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When Silence Is Not Golden: Engaging Adolescents and Young Adults in Discussions Around End-Of-Life Care Choices

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Managing end-of-life care (EoL) is always emotionally taxing. Honest discussions about prognosis and EoL decision-making are often delayed due to questions about the legal competence of adolescents and young adults (AYA) to make decisions for themselves [1], providers feeling unprepared or without adequate skills to guide EoL discussions, or parental concern that discussing plans, including life support options or presenting an EoL planning document may send the message that the medical team wishes to withdraw care or that death is imminent. Data suggest that allowing AYA involvement in EoL planning can help parents and healthcare providers make informed decisions, alleviate distress, avoid decisional regret, and perhaps improve the patient's quality of life (QoL) by respecting their values, beliefs, and preferences [2–4]. This commentary addresses recent progress in the field and focuses on how healthcare professionals can approach advance care planning (ACP) with AYA, involve their family members, and engage the entire health care team.

Implement a Consistent Approach

Healthcare provider discomfort with ACP could improve if providers had a systematic approach they could implement consistently with all patients living with a life-limiting illness [5]. Part of developing a systematic approach begins with identifying specific time points at which a patient's preferences and goals are discussed. This discussion should begin when treatment is initiated and tailored to the individual needs of the AYA and family. Having this exchange early on ensures attention to QoL and allows subsequent discussions to be less unexpected. If the illness is becoming refractory to treatment, the provider can go back to this earlier conversation. Table 1 provides sample phrases that can be adapted to introduce the topic of ACP and foster discussions over the disease trajectory.

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Assess Advance Care Planning Readiness

Specific factors can be used to determine and verify individual readiness. First, the AYA and family must acknowledge that cure may not be possible. They also need to be willing to engage in conversations about future treatment and lack of future treatment, and should be at least amenable to explore the AYA's thoughts, preferences, and/or goals. Ideally, the AYA should be in relatively stable health at the time ACP is introduced. A member of the healthcare team who has the confidence and trust of the AYA and their family, can talk frankly about EoL without it being portrayed as a loss of hope, and who understands their specific psychosocial needs should initiate the discussion [6]. As discussions of death at a time when the AYA has been working toward gaining independence, strengthening peer and romantic relationships, and considering their future role in life is a threat to these developmental milestones, the focus of the discussion should be about issues that are meaningful to the AYA rather than simple completion of a document. In fact, AYA concerns regarding EoL may center around pain, unresolved relationships, location of death, or how they wish to be remembered rather than deciding specific medical options, such as resuscitation orders.

Engage the Family

Parents may wish to avoid conversation about EoL in order to maintain a stance of support. It is important to share with parents that lack of communication can lead to emotional distance at a time when closeness is most needed. If parents remain unable to initiate this conversation with their child, offering to help, i.e., "*With your permission, I would like to explain to Katie where we are at and to see if she has any questions. Would you be comfortable with this?*" may be an easier approach that can hopefully lead to better understanding of their child's preferences. If the parent asks that the child not be told that s/he will die, the provider should explore the parent's concerns, beliefs and customs so as to avoid misunderstandings. It is best if the parent and provider can agree that s/he will not lie if the AYA asks.

While all AYA deserve the opportunity to prepare for and cope with the realities of advancing illness, not everyone will be developmentally or cognitively capable or even desiring to do so. Making one's own needs known can be frightening, and others will try to protect their parents from their own distress. This is a process, not a one-time conversation. The goal is to pave a road so that conversations can be revisited at a later point, if needed.

Team Approach

Physicians, by nature of their role, are uniquely responsible for relaying bad news. Despite one's interpersonal skills, the family's spiritual, ethical, cross-cultural, practical, and existential issues that factor into EoL plans can challenge both the physician's time and expertise [7]. Professionals, including nurses, social workers, clergy, and psychologists can play key roles in EoL discussions. When involving additional staff members, the AYA must be asked how much s/he wishes to share with the team, so as to not breach confidentiality. When multiple team members are working with the same patient and family, communication between team members is essential so that the message from all members of the team about prognosis remains the same.

