

VIEWPOINT

The Complicated Legacy of Cassandra Callender

Ethics, Decision-making, and the Role of Adolescents

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On May 12, 2020, Cassandra Callender died at the age of 22 years. Pushed off the front pages by the latest news about coronavirus disease 2019 (COVID-19), her untimely death invites reexamination of her story and the lessons it provides. "Cassandra C," as she was referenced in news reports to protect her identity as a 17-year-old, was diagnosed as having Hodgkin lymphoma in September 2014.¹ Although believed to have a more than 80% chance of cure, she refused further treatment after receiving several cycles of chemotherapy in her home state of Connecticut. Her mother, who supported her decision, stated at the time, "My daughter does not want poison in her body....She is very bright, very smart....Does she know she will die? Yes. And do I know that? Yes."¹ The hospital contacted the Connecticut Department of Children and Families, who took legal custody of Cassandra, precipitating a lengthy, contentious legal battle.

The Connecticut Supreme Court ultimately ruled that Cassandra did not meet the standards set forth by the mature minor statute and thus could not legally refuse treatment. Since Cassandra was deemed not to be a mature minor, she was held in the hospital for 5 months against her will and given intravenous chemotherapy over her objections. Regrettably, despite treatment, her cancer returned the following year. Then legally an adult, Cassandra initially took alternative treatments but ultimately decided to pursue chemotherapy, immunotherapy, and other standard treatments. Despite these efforts, she died due to her disease.

Cassandra's story is troubling unto itself but perhaps even more so when contrasted with the cases of Billy Best and Abraham Starchild Cherrix, 2 oft-cited teenagers diagnosed with Hodgkin lymphoma who similarly refused recommended therapies. Both adolescent boys refused further treatment after their initial cycles of chemotherapy. No legal action was taken in the case of Billy, a resident of Massachusetts; Abraham's case went to court and culminated in Abraham's law in Virginia, increasing rights of adolescents to refuse medical treatments.

Although uncommon, cases in which adolescents refuse recommended therapies are legally and ethically complex. Legal provisions, such as mature and emancipated minor statutes, provide guidance regarding when minors can provide legal consent for—or refuse—medical interventions. For example, many states allow adolescents access to sexual health care and treatment for substance use and mental health without parental notification, but these provisions vary by state.² The American Academy of Pediatrics emphasizes the importance of communicating information about treatment options in understandable, age-appropriate and develop-

mentally appropriate language.² However, it is less clear whether adolescents should be legally supported in refusing potentially life-saving interventions, even when parents agree with them, as did Cassandra's mother.^{3,4}

Legal issues notwithstanding, these refusals warrant further examination of the decision-making role of adolescents and young adults (AYAs)—particularly those with cancer, a life-threatening but typically curable disease in this age group. AYA decision-making has received increased interest in research and clinical forums in recent years, due in part to the medical, developmental, and psychosocial complexity of AYAs. Survey data from AYAs with cancer demonstrate that most wish to share decision-making responsibility with their oncologists, but 24% of AYAs ultimately express experiencing regret about the role they played in initial cancer-related decisions.⁵ Heightened regret is reported among AYAs whose oncologists told them what their treatment would be without offering alternatives, highlighting the need for improved early engagement with all patients and not merely with those who refuse treatment. Nearly half of AYAs report receiving suboptimal information about long-term treatment toxic effects, for example, despite 87% considering this information to be very or extremely important.⁶ These shortcomings in information delivery and decision-making role could contribute to larger problems with communication and trust for this already vulnerable population.

We have a particularly limited understanding of decision-making in adolescents like Cassandra, both about the decision-making role they typically play and the role they prefer. In most jurisdictions, prior to a teenager's 18th birthday, their parents or guardians have legal decisional authority. There is, of course, nothing magical about that moment in time; nothing imparts a newly-minted 18-year-old with new capacity for making independent medical decisions. It is a semiarbitrary but legally necessary demarcation. In practice, it is recommended that adolescents be included in decisions about their treatment—and their assent sought—until they reach the age of majority, when decisions become legally their own.² However, the extent to which this takes place remains unclear. It appears that adolescents are less likely to hold their desired decision-making role than those several years older when faced with cancer treatment decisions,⁵ raising important questions about whether and when this discordance is ethically justifiable.

This limited decisional involvement by adolescents may be even more pronounced among those whose cancer has not adequately responded to treatment. Despite adolescents' well-documented desire to actively engage in health care decisions, recent work

demonstrates their scant involvement in conversations with clinicians and parents about their relapsed and refractory cancer.⁷ Further, when adolescents are engaged in these conversations, it is more frequently regarding their general medical history and personal life than about their treatment preferences or values,⁷ the latter far more germane to advanced cancer treatment decisions. This becomes increasingly concerning in light of data demonstrating that parents often have poor understanding of their adolescent's values and preferences about end-of-life care. A 2020 analysis⁸ reports that despite adolescents expressing strong end-of-life perspectives, these are frequently incongruent with what their parents believe them to be. This incongruence is especially worrisome as it relates to consequential domains, like preferences regarding life-sustaining interventions and beliefs about death.

It is difficult to know how involved Cassandra was in discussions about her treatment at the time of diagnosis and impossible to predict with certainty whether her story could have turned out differently. Moreover, it is not clear whether the complex legal and psychosocial features of Cassandra's case had any impact on her lymphoma and/or eventual death. Nonetheless, after her death, Cassandra's mother stated, "She basically said, 'Ma, nobody was here for me.' And she said, 'Every time I tried and tried, I get kicked in the gut.'"⁹ It is difficult to read those words and not wonder what we

could do better on behalf of our adolescent patients and their families. How could we have better served Cassandra, and perhaps even more importantly, how can we better care for adolescents going forward?

The time has come for us to commit to more deeply respecting adolescents by optimally integrating them into their health care decision-making. Among factors to consider are the risks and benefits of the decision, the adolescent's maturity, their desired decision-making role, and their lived experience.²⁻⁴ Improved engagement has the potential to promote communication and trust, the latter associated with less decisional regret.⁵ Only with improved engagement from the start can we better navigate the dilemma of treatment refusals like Cassandra's, which may be best addressed via these preventive efforts. Although courts play a fundamental role in such cases, ideally, communication and engagement will decrease the need for court involvement, which many find confrontational and damaging to the clinician-patient-parent relationship.

Cassandra Callender's untimely death, like that of any young person, is a tragedy. Hers also serves as a call to action. We can honor Cassandra as the impetus for improved engagement of adolescents in decisions about their health care, particularly potentially life-saving interventions. Such improvements would make for a worthy, befitting legacy.

ARTICLE INFORMATION

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