance of extending ACP conversations beyond medical goals of care, beginning early in the child’s disease trajectory (before the patient is in critical condition), and continuing across the child’s life span was emphasized by both parents and HCPs. Also essential is reframing discussions to align the patient and family’s goals of care with the plan of care and revisiting discussions across the life span in order to allow for goals to evolve as the child’s health changes [3,5].

**Adolescents and Young Adults**

Little is known about the readiness of young adults to

engage in ACP outside of studies using hypothetical examples with college students. What is known comes mostly from data collected with adolescents living with cancer, but also HIV and other life-limiting conditions. Cancer is the leading cause of disease-related deaths in adolescents and young adults (AYAs). Each year, more than 70,000 AYA cancer patients are diagnosed in the United States [6]. Evidence suggests that honest disclosure regarding prognosis and end-of-life issues is preferred and can lead to less suffering. These conversations can have important implications for how AYAs live the remainder of their life, by whom they wish to be cared for, and where they prefer to die [7]. These conversations can also help families prepare for and cope after their death [8].

In a study designed to examine patient-reported end-of-life values and needs of adolescents with cancer (ages 14–21) and congruence with their families’ understanding of these needs, only 39% of those approached were willing to participate in the trial [9]. Of those who declined, 23% had at least one member of the dyad report who did not want to talk about ACP. The major reason given for declining was lack of time to commit to a two-year study. More males than females declined to participate. “Age, race, ethnicity, diagnosis, and active treatment status were not statistically significantly different between those who enrolled and those who declined participation” [10]. These findings highlight the complexity of readiness to engage in the ACP process [10].

**Advanced Illness**

Most data about communication patterns and ACP readiness come from the literature with persons of advanced illness. In a study by Zwakman et al. that included ACP conversations of adult patients with advanced cancer, a sign of being ready to have ACP conversations was being able to anticipate possible future scenarios or demonstrate an understanding of one’s disease [11]. While those who limit their perspective to the here and now or indicate a preference not to talk about an ACP topic were signs of not being ready, these individuals were still able to continue a conversation when a new topic was introduced. These findings support how readiness can continuously fluctuate and change, even during the course of the ACP conversation itself, suggesting that the current state of readiness should not be the only indicator for whether or not to initiate or postpone an ACP conversation. This has direct relevance to the dynamic process of readiness to engage in ACP conversations with C-AYA and

**Table 1 | Readiness Considerations and Inquiries**

Domain	Example Questions for Older Children, Adolescents, and Young Adults	Example Questions for Younger Children*
Knowledge	Tell me what you understand about your illness. What are your care options? What do you understand might happen in the future?	How is your body feeling today? What’s going on with your (child’s name for their illness)? What have you heard?
Information Sharing	How much information do you find helpful about your diagnosis and potential complications? Whom do you prefer to receive information from? Whom do you want present when information is shared?	Do you want to hear updates or news from the doctors? Or from your parents? Or both?
Culture and Family	How do your personal values or community values impact your preferences for receiving information? Do you openly talk about your health and your future with those you love? How does your role in your family impact your readiness to discuss certain health topics? How do your family members’ preferences about discussing medical information impact your ability to access information?	Who can you talk to about how you are feeling?
Emotions	Can you tell me about any worries that you have about your illness or the future? Can you tell me what it feels like to talk about your illness or the future?	What made you happy today? Yesterday? Lots of boys and girls like you have worries. What are you worried about right now? What other types of feelings are you having?
Hopes	What do you hope for with your current medical care? These hopes are meaningful. If these hopes do not come true, what else would you hope for?	If you had three wishes, what would they be? What are you hoping for?
Quality of Life	What does living well (a good day) look like for you? What is important for you?	What makes today a good day? What would make tomorrow a good day? What helps you feel better/your best?

\*Readiness for young children may be demonstrated/assessed verbally, but other tools include the use of games, creative arts therapies (e.g., art and music), and play.

