Mature Minors, Mature Decisions: Advance Care Planning for Adolescent Patients with Life-Limiting Illness

Jennifer Needle, Maureen Lyon, Donald Brunquell, and Catherine Heith

ABSTRACT

Advance care planning (ACP) for adolescents is not yet a standard of care; as such, adolescents with life-limiting disease are often left out of important discussions about end-of-life (EOL) care, namely, advance care planning. This narrative review will describe the ethical, legal, developmental, and biological concepts and perceived barriers to including adolescents in EOL decision making. We will briefly explore adolescents' autonomy, the legal definition of capacity, and how these evolve through adolescence as minors mature and become more experienced with their illness. We argue that adolescents' participation in ACP not only supports adolescents who want to participate, but also assists the parties who are legally responsible for making decisions. This participation leads to goal-concordant care and reduced conflict. Finally, we address common misconceptions about EOL discussions and argue that EOL care does not diminish hope in patients or families and is still possible in the face of prognostic uncertainty. Involving adolescents in ACP respects the autonomy and growing capacity of adolescents and promotes patient- and family-centered care at EOL.

Nearly 400,000 children in the United States live with potentially life-limiting diagnoses, including cancer, cystic fibrosis, heart disease, and progressive neurologic disease.[1] Many older children and adolescents with life-limiting illness have a long history with their disease and understand its potential complications, including the possible need for life-sustaining treatment. For many of these patients, initial discussions about their preferences for end-of-life (EOL) care happen late in the course of their disease, when there is often inadequate time for deliberative discussion.[2] The patients' perspectives, preferences, and goals for future medical care may not be elicited because their parents or guardian are their legal decision makers. Exploring the perspectives of adolescent patients demonstrates respect for their evolving autonomy and can enhance patient-centered care related to decisions at the EOL.

Advance care planning (ACP) is a process that supports individuals' choice of treatment options and their right to refuse unwanted medical interventions. ACP promotes patients' autonomy, a fundamental principle of clinical ethics. When persons are not in a position to make or communicate their own healthcare choices, ACP is critical to help guide healthcare professionals (HCPs) and surrogate decision makers in making patient-centered medical

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decisions. The advance directive documents that may follow ACP are legally binding for patients who are 18 years and older. ACP in pediatrics is complicated by several factors: uncertain prognoses, legal requirements to obtain patients' informed consent and determine their capacity to make decisions, and the need to balance the evolving autonomy and capacity of minors with the need to protect them from emotional and difficult conversations. Because they lack the legal right to make decisions for themselves, adolescents have not traditionally been included in the ACP process, even when there is evidence they have well-considered goals and preferences. Although there is increased attention to the rights of adolescents as autonomous decision makers, significant barriers remain that have ethical and practical implications for patients, families, and HCPs.

There is a growing research interest in the experience and preferences of adolescents, as well as a growing consensus among professional societies[3] that ACP is an important and necessary component of adolescents' care and treatment. Despite this, adolescent ACP is not yet the standard of care. There are only a handful of formal pediatric ACP programs in the U.S., and research on adolescent ACP is even more sparse. Unsubstantiated beliefs and biases among HCPs that preclude adolescents from participating in ACP may result in a lack of, or late, referrals to palliative care, and to potentially undesired treatment at the EOL.[4]

The purpose of this narrative review is to address the concepts, potential barriers, and evidence related to adolescent ACP in the framework of key bioethical principles. Our goal is to foster a professional discussion about the benefits of ACP for adolescent patients and their families.

ETHICAL PRINCIPLES AND LEGAL CONSTRUCTS RELEVANT TO ADOLESCENTS' DECISION MAKING

Autonomy is a key bioethical principle related to decision making. The principle of autonomy requires that patients have the capacity to act intentionally, with understanding, and without controlling influences that would mitigate against a free and voluntary act.[5] Autonomy is tied to the legal concept of decision-making capacity, which requires (1) an understanding of necessary information, (2) an appreciation of the situation and its likely consequences, (3) the ability to reason about treatment options, and (4) the ability to communicate a choice.[6] From a legal standpoint, with few exceptions, once they reach the age of majority—18—adults are assumed to be competent to make medical decisions. On the other hand, adolescents are presumed to be incompetent to make autonomous medical decisions, and a "burden of proof" rests on individual patients to demonstrate their capacity to make autonomous decisions. Importantly, the ethical and legal requirements for autonomy do not preclude adolescents from being aware of their medical condition or prognosis, nor their contributing to decisions regarding their care. We advocate for individualized determinations of autonomy based on the definition above, not chronological age or state law, as the determinant of whether or not an adolescent can, and should, participate in EOL decision making.

Parents have the legal and ethical duty and responsibility to make medical decisions for their child. This duty is best understood as a right in trust that is held to provide a child's "right to an open future."[7] For young children, the *best interest standard* for decision making is used, since these children do not yet have the intellectual or developmental capacity to make decisions about EOL care. The capacity for mature thought processes and decision making grows with time. Parents may use the principle of *substituted judgment* to make decisions for older children, based on what they believe their child would choose. While parents retain the legal right to make decisions for adolescents, at this age patients often have capable, stable preferences regarding their own medical care. Adolescents should be included in EOL discussions to the extent of their

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capacity, which appropriately acknowledges their autonomy.

Many states have established some version of the "mature minor doctrine," either by statute or in the courts, which allows adolescents to be emancipated to make their own decisions or provides a degree of freedom for minors to provide informed consent or to refuse medical treatment. Specific regulations vary by state. The circumstances around which this consent is considered are the following.

1. The minor is an older adolescent (14 years or older).
2. The minor is capable of giving informed consent.
3. The treatment will benefit the minor.
4. The treatment does not present a great risk to the minor.
5. The treatment is within established medical protocols.[8]

It is beyond the scope of this article to address the conflicts that exist between the principle of autonomy and the law as it relates to adolescent decision making. However, HCPs are encouraged to consider the necessary elements of autonomy and decision-making capacity in granting minors a voice in their healthcare decision making. Hospital ethics committees and legal counsel should be utilized should conflict arise in unique cases.

THE EVOLUTION OF CAPACITY AND AUTONOMY IN ADOLESCENT PATIENTS

For adolescents, maturity and decision-making capacity increase along a spectrum. Some of this variation is neurobiological, some is due to adolescents' environment and social structure, and some is experiential. Prior illness experience may give adolescents insight into their treatment preferences and a better understanding of the context of their decisions. The American Academy of Pediatrics supports the recognition that "some pediatric patients, especially older adolescents and those with medical experience because of chronic illness, may possess adequate capacity, cognitive ability, and judgment to engage effectively in the informed consent or refusal process for proposed goals of care."[9]

Theories of cognitive development suggest that by the time adolescents are 15, they possess a capacity to make informed decisions that is similar to that of adults.[10] It is known that the appraisal of risk and reward may lead adolescents to make decisions differently than adults do.[11] The Dual Systems model suggests that risk taking, and thus risky decision making, is the result of competition between the early maturing affective system and the more slowly maturing cognitive control system.[12] Cognitive control, which is responsible for planning and judgment, is critical for informed medical decision making and is believed to be not fully mature until individuals reach their middle 20s.[13] This developmental model may be different for adolescents with chronic illness, due to the alteration of their normal developmental processes due to school interruptions, altered social experiences, changes in self-image due to illness, and changes in family dynamics. Hinds and colleagues found that 90 percent of patients with cancer aged 10 to 20 years understood their treatment options and the consequences of EOL decisions in which they participated.[14] Among the most commonly cited factors influencing EOL decision making by adolescents with cancer was "having previous experience with life support measures."[15] These findings suggest that some children, and most adolescents, possess the competencies needed to make informed decisions.

Decision-making processes in adolescents are more significantly influenced by peers and social networks than in mature adults.[16] Peers play a large role in social support for healthy adolescents, however those with chronic illness rely more on their family members (particularly their mother) during treatment and find them more supportive than their friends.[17] It is recommended that ACP involve parents to open the lines of communication about these sensitive topics and to enhance adolescents' support systems. Additionally, given the variability with which adolescents develop the capacity to make complex decisions, we recommend ACP programs with an interdisciplinary focus (that include HCPs, social workers, chaplains, ethicists) that enable highly individualized conversations and ongoing inquiry into adolescents' interests and capacity to participate in decision making.

