Commentary

"Could this be cancer?" Addressing diagnostic delay disparities in adolescents and young adults with cancer through targeted awareness and mitigation of barriers to help-seeking behaviors

Lorna L. V. Larsen*

Abstract Adolescents and young adults (AYAs) with cancer worldwide face unique challenges throughout the course of their disease. Disproportionately long diagnostic delays have been identified as one of the disparities in their care. Decreasing delays in diagnosis requires a multifaceted approach targeting a number of stakeholders including well AYAs and ultimately AYAs with cancer not yet diagnosed. Identifying help-seeking barriers and taking steps to mitigate them has the potential to reduce diagnostic intervals and improve outcomes. AYAs need to understand their cancer risk and early cancer warning signs and be reassured about high cure rates for early cancer. Effective health promotion approaches designed to reach AYAs with symptoms and early detection messages help reduce help-seeking barriers and empower AYAs to ask the question "Could this be cancer?" Upstream cancer awareness and education strategies have the potential to expedite time to diagnosis and treatment, decrease distress, improve patient outcomes, and reduce survivorship disparities.

Keywords: AYA cancer, late diagnosis, early detection, cancer awareness, help-seeking barriers

1. Background

Adolescents and young adults (AYAs) with cancer worldwide face well documented challenges throughout the course of their disease.[1] Disparities in their care have had a suboptimal impact on outcomes including quality of life and survival. The lag in survivorship improvement between AYAs with cancer and all other age groups has been consistently reported over the past 2 decades.[2,3]

Disproportionately long delays in diagnosis have been identified as one of the unmet needs of AYAs with cancer.[1] Owing to patient or physician inaction, delays may lead to late stage diagnosis, poorer outcomes, and added distress. A recent study of younger AYAs (12–24 years) with cancer from the United Kingdom reported that "prolonged diagnostic time intervals in AYA are associated with an increased risk of impaired health-related quality of life, anxiety, and depression."[4] Age disparities have also been reported in stage-at-diagnosis data for certain cancer types. For example, Statistics Canada 2016-2017 data reported 22.1% of 20- to 39-year-old women were diagnosed at Stage 3 compared with 11.1% of women older than 40 years.[5] Decreasing delays in diagnosis requires a multifaceted approach targeting a number of stakeholders including the well AYA population.[6] The need to investigate help-seeking barriers for AYAs with cancer and identify effective strategies to reach well AYAs with vital cancer information were acknowledged as key takeaways from the AYA cancer late diagnosis workshop facilitated at the 2021 Canadian Association of Psychosocial Oncology conference. In follow-up to the workshop, this commentary highlights learnings from an informal literature review of AYA help-seeking barriers, efforts to mitigate modifiable barriers, and inform AYA cancer awareness and education needs for the well AYA population. Educating AYAs about their cancer risk, symptoms, and self-detection has the potential to meet their cancer information needs, increase risk reduction behaviors, and earlier detection.[7]

2. AYA help-seeking barriers

AYA help-seeking barriers have been identified in a number of publications including, but not limited to, contextual barriers: ethnicity, knowing someone who has cancer; developmental barriers: feeling invincible, lack of awareness of cancer risk, assume other causes of symptoms, ignore symptoms; emotional barriers: lack of confidence to talk about symptoms, worried about the doctor might find, too scared, too embarrassed, anxiety issues; practical barriers: other things to worry about, too busy, difficult to arrange transport, concerns about missing school or work, no health insurance; and service barriers: no regular source of medical care, limited access to medical care, not sure where to go for help, difficult to make an appointment, worried about wasting a doctor's time, difficult to talk to doctor.[7,8,9] Contextual, practical, and service help-seeking barriers may vary from one jurisdiction to another but need to be identified and addressed. AYA cancer awareness and education strategies designed to mitigate developmental and emotional barriers have met with success. Learnings from effective strategies, including

Team Shan Breast Cancer Awareness for Young Women (Team Shan), Huntsville, Ontario, Canada

** Corresponding author. Address: Lorna L. V. Larsen, 18 Beechwood Path, Huntsville, Ontario, P1H 1S8, Canada. Email address: lorna.larsen@hotmail.com (L.L.V. Larsen).*

J of Psychosocial Oncology Research and Practice (2023) 5:1

Received: 8 April 2022 / Received in final form: 23 November 2022 / Accepted: 7 December 2022

http://dx.doi.org/10.1097/OR9.0000000000000092

the examples below, inform targeted approaches to reach AYAs with vital cancer awareness and promote overall health and well-being across their lifetime.

3. AYA cancer awareness and education strategies

Awareness and education strategies tailored for the target population show promise in increasing knowledge and reducing help-seeking barriers. AYAs need to understand their cancer risk and early cancer warning signs and be reassured about high cure rates with early cancer.[8] Knowledge is power, and empowering AYAs with cancer symptoms and early detection information can increase their confidence to ask the question "Could this be cancer?" School-based initiatives, cancer awareness campaigns, and social media messaging are examples of health promotion strategies designed to reach AYAs.[9,10,11] The use of storytelling has also emerged as a helpful strategy to convey messages to the AYA population.[10] Evaluation of the Teenage Cancer Trust "Let's talk about it" classroom presentation in schools in Scotland and England reported increased younger AYA (11–17 years) cancer awareness, especially symptoms postpresentation.[9] The intervention also helped identify barriers to help-seeking behavior postintervention (eg, "not confident to talk about symptoms").[9] Findings supported school-based initiatives, increased our understanding of younger AYAs help-seeking behaviors, and provided valuable information for future interventions.[9]

Team Shan Breast Cancer Awareness for Young Women (Team Shan) breast cancer awareness campaigns were successful in reaching young women (17–29 years) on college and university campuses across Western Canada. Young women responded positively to the campaign activities, understood their breast cancer risk, and overall postcampaign knowledge levels of breast cancer facts, risk factors, symptoms, and self-care strategies increased.[10] Postcampaign personal action taken or planned to take included "self-checks" and "getting checked."[10] Respondents also shared campaign messaging with others.[10] The use of a real person (Shanna) appealed to young women and made a difference in communicating messages. Shan's story was memorable and resonated with young women on campus as an indication that breast cancer can occur in young women (eg, "The campaign touched me because I am the same age as Shan").[10] Team Shan has realized long-term campaign goals for earlier detection and improved outcomes for young women diagnosed with breast cancer (eg, "There is one organization I thank for my life. My early detection was due to Team Shan").[12] Effective social media approaches have also supported specific AYA cancer risk reduction messaging. Tailored YouTube style videos were designed in Canada to raise awareness with adolescent girls and boys about tobacco exposure as a modifiable risk factor for breast cancer. The sex-specific videos "Too young to think about breast cancer" and "Guys: a lesson on Breasts" appealed to the target audiences and both reported an interest in sharing the videos through social networking (eg, Facebook).[11] Tailored messages based on sex were important to the project and may be equally helpful in AYA cancer awareness and early detection messaging.[11]

4. Health care provider implications

Health care providers are in a position to share the impact of late diagnosis on AYAs with cancer in their practice. Increasing their understanding of AYA help-seeking barriers and AYA cancer information needs provides the opportunity for health care provider to both support and advocate for strategies to mitigate barriers and expedite time to diagnosis. Public health mandates and school health curriculums provide sustainable health promotion opportunities for AYA cancer awareness and education. Effective interventions support the engagement of AYAs in their design, public health and educational expertise, and the utilization of health promotion best practice.

5. Conclusion

In order for AYAs with cancer to have the best start possible, policy makers need to prioritize improving early cancer diagnosis and encourage collaboration and partnerships along with identifying potential stakeholders, resource, and research opportunities. Upstream health promotion approaches designed to reach AYAs, their parents, peers, and the general public with the message "Could this be cancer?" have the potential to expedite time to diagnosis and treatment, decrease distress, improve patient outcomes, and reduce the AYA with cancer survivorship disparities.

Conflicts of interest statement

The authors declare no conflicts of interest.

References

[1] Wen YF, Chen MX, Yin G, et al. The global, regional, and national burden of cancer among adolescents and young adults in 204 countries and territories, 1990-2019: a population-based study. *J Hematol Oncol.* 2021;14:89.

[2] Bleyer A, O'Leary M, Barr R, Ries LAG, eds. *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975-2000*. Bathesda, MD: National Cancer Institute 2006:5767.

[3] Islami F, Ward EM, Sung H, et al. Annual report to the nation on the status of cancer, Part 1: National Cancer Statistics. *J Natl Cancer Inst.* 2021;113:1648-1669.

[4] Forster AS, Herbert A, Koo MM, et al. Associations between diagnostic time intervals and health-related quality of life, clinical anxiety and depression in adolescents and young adults with cancer: cross-sectional analysis of the BRIGHTLIGHT cohort. *Br J Cancer*. 2022. 126: 1725-1734.

[5] Statistics Canada. *Number and Rates of New Primary Cancer Cases, by Stage at Diagