Implementing Screening for Eating Disorders in Adolescents and Young Adults with a History of Cancer

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Abstract

Background Eating disorders are prevalent in the adolescent and young adult population, with 2.7% of adolescents affected. The American Academy of Pediatrics recommends yearly screening for eating disorders in adolescents. Even with this recommendation, eating disorders often go underdiagnosed. AYAs with cancer possess several risk factors for eating disorders that may place them at an even higher risk, including receiving weight-altering therapies and having their weight/nutrition emphasized. Since these patients see their oncology team frequently, oncology clinics are opportune settings for eating disorder screening. This describes a single-institution study to implement screening for eating disorders in AYA patients in an oncology clinic. Procedures During regularly scheduled oncology visits, eligible patients were given the SCOFF questionnaire. Patients with an oncologic diagnosis aged 13 and older were screened. Patients with known eating disorders and patients receiving cytotoxic therapy were excluded. The questionnaire was scored by a study team member. Patients with a positive screening were referred to adolescent medicine. Results 163 eligible patients filled out the SCOFF questionnaire with 11 positive results (6.75%). Conclusions Our results demonstrate that eating disorder screening was successfully implemented in our pediatric oncology clinic. With a rate more than double than the general population, we observed that AYA patients with a history of cancer are indeed at a higher risk for eating disorders and should undergo routine screening. Since these patients have frequent oncology appointments, oncology clinics should implement screening for eating disorders. Further studies are needed to develop appropriate screening methods for on therapy patients.
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Procedures
During regularly scheduled oncology visits, eligible patients were given the SCOFF questionnaire. Patients with an oncologic diagnosis aged 13 and older were screened. Patients with known eating disorders and patients receiving cytotoxic therapy were excluded. The questionnaire was scored by a study team member. Patients with a positive screening were referred to adolescent medicine.

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Introduction
Eating disorders are prevalent in the adolescent and young adult (AYA) population. It is difficult to ascertain the true prevalence of eating disorders in adolescents, as estimates vary greatly – ranging anywhere from 1-22% in the literature depending on the source and specific eating disorder diagnosis.\textsuperscript{1} According to the mental health section of the National Institutes of Health (NIH), the overall prevalence of eating disorders in adolescents is 2.7%\textsuperscript{2}. Risk factors for the development of an eating disorder include underlying
Psychiatric conditions, stressful life events, family history of eating disorders, and underlying chronic illnesses (especially those with steroid-dependent treatments). Eating disorders have a high rate of morbidity and mortality, especially the longer they go undiagnosed, and impact all aspects of patients' mental and physical well-being. When undiagnosed, eating disorders can cause adverse and/or fatal electrolyte derangements, cardiac arrhythmias, and cardiomyopathy. Emotionally, eating disorders are associated with depression, anxiety, and suicidal ideation. Early identification and intervention are key in limiting the morbidity associated with eating disorders. The American Academy of Pediatrics (AAP), therefore, recommends yearly screening for eating disorders in the general adolescent population. Even with this recommendation, eating disorders in the general population often go underdiagnosed and undertreated.

Adolescent and young adult (AYA) cancer survivors (those who have had or had cancer ages 15-39 years per the National Cancers Institute (NCI) definition) possess several of the general risk factors for eating disorders – including coping with chronic underlying diseases and stressful life events. During treatment, AYA patients are also exposed to weight and appetite-altering therapies and often have their weight and nutrition emphasized, all of which may impact body image. Currently, however, there is a lack of data regarding the development or incidence of eating disorders in the AYA patient population. Additionally, there is no standard for routinely screening for eating disorders in oncology clinics. Patients with cancer, even when off-therapy, often see their oncology team monthly or every few months, typically more frequently than their primary care providers, therefore, oncology clinic is an opportune setting to screen patients and identify eating disorders early.

The purpose of this quality-improvement project was to implement a standardized process for screening AYA oncology survivors for eating disorders in oncology clinics using a validated questionnaire. We postulated that AYAs with cancer have an increased risk for eating disorders compared to their healthy peers, as they are exposed to weight-altering therapies, face consistent scrutiny over their weight and nutrition, and may be at risk for maladaptive coping strategies, such as disordered eating behaviors, in the face of a significant life-altering disease.

Methods
This was a single-institution quality improvement project conducted at a tertiary pediatric cancer center. The study team, consisting of a pediatric hematology/oncology fellow and attending, partnered with an eating disorder specialist in the adolescent medicine department for guidance on an appropriate screening process. This allowed the team to create a pipeline to the adolescent medicine team for patients with a positive screening for further management.

Participants
Participants included patients with an oncology diagnosis aged 13-39 years and older who were treated with chemotherapy. Participants were excluded if they were receiving cytotoxic chemotherapy, those receiving targeted therapy post-active treatment were allowed. Patients on active therapy were excluded to eliminate confounding factors that could iatrogenically alter weight or appetite (ex: chemotherapy-induced nausea or vomiting, change to taste perception, and weight-altering medications). Similarly, patients on maintenance therapy that included steroids due to the known side-effects of increased appetite and weight, making it difficult to truly assess for an eating disorder.

Procedures
There are several questionnaires that are utilized in primary care offices that are validated screening devises for eating disorders. The SCOFF questionnaire (Table 1) is an easy-to-use tool that can be implemented in outpatient settings. The self-administered questionnaire consists of 5 yes/no questions designed to screen for both restrictive and binge-eating habits. Patients receive a point for each question answered “yes.” A score of 2 or greater is considered a positive screening.

At check-in for their scheduled oncology appointments, participants were given a one-time SCOFF questionnaire by the clinic medical assistant (MAs) to complete prior to their appointments. Patients were identified...
prior to their appointments and the study team entered a note to indicate to the MAs which patients were eligible for screening. An informational sheet was provided to participants regarding the questionnaire. Questionnaires were then scored by a member of the research team. If a participant scored 2 or above, they were referred to the Adolescent Medicine clinic for further resources and discussion and their oncology providers were notified. All screenings were destroyed and not made part of the permanent medical record. Participants were aware that they would be referred to adolescent medicine should they screen positive. Screenings were collected from September 2022 to June 2023. Participants were only screened one time each during this time frame.

Results
During the 9-month screening period, 163 patients filled out the SCOFF questionnaire. Of the 163 patients screened, 11 had positive results (6.75%). All 11 patients received referrals to adolescent medicine. 6/11 patients were female, 4/11 male, and 1/11 was non-binary. Ages of patients who were positive ranged from 14-24 years.

Discussion
Our findings demonstrate that screening for eating disorders is feasible in oncology clinics – as over 150 patients were successfully screened in only a 9-month period. With a 6.75% positive screening rate, our findings are also consistent with prevalence data in the general population and over two times higher than the general AYA population when compared to the NIH’s prevalence data - confirming that oncology survivors are at a higher risk and indeed should be screened for eating disorders. Since early recognition is key for the treatment of eating disorders and limiting the long-term morbidity, it is especially important to screen oncology patients, particularly if they are not regularly seeing their primary care physician. The SCOFF questionnaire is an accessible, feasible, and time-efficient tool for patients to use and for providers to interpret. We found that it was simple for the clinic medical assistants to pass out the questionnaire to the designated patients. This screening process was widely accepted by both the adolescent patients as well as the oncology providers.

It is well documented that adolescents with childhood trauma and adverse childhood events, including coping with a chronic disease, are at increased risk of developing an eating disorder. Adolescents with chronic health conditions, including oncology patients, experience a loss of normalcy and autonomy during a time when they are seeking independence and developing a sense-of-self. Fixation on eating and weight loss lends a sense of structure, predictability, and security. Indeed, this has been reported in other adolescents with chronic conditions, such as systemic lupus erythematosus (SLE), diabetes mellitus, and chronic hypertension.