Discussing EoL with AYA is difficult, not only because of the sensitive nature of the issue, but also because of the need for a developmentally appropriate approach and language. Fortunately, progress has been made in ACP and a few resources are available to assist AYA and medical providers, including FOOTPRINTSSM, a model that assures continuity between hospital and community-based medical services [8]; the FACE program, developed

for AYA living with HIV/AIDS that facilitates discussions and EoL decision-making with caregivers [9]; and Voicing My CHOICES, an ACP guide designed to help AYA make decisions about their care and how they wish to be remembered after their death [2] (www.agingwithdignity.org/vmc). Future empirical research will determine whether these or disease-specific models impact outcomes. Regardless of the tool used, more trained facilitators in conducting ACP are needed, supporting the important role of interdisciplinary pediatric palliative care programs when available. A comprehensive training for pediatric providers will soon be available for physicians through the training module, Education in Pediatric Palliative Care (EPEC) (www.epec-pediatrics@childrensmn.org).

A critical aspect to providing better care to dying patients is better communication, that is, understanding their experiences and concerns so that more control of events and choices can be made [10]. Ideally, the AYA understands cure may not be possible, but more important than prognostic discussions are ongoing opportunities to honor their priorities [9]. While this commentary suggests ways to promote such opportunities, empirical research is needed to determine whether such approaches are effective, cost-effective and plausible for providers in resource limited and culturally diverse settings. If the AYA is to have their voice heard, waiting until a medical crisis or the EoL is near, is too late for planning conversations to occur. While always heartbreaking, the most intimate and peaceful adolescent deaths are those where the AYA trust their choices are respected, believe that they made a footprint on others' lives, and are assured that they will be remembered. It is then that they can find meaning in the dying experience and the strength to say good-bye.

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References

1. Hammes BJ, Klevan J, Kempf M, Williams MS. Pediatric advance care planning. *J Palliat Med*. 2005; 8:766–773. [PubMed: 16128650]
2. Wiener L, Zadeh S, Battles H, et al. Allowing adolescents and young adults to plan their end-of-life care. *Pediatrics*. 2012; 130:897–905. [PubMed: 23045560]
3. Jankovic M, Spinetta JJ, Masera G, et al. Communicating with the dying child: An invitation to listening—a report of the SIOP working committee on psychosocial issues in pediatric oncology. *Pediatr Blood Cancer*. 2008; 50(5):1087–1088. [PubMed: 18360885]
4. Kane, JR.; Joselow, M.; Duncan, J. Understanding the illness experience and providing anticipatory guidance. In: Wolfe, J.; Hinds, PS.; Sourkes, BM., editors. *Textbook of Interdisciplinary Pediatric Palliative Care*. Philadelphia, PA: Elsevier Incorporated; 2011. p. 30-40.
5. Weissman DE. A faculty development course for end-of-life care. *J Palliat Med*. 1998; 1:35–44. [PubMed: 15859870]
6. Fraser J, Harris N, Berringer AJ, Prescott H, Finlay F. Advanced care planning in children with life-limiting conditions—the Wishes Document. *Arch Dis Child*. 2010; 95(2):7982.
7. Larson DG, Tobin DR. End-of-life conversations. *Evolving practice and theory JAMA*. 2000; 284:1573–1578.
8. Toce S, Collins MA. The FOOTPRINTSSM Model of Pediatric Palliative Care. *J Palliat Med*. 2003; 6(6):989–1000. [PubMed: 14733693]
9. Lyon ME, Garvie PA, McCarter R, et al. Who Will Speak for Me? Improving End-of-Life Decision-Making for Adolescents With HIV and Their Families. *Pediatrics*. 2009; 123:e199. [PubMed: 19171571]
10. Emmanuel EJ, Fairclough DL, Wolfe P, Emanuel LL. Talking with terminally ill patients and their caregivers about death, dying, and bereavement. *Arch Intern Med*. 2004; 164:1999–2004. [PubMed: 15477434]

TABLE I

Approaching EoL conversations with adolescents, young adults and family^{*#}

Time	Goal	Sample Conversation
Time of Diagnosis	<ul style="list-style-type: none"> Establish an open relationship based on honesty 	<p>“Can you tell me what you understand about your disease at this point?”; “What do you understand about your treatment options and plan?”</p> <p>“How much information do you want us to share with you?”</p> <p>“Do you do better with written materials that you can read on your own?”</p> <p>“Are there things you would like to speak privately to me about (or, conversely)” “How do you feel about giving your parent(s) the opportunity to speak privately with me.”</p>
Initiation of Treatment	<ul style="list-style-type: none"> Early conversation about the possibility of cure not being achievable or likely Introduction to ACP Ensure the AYA and family understand that these are precautionary measures Inclusion of the AYA in discussions and providing the AYA with a sense of control Encourage conversations to occur between parent and AYA 	<p>“Are there parts of the treatment plan that concern you?”</p> <p>“While we are hopeful that your treatment will be effective against your disease, we have learned from other families like your own that not suggesting that you give some thought to some difficult issues early on is irresponsible of us. For example, it would be ideal if you would communicate with each other about who would be the person to make medical decisions for you if you became very ill and were not able to do so on your own. Or, if you have strong religious or cultural beliefs about things such as life support in the case that a sudden event happens, that is always helpful to talk about and share with the staff. Again, we are not anticipating these issues will present themselves at this time - it is just that such conversations are easier to have when you are well than if a sudden problem arises. Please know that you can change anything you decide now at a later point. Does this make sense to you? Do you have any questions?”</p>
Recurrence/Progression	<ul style="list-style-type: none"> Determine if there is anything that the AYA is worried about or afraid of Explore if the family has had initial ACP discussions Ask if the patient ever thought about how aggressively they would want to be treated if cure were not possible Assess family communication; family concerns 	<p>“We have some new findings about your disease. How much do you want to know?” or “Are there things you would rather we talk to your parents about first?”</p> <p>(Once findings shared) “Do you remember when we had talked about difficult topics that families might want to think about if treatments were not as effective as we had hoped? While we have other options for continuing treatment, I just want to make sure we are considering what you want. Have you had any of those conversations? [If so], can you share with me what your thoughts are? [If not] For example, if you would like us to focus more on you having the best quality of life, such as being away from hospital as much as possible, decisions we make from this point forward will be geared to help this happen. Can you tell me what is most important or concerning to you at this moment?”</p>
Continued disease progression	<ul style="list-style-type: none"> Inquire about what worries or concerns them most and about any immediate goals that they wish to fulfill Describe advance care planning and directives Introduce planning guide Provide materials (legal resources regarding a health care agent if needed) and an age appropriate planning document Offer to go through a document together 	<p>“We are at a place now where we no longer know if cure is possible” or “You are at risk for (e.g. continued disease progression, spinal cord compression). We want to make sure that we know how you would like us to treat you if this happens. Would you like us to talk with you about what we know and some decisions we might be able to make together at this point?” (If AYA says little, add) “For example, some people get to a place where they feel they ‘had enough’ and do not want more aggressive treatments that make them feel bad - especially when the medicines are not able to cure their cancer. Others want ‘everything you got’ not caring if they are in an ICU or feeling really badly. There is really no right or wrong here.” (Listen to see which camp the AYA falls in)</p> <p>We thought you might like to know that there is a guide that was created by and for persons your age who had concerns about what would happen if they got sicker. It allows you to make decisions about things that may be important or meaningful to you – for example, how you want to be treated if you were in pain, if there are certain friends you would like around, if you would want doctors in the future to learn about your cancer from your cells, or how much time you want to spend in the hospital.</p>

Time	Goal	Sample Conversation
	<ul style="list-style-type: none"> Convey the goal for the AYA to do things he/she enjoys most each day 	<p><i>If you would like, we can have [name] show you the guide after we are finished here.</i></p>
End-of-life care	<ul style="list-style-type: none"> Revisit ACP - ask to be informed of decisions if already made. Assess whether the patient/family is comfortable with the decisions. If decisions not made, narrow down areas of greatest discomfort Inquire whether the AYA has a preference for where s/he would like to be as EoL nears 	<p><i>“Many parents share your worries that after all these years of focusing on what you can do to extend life, talking about death can send a message that you are giving up. We will work as hard as we always have to provide the very best care possible.”</i></p> <p><i>“What we do know from parents who have lost a child, is that many of those who did not talk to their child about what was happening before their child’s death, suffer due to regretting that decision.”</i></p>
Addressing resistance to discussing end-of-life between AYA and family	<ul style="list-style-type: none"> Reduce chance of AYA dying in emotional isolation Encourage open and honest communication 	<p>AYA. <i>“Are there things about your care that you would rather not talk about? (if so) “With whom would you like me to talk about those things?”</i></p> <p>Family. <i>“Do you think there is a chance that your child is thinking about his/her own death but may not want to talk to you about this for fear of upsetting you or disappointing you?” “Our goal is for [name] to leave this world as peacefully as possible – which means, having the opportunity to share his/her thoughts with you.”</i></p>

* Conversations should always begin with asking what the AYA and family’s questions and concerns are. This way, responses can be formulated to address EoL issues but in the context of what the patient and family wants, needs, and is ready to discuss.

The suggested conversations are not designed to be a script but rather to be tailored to the individual AYA and family. They are based on the authors’ collective clinical experience in pediatric oncology.