

“Just Let Me Go”; When Suicidal Ideation and Goals of Care Collide in Adolescent Cancer at the End of Life

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February 14, 2024

BRIEF REPORT

“Just let me go”; When suicidal ideation and goals of care collide in adolescent cancer at the end of life

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Patient name changed to ensure anonymity.

Abstract

Cancer in adolescents and young adults is associated with an increased risk for suicidal ideation (SI). There are no reported pediatric oncology cases describing management of SI during end of life. We present the case of a 14-year-old male with relapsed, high-risk, B-cell acute lymphoblastic leukemia who received a haploidentical stem cell transplant and was suicidal at various points in his treatment. We discuss how to manage acute suicidality in this patient population, the importance of giving a voice to the adolescent patient, the impact of discordant goals of care, and potential preventive strategies for similar cases.

KEYWORDS

adolescent, oncology, palliative, suicidal ideation

1 | INTRODUCTION

Adolescents and young adults (AYAs) (defined as ages 15–39 years per National Cancer Institute) with cancer have a 20% higher incidence of suicide than the general population, with most suicides occurring within 5 years of diagnosis.¹ Suicidal ideation (SI) has been reported in up to 22.6% of surveyed young adults with incurable, recurrent, or metastatic cancer.² For pediatric patients with acute lymphoblastic leukemia (ALL), higher rates of SI have been reported within the first year of treatment, particularly for those younger than 12 and those endorsing increased physical and depressive symptoms.³ While depression and anxiety are frequent symptoms for AYA patients at end of life,⁴ there are no reported pediatric oncology cases of acute suicidality in this setting.

2 | CASE DESCRIPTION

Mateo was a 14-year-old Hispanic male diagnosed with high-risk B-ALL at age 12, initially treated according to Children's Oncology Group

(COG)-AALL1732. Shortly after diagnosis, he developed multiple distressing symptoms including depression and anxiety. Several times during treatment, Mateo asked his mother to “let me go,” stating he did not want treatment and endorsed active SI with specific lethal means (i.e., hanging himself with a belt). Mateo's mood improved with psychotherapy and medication (fluoxetine), and concerns resolved upon achieving remission.

During maintenance therapy, at age 14, Mateo's disease relapsed and he was transferred to our center. Psychology and Palliative Care were consulted upon admission for symptom management, coping, communication, and to elucidate goals of care. Psychology followed Mateo closely, utilizing cognitive-behavioral therapy to address his anxiety about side effects and risk for relapse of depression. Mateo expressed a desire to receive information about his condition from his parents and be involved in conversations about his care. His parents were legally married, had shared legal decision-making rights, and resided together; however, Mateo's mother disclosed they were separated and described their relationship as “complicated.” Mateo's mother quit her job upon Mateo's diagnosis and was his primary caregiver. His father worked full time and was not physically present in the hospital.

Mateo achieved remission after re-induction, and underwent haploidentical hematopoietic stem cell transplant (HSCT) from his mother

Abbreviations: ALL, acute lymphoblastic leukemia; AYA, adolescents and young adults; GVHD, graft-versus-host disease; HSCT, hematopoietic stem cell transplant; PRISM, Promoting Resilience in Stress Management; SI, suicidal ideation.

with engraftment on Day +17. Bone marrow biopsy on Day +35 confirmed relapse and Mateo experienced rapid leukemic progression, with concurrent development of grade IV acute graft-versus-host disease (GVHD). Multidisciplinary discussions with Mateo and his parents focused on his poor prognosis and how simultaneous treatment of leukemia and GVHD would be difficult to achieve with multiple potential adverse side effects. At this time, family wanted to continue all supportive measures with curative intent despite Mateo expressing his desire to “be done” with treatment. He described frustrations with high symptom burden, continued complications, and lack of control in decision-making. His clinical status progressively worsened, requiring intensive care and multiple invasive medical procedures. While Mateo’s mother was conflicted, Mateo’s father, recently returned after working out of town for many months, was resolute in his desire to continue with disease-directed therapy.

Mateo did not want continued treatment, stating it was “pointless” and that he was “being lied to,” as he had “done everything they told me to but I only get worse.” Mateo endorsed active SI with a plan, stating “I will slice myself with a scalpel.” A bedside sitter was instituted for continuous monitoring. The care teams, Mateo, and his parents had many hours of conversations in which Mateo and his parents shared their respective wishes. Providers acknowledged and supported his parents’ desire to continue disease-directed therapy, while also highlighting that Mateo would die no matter the treatment plan, and redirecting goals of his care would be an equally loving decision.

A comfort-based care plan including home hospice with concurrent care was introduced. After Mateo and his family agreed to this, Mateo no longer desired to kill himself. However, given his recent active SI, a safety plan was enacted to have an adult caregiver present with Mateo at all times. Mateo’s symptoms were well managed at home with hospice, and he died comfortably 2 months later from disease progression.