SOURCE: Created by authors.

their parents and conversations about ACP with their HCP.

### Strategies and Priorities

Early initiation and ongoing ACP conversations will promote the alignment between the care desired by the C-AYA and their family caregivers with the care delivered. Readiness to talk will need to be assessed and reassessed as the disease course evolves, with attention to the dynamic nature of this process. The HCP is a companion along the illness trajectory and can offer therapeutic interventions and guidance that promote this alignment and ensure the values shared by the C-AYA and family caregivers are central in the discussions taking place and care being rendered. This ongoing partnership is essential when striving to provide the highest quality of care. To facilitate HCPs' ability to assess their own readiness, as well as the readiness of patients and families, we provide some important considerations, as well as strategies for clinical practice, below.

HCPs must consider several factors when assessing patient and caregiver readiness to engage in ACP discussions. In the pediatric setting, a developmental perspective is critical, as children's understanding of illness, death, and dying (and therefore their ability to communicate about these topics) grows more sophisticated with age. Even young children have the potential to understand more about health and illness than previously given credit for, especially if they are provided developmentally appropriate psychoeducation. It is not uncommon for children and adolescents who have been living with chronic and life-limiting illnesses to be ready for these discussions before their caregivers or even their medical providers. In efforts to protect caregivers from worry and/or recognizing that their caregivers themselves may not be ready, children and adolescents may share concerns about their disease course or ask questions about death and dying with trusted team members and appreciate the chance to talk about fears, hopes, and goals of care. Complicated issues can arise when children and adolescents

are in a state of readiness before their family caregivers, and HCPs may have to navigate challenging clinical scenarios with care (e.g., a minor child asks directly, "Am I going to die?" when their family caregivers are not present).

As with all patients, readiness assessments with C-AYA include assessment of a person's developmental level and cognitive abilities, as well as the impact of disease and treatment on orientation and mental status. There continues to be a need for communication strategies and tools for those with different abilities (e.g., children who are nonverbal, children with auditory processing deficits). Family systems-level factors are also key; family dynamics, communication styles, preferences for information sharing, norms around sharing difficult information, and more will impact the family's readiness as a unit and individual family members within that system. Finally, consideration of cultural and religious values, expectations, and norms are critical to understanding ACP readiness. Respecting and exploring a patient's belief systems, as well as understanding views on life, death, dying, suffering, and the afterlife through the lenses most important to them (e.g., a specific cultural or religious tradition) will help guide and shape subsequent ACP discussions.

Readiness requires not just a willingness to discuss difficult topics with patients and families, but the skill and ability as well. Limited education or experience having ACP discussions is not uncommon among HCPs and has been identified as a significant barrier to initiating and continuing these conversations [12]. *Table 1* provides guidance in the form of questions that may be helpful in assessing readiness and initiating these discussions across development. Increased comfort with ACP discussions will allow HCPs to shift toward elucidation and sharing of values and preferences when they recognize signs that their patients and/or family caregivers are in a state of readiness.

The road to readiness will inevitably have twists and turns along the way, but strategies can be helpful for mapping the journey to avoid roadblocks for HCPs looking to build confidence in these skills (see *Box 1*). These strategies include HCPs navigating their own readiness as well as that of their patients, working to increase their own comfort with having these meaningful conversations, and collaborating with their interdisciplinary team around these conversations, if appropriate. HCPs must always consider that C-AYA and their caregivers may want to engage in conversations to varying degrees of intensity on different days. Each

opportunity should be seized, as ACP is a process, not a one-time event, with each conversation building on the next, guiding care and paving a road for future discussions. Although this is a difficult exercise that challenges HCPs to put their own perceptions and readiness aside in an effort to optimize the experiences of patients and their family caregivers, it is essential when caring for C-AYA patients living with life-threatening diseases.