ADOLESCENTS HAVE A DESIRE TO PARTICIPATE IN ACP AND HEALTHCARE DECISION MAKING

Several research studies have found that the majority of adolescents with chronic illness desire to participate in making their own healthcare decisions[18] and to be informed of their illness and treatment options when they are terminally ill.[19] These researchers report that adolescent patients with possibly life-limiting illness prefer to have discussions about EOL care early in the course of their illness.[20] But the data also suggest that adolescent patients' preferences for participation in healthcare decisions, as well as receiving prognostic information, is highly individual and may change over time.[21]

Studies with older adults found that ACP provides benefits to patients and their surrogate decision makers: ACP has been found to reduce stress, anxiety, and depression by engaging surrogates in discussions regarding their loved one's preferences,[22] and to reduce decisional conflict.[23] Hinds and colleagues report that, of the parents they studied who had children with terminal cancer, 94.7 said that "choosing as the patient would want or as the patient previously directed the parent to choose" was a factor in EOL decision making.[24] Research conducted using the Family-Centered Advance Care Planning for Teens with Cancer (FACE-TC) intervention found that a significant majority of patients said early discussions about potentially serious outcomes was "helpful."[25] A study that used the FACE intervention with adolescent patients who had HIV reported that 25 percent of the patients said ACP made them "feel sad," but 98 percent said "it was worthwhile," and 94 percent felt that "it was something that I needed to do."[26]

ACP DOES NOT DIMINISH HOPE AND CAN BE USED IN THE FACE OF PROGNOSTIC UNCERTAINTY

One of the primary barriers to EOL discussions in pediatrics is a concern that the discussion itself will take away the hope of patients and family members,[27] but research findings do not support this concern.[28] Mack and colleagues report that parents who receive greater disclosure of prognostic information about their child's cancer were less likely to find the information extremely or very upsetting. For children with cancer with a low likelihood of cure, honest and open communication about prognosis and decision making made parents feel more, not less, hopeful.[29] Numerous studies report that parents and adolescents want information from HCPs that is complete, honest, and delivered with sensitivity.[30] ACP interventions should explore patients' wishes when cure is not possible, including discussion of care and services such as pain control and dying at home.

Prognostic uncertainty is another barrier to initiating ACP.[31] HCPs may provide overly optimistic prognostic estimates to patients,[32] which may lead to ineffective aggressive treatment at the EOL.[33] This may be more reflective of HCPs' discomfort in discussing EOL issues rather than patients' lack of readiness.[34] Sharing best estimates of prognosis is an important element of ACP;[35] however, eliciting goals, values, and preferences regarding a possible negative outcome can be done with an estimate of the likelihood of that outcome. By conducting discussions early in the disease course and working toward normalizing these conversations as a standard of care for all adolescents with potentially life-limiting illness, ACP can foster trusting communication and establish patients' and family members' preferences for sharing information, and not diminish their hope.

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CONCLUSION

Despite evidence that many adolescents possess decision-making capacity that is similar to that of adults, adolescents' participation in medical decision making has been limited. From the perspective of pediatric HCPs, the legal and ethical constructs surrounding adolescent decision making may appear to be in conflict. HCPs may rightfully be concerned about the legal consequences of supporting adolescents' EOL preferences, especially if they are in conflict with those of their parents.[36] By facilitating frank discussions during a time of relatively good health and utilizing a framework for determining adolescent patients' maturity and capacity for decision making, ACP has the potential to reduce conflict between patients, their parents, and HCPs. To this end, ACP gives patients a voice in the medical care they receive, helps family members to better understand the values and preferences of their loved one, and provides an extra layer of support to HCPs. By normalizing discussions about goals and values, models of care that routinely include ACP can reduce possible social and systems barriers to adolescents' participation in decision making, and reduce the possibility that conversations about future decisions do not reduce patients' hope for desired outcomes. The inclusion of adolescents in ACP supports a patient- and family-centered approach to decision making that is desirable for all stakeholders.

NOTES

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