One review of patients with juvenile SLE patients demonstrated an association between SLE and anorexia nervosa. In this review, it was suggested that these patients developed anorexia due to the chronic use of steroids and the subsequent body-image issues secondary to steroid-related body changes. They also develop eating disorders because of an emphasis on weight and nutrition, as both these factors can impact prognosis, with adhering to a stricter diet ultimately having the opposite effect and leading to an eating disorder. Adolescent patients with diabetes mellitus are at 2-3 times higher risk than the general population to develop an eating disorder, with a prevalence anywhere between 15-40%. This is the case as patients with diabetes must adhere to a strict medication regimen that emphasizes portion and weight control, leading to food preoccupation. Underdosing or skipping insulin doses entirely is commonly used as a form of weight loss among these patients, as this both helps patient lose weight and gives them a sense of independence and control over their treatment. The same has been noted in adolescent patients with chronic hypertension due to the emphasis on lifestyle modification, including diet and exercise.

The above supports our hypothesis that AYA oncology patients are at high risk for the development of eating disorders given several similar characteristics with patients with SLE, diabetes, and chronic hypertension – including treatment with weight-altering therapies, emphasis on weight and nutrition, stringent treatment regimens, and significant stress - and therefore should be routinely screened.
Though the NCI has designated AYA patients as those 15 years and over and the AAP defines adolescence as beginning at 11 years, we elected to starting the screening age at 13 years. Starting at the onset of the teenage years seemed reasonable as we did not want to miss patients under 15 – they are certainly at risk – but did not think starting at 11 was appropriate as our and adolescent medicine team, who was evaluating patients with a positive screening, does not accept patients as young as 11.

One other consideration when implementing screening for eating disorders in this patient population is how to respond to a positive result. Our institution is fortunate to have a dedicated adolescent medicine clinic with specific expertise in managing eating disorders. Other facilities without an adolescent medicine team should find other resources and/or the oncology team will need to be comfortable with subsequent follow up, workup, and management for potential eating disorders. In this situation, oncology providers can refer to social work for resources or refer the patient back to their general pediatrician.

An important limitation to this study to note is that AYA oncology patients receiving active therapy were excluded. There is currently a lack of data regarding the prevalence of eating disorders in the AYA oncology population. This initiative only screened AYA oncology survivors who were not receiving active therapy. We also excluded patients who were currently receiving steroids as these are known to affect appetite and body habitus. AYA patients receiving active chemotherapy have several factors that could affect their weight and appetite – nausea with chemotherapy, a change in taste, medication side effects resulting in weight gain/loss - and are therefore tricky to screen for eating disorders as their answers on questionnaires may be influenced by from their treatment.

An important next step in preventing eating disorders in AYA cancer patients on active therapy is to develop an appropriate screener that accounts for these confounding factors. Adequate nutrition is a necessity for patients who are actively receiving chemotherapy as this allows for a better tolerance for intensive therapies. Severe cases of eating disorders can also cause significant electrolyte derangements, limiting the ability to give certain chemotherapies. Additionally, variations in weight also impacts the dosing of chemotherapy and may lead to subtherapeutic treatment. The presence of an eating disorder also portends other psychosocial issues, which can worsen patients’ overall quality of life and survival. For these reasons and knowing that on-therapy AYA patients carry risk factors for developing eating disorders, it would be in active oncology patients’ best interests to develop a method for eating disorder screening.

Conclusions
Adolescents and young adults with a history of cancer are at a higher risk than the general adolescent population for developing eating disorders and should undergo routine screening per general adolescent guidelines. Screening was feasible in our pediatric oncology clinic, and results were higher than the prevalence of eating disorders in the general AYA population. Though AYA patients see their oncology providers primarily for disease surveillance in the post treatment period, it is important to remember that they also continue to experience general AYA issues. Since these patients may not visit their primary care physicians as often as their oncology team, oncology clinics should implement screening for eating disorders in off therapy patients. Further studies are needed to develop appropriate screening methods for on therapy patients.

Conflict of Interest Statements:
The authors have no conflicts of interest.

References:


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