### References

- Lichtenthal, W. G., K. E. Roberts, C. Catarozoli, E. Schofield, J. M. Holland, J. J. Fogarty, T. C. Coats, L. P. Barakat, J. N. Baker, T. M. Brinkman, R. A. Neimeyer, H. G. Prigerson, T. Zaider, W. Breitbart, and L. Wiener. 2020. Regret and unfinished business in parents bereaved by cancer: A mixed methods study. *Palliative Medicine* 34(3):367-377. <https://doi.org/10.1177/0269216319900301>.
- Bell C. J., G. D. Zimet, P. S. Hinds, M. E. Broome, A. M. McDaniel, R. M. Mays, and V. L. Champion. 2018. Refinement of a conceptual model for adolescent readiness to engage in end-of-life discussions. *Cancer Nursing* 41(2):E21-E39. <https://doi.org/10.1097/NCC.0000000000000465>.
- Orkin, J., L. Beaune, C. Moore, N. Weiser, D. Arje, A. Rapoport, K. Netten, S. Adams, E. Cohen, and R. Amin. 2020. Toward an understanding of advance care planning in children with medical complexity. *Pediatrics* 145(3):e20192241. <https://doi.org/10.1542/peds.2019-2241>.
- DeCoursey, D. D., M. Silverman, A. Oladunjoye, and J. Wolfe. 2019. Advance care planning and parent-reported end-of-life outcomes in children, adolescents, and young adults with complex chronic conditions. *Critical Care Medicine* 47(1):101-108. <https://doi.org/10.1097/CCM.0000000000003472>.
- Hutchison, L. A., D. S. Raffin-Bouchal, C. A. Syme, P. D. Biondo, and J. E. Simon. 2017. Readiness to participate in advance care planning: A qualitative study of renal failure patients, families and healthcare providers. *Chronic Illness* 13(3):171-187. <https://doi.org/10.1177/1742395316675023>.
- Bleyer, A. 2005. The adolescent and young adult gap in cancer care and outcome. *Current Problems in Pediatric and Adolescent Health Care* 35(5):182-217. <https://doi.org/10.1016/j.cppeds.2005.02.001>.
- Snaman J., S. McCarthy, L. Wiener, and J. Wolfe. 2020. Pediatric palliative care in oncology. *Journal of Clinical Oncology* 38(9):954-962. <https://doi.org/10.1200/JCO.2019.8954>.

### BOX 1 | A Call to Action around ACP Conversations

#### What can I do?

Cultivate awareness. Be aware that readiness to have ACP discussions is a complex cognitive and emotional phenomenon that waxes and wanes over the illness trajectory, from one day to the next, and sometimes within the course of a single conversation.

Understand and attend to factors impacting patient and family readiness (e.g., developmental stage, cognitive abilities, communication styles, cultural and religious factors), as they can either facilitate or hinder progress toward honest sharing of values and preferences.

#### What if I'm not ready?

HCPs must be aware of not just patient and caregiver readiness, but their own emotions and what triggers hesitancy. Steps should be taken to increase your comfort and ability to explore readiness with families (e.g., trainings, role plays, supervision). Companioning with C-AYA and their caregivers on the road to readiness may be necessary before an HCP feels "ready," while remaining cognizant that perceived personal unreadiness may become a roadblock to guiding these meaningful discussions.

Due to the interdisciplinary nature of pediatric care of C-AYA with chronic or life-threatening illnesses, it is recommended that a team choose the member or members who have strong, trusting relationships with the child and family and the skills and comfort to engage in readiness assessments and ACP discussions. This may be the primary specialist physician, the pediatric intensivist, or the palliative care physician; advance practice provider (nurse practitioner or physician assistant), registered nurse, psychologist, social worker, child life specialist, or chaplain; or some combination thereof.

**SOURCE:** Developed by authors.

org/10.1200/JCO.18.02331.

8. Kaye E. C., S. Friebert, and J. N. Baker. 2016. Early integration of palliative care for children with high-risk cancer and their families. *Pediatric Blood & Cancer* 63(4):593-597. <https://doi.org/10.1002/pbc.25848>.
9. Friebert S., D. H. Grossoehme, J. N. Baker, J. Needle, J. D. Thompkins, Y. I. Cheng, J. Wang, and M. E. Lyon. 2020. Congruence gaps between adolescents with cancer and their families regarding values, goals, and beliefs about end-of-life care. *JAMA Network Open* 3(5):e205424. <https://doi.org/10.1001/jamanetworkopen.2020.5424>.
10. Schnur K., and K. Radhakrishnan. 2019. Young adult knowledge and readiness to engage in advance care planning behaviors. *Journal of Hospice and Palliative Nursing* 21(1):54-60. <https://doi.org/10.1097/NJH.0000000000000487>.
11. Zwakman M., M. M. Milota, A. van der Heide, L. J. Jabbarian, I. J. Korfage, J. A. C. Rietjens, J. J. M. van Delden, and M. C. Kars. 2020. Unraveling patients' readiness in advance care planning conversations: A qualitative study as part of the ACTION Study. *Supportive Care in Cancer* 29(6):2917-2929. <https://doi.org/10.1007/s00520-020-05799-x>.
12. Durall A., D. Zurakowski, and J. Wolfe. 2012. Barriers to conducting advance care discussions for children with life-threatening conditions. *Pediatrics* 129(4):e975-982. <https://doi.org/10.1542/peds.2011-2695>.

## DOI

<https://doi.org/10.3147/202108a>

## Suggested Citation

Wiener, L., C. J. Bell, J. L. Spruit, M. S. Weaver, and A. L. Thompson. 2021. The Road to Readiness: Guiding Families of Children and Adolescents with Serious Illness Toward Meaningful Advance Care Planning Discussions. *NAM Perspectives*. Commentary, National Academy of Medicine, Washington, DC.

## Author Information

**Lori Wiener, PhD, DCSW**, is Director, Psychosocial Support and Research Program, Pediatric Oncology Branch, National Cancer Institute. **Cynthia J. Bell, PhD, RN**, is Associate Professor, College of Nursing, Wayne State University. **Jessica L. Spruit, DNP, CPNP-AC**, is Pediatric Acute Care Nurse Practitioner Program Coordinator, Wayne State University. **Meaghann S. Weaver, MD, MPH, FAAP**, is Division of Palliative Care, Department of Pediatrics, University of Nebraska Medical Center, and National Center for Ethics in Health Care. **Amanda L. Thompson, PhD**, is Chief, Pediatric Psychology and Director, Pediatric Programs, Life with Cancer, Inova Schar Cancer Institute.

## Acknowledgments

We would like to acknowledge **Dr. Pamela Hinds** for her exceptional leadership of our Pediatric Palliative Care Special Interest Group. We would also like to acknowledge all of the children, adolescents, young adults, and families whom we have had the honor to work with and who continue to teach us and inspire our work.

## Role of Funding/Support

This work was supported, in part, by the Intramural Program of the National Cancer Institute, National Institutes of Health (Dr. Wiener). Dr. Weaver contributed to this paper in a private capacity. No official support or endorsement by the US Department of Veterans Affairs is intended, nor should be inferred.

## Conflict-of-Interest Disclosures

The authors have no conflicts to disclose.

## Correspondence

Questions or comments about this paper should be directed to Lori Wiener at [wieneri@mail.nih.gov](mailto:wieneri@mail.nih.gov).

## Disclaimer

The views expressed in this paper are those of the author and not necessarily of the author's organizations, the National Academy of Medicine (NAM), or the National Academies of Sciences, Engineering, and Medicine (the National Academies). The paper is intended to help inform and stimulate discussion. It is not a report of the NAM or the National Academies. Copyright by the National Academy of Sciences. All rights reserved.