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Setting: Commentary on *Lucas et al.*

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Abstract:

This TPPCR commentary discusses the 2024 paper by Lucas, ““Just let me go”; When suicidal ideation and goals of care collide in adolescent cancer at the end of life.” published in *Pediatric Blood Cancer*.

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The article "Just Let Me Go": When Suicidal Ideation and Goals of Care Collide in Adolescent Cancer at the End of Life, brings to light a complex and emotionally charged dilemma faced in palliative care. It emphasizes the intersection of medical, psychological, and ethical challenges when adolescents, with life limiting disease, express a desire to end their lives. This raises a profound question about autonomy, mental health, and the role of healthcare providers.

This is a case of a 14-year-old male who had relapsed, progressive high-risk B-cell acute lymphoblastic leukemia and who experienced suicidal ideation during his treatment. This teen had received multiple lines of treatment including a bone marrow transplant. Despite best medical efforts, he continued to have progressive disease and expressed that he did not want any further treatment. His family, however, wanted to continue all supportive measures with curative intent, despite the teen's request. He was frustrated with high symptom burden, complications, and lack of control. Throughout treatment he made statements such as "let me go" and his desire to "be done" and expressed active ideas about suicide. His health care team knew that his prognosis was poor, and that he would eventually succumb to the disease, no matter what treatment he had received. As patient advocates, his healthcare team helped to give him a voice, and redirected family to the idea of comfort-based care, preserving a sense of control. His symptoms were well managed at home, and he subsequently passed away comfortably, 2 months later from expected disease progression.

I am a paediatric haematology and oncology fellow, with special interest in adolescents and young adults (AYA). I have limited experience in AYA palliative care thus far, but throughout my fellowship I have encountered adolescents with life limiting disease and wonder how I may approach a situation similar to that presented in the article. Patients as young as 13 can be

considered AYA, and in Canada patients under 18 are treated in a pediatric hospital. It is well established that AYA patients have distinct psychosocial needs that differ from pediatric and adult patients, which is a recurring theme in AYA literature. As Abby Rosenberg and Joanne Wolfe summarize in their 2017 review, these psychosocial challenges include, patients developing their individual identity, such as their sense of self and sexual identity, gaining independence from their parents, and establishing peer relationships¹⁻⁵.

One of the tensions explored in this article is autonomy of the adolescent patient. Traditionally when patients are treated in a pediatric centre, parents or guardians are the primary decision makers. In this article, as is the case often in clinical practice, patient autonomy is perhaps not fully respected. This complicates matters particularly when the patient's wishes diverge from those of their parents/caregivers. Further, this situation challenges health care providers to have candid discussions with patients, and families, about end-of-life preferences, but often times only after failure of treatment. When reflecting on my fellowship experience, I've noticed that each oncologist has a unique and variable approach to integrating palliative care into the AYA treatment plans. Some clinicians actively engage their patients in treatment plans and discussions, leaving the patient with a more profound sense of empowerment for control of their care. This experience highlighted how an oncologist's training and expertise in AYA care can profoundly influence patient management. Despite having didactic teaching on the principles of autonomy, consent for minors, and palliative care, I believe fellowship education could be strengthened through hands-on experience. I believe team-based simulation could be a valuable addition to the fellowship training regiment to help bridge this perceived deficit.

This article “Just Let Me Go” calls for a greater awareness of the unique psychosocial and ethical dilemmas which are at play in AYA palliative care. It’s important that clinicians and caregivers appreciate that these deeply challenging scenarios require compassion and respect. We need to not only address the physical aspects, but the profound emotional and existential struggles AYA patients face at end of life.

Additional References

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