3 | DISCUSSION

Many patients at the end of life express the wish to stop pursuing curative therapy and allow a natural death; however, it is important to recognize when this becomes acute suicidality. No matter the circumstances, SI should never be ignored, and safety plans should be implemented. The goal of safety precautions is not to prevent the patient’s ultimate death, but rather to provide an opportunity for appropriate symptom management and psychosocial support for patients and families at the end of life. In Mateo’s case, his desire to stop disease-directed therapies was reasonable, yet escalated to the extent of active SI with a plan, because he felt unheard and lacked control. The turning point was when the discordance between Mateo’s preferences and those of his parents was acknowledged and discussed. The care teams helped give a voice to Mateo and helped his parents to hear him whilst affirming their love for him. By openly sharing the inevitability of his poor prognosis, some of the decisional burden was relieved, allowing parents to move forward with a comfort-based care plan and giving Mateo the sense of control that he so desperately wanted.

Discordance between parents and AYAs with cancer in decision-making and care preferences is well documented. Mack and colleagues surveyed patients aged 15–29 regarding their experiences with cancer-related communication and decision-making.⁵ Younger patients were less likely to possess a decision-making role and, although many wanted some degree of parental involvement, parents tended to take on more decisional involvement than patients wanted.⁵ Friebert and colleagues found poor congruence regarding “dying a natural death,” “being off machines that extend life,” and desired timing of end-of-life discussions between AYAs and their parents.⁶

Patients undergoing HSCT have low rates of early palliative care involvement (i.e., initial consult >30 days prior to death), despite high rates of morbidity and mortality.⁷ AYA patients who underwent HSCT were less likely to discuss end-of-life preferences early in their disease course, experienced greater symptom burden during the last month of life, and were more likely to die in a hospital setting and receive aggressive interventions immediately prior to death, compared to those who did not receive HSCT.⁴

Tools for patients to express their wishes and fears and guide advance care planning can decrease anxiety and increase communication with family members and friends.⁸ Examples of such are *Voicing My Choices* and *Five Wishes*.⁹ These tools and conversations can be facilitated by any member of the care team or be completed without a healthcare provider.

Targeted interventions have been developed to improve psychosocial outcomes for AYAs with cancer. The Promoting Resilience in Stress Management (PRISM) intervention is a brief, skills-based coaching program, which targets four resilience resources (stress management, goal setting, cognitive reframing, and meaning making). PRISM was associated with improved quality of life, hope, resilience, and distress compared with usual care.^{10,11} Currently, a randomized controlled trial involving AYA patients undergoing HSCT is in progress to examine the efficacy of PRISM in reducing patient-reported symptoms of anxiety and depression.¹²

One area to target efforts in addressing SI is strengthening the patient–oncologist alliance, which has been reported to be protective against SI in young adults (age 20–40 years) with advanced cancer.² This remained a significant predictor of suicidality even after controlling for social support, and was independent of young adults’ physical and mental health status. While guidelines have previously been published on developing a therapeutic alliance with pediatric oncology patients,¹³ similar guidelines for AYA patients could be useful.

Receiving treatment at a comprehensive cancer center, where patients are more likely to have access to a multidisciplinary AYA healthcare team, including dedicated mental health providers, has been shown to lead to improved overall survival.¹⁴ We believe it is critical to develop strategies that will lead to early identification of SI and to implement established and burgeoning interventions aimed at improving psychosocial outcomes. Recommendations include incorporating early and frequent assessments of mental health, as well as universal screening for SI with validated tools^{15–18} in all pediatric and AYA oncology patients.¹⁹ It should be noted that screening for suicide does not increase the risk for suicidal behavior or psychological distress.²⁰

The American Academy of Pediatrics and the American Foundation for Suicide Prevention created the “Blueprint for Youth Suicide Prevention,” which is an educational resource to support providers in identifying strategies to support youth at risk for suicide.²¹ In addition, resources such as the 988 Suicide and Crisis Hotline²² and suicide safety precautions²³ should be discussed prior to discharge.

We recommend early involvement of palliative care and mental health experts in AYAs who have relapsed, refractory cancer, particularly when there are conflicts in goals of care or complicated clinical circumstances. For centers without these resources, strengthening the oncologist–patient relationship, implementing regular mental health and suicide assessments, and using advance care planning tools designed to amplify the AYA voice may be helpful. Should a patient express SI at any point in treatment, even at end of life, immediate action should be taken to ensure the safety of the patient and emergent consultation with psychiatry and psychology should be considered.

CONFLICT OF INTEREST STATEMENT

The authors declare they have no conflicts of interest.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article, as no new data were created or analyzed in this study.

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How to cite this article: Lucas B, Friend B, Jarrell JA, Kentor R. “Just let me go”; When suicidal ideation and goals of care collide in adolescent cancer at the end of life. *Pediatr Blood Cancer*. 2024;e30893. <https://doi.org/10.1002/pbc.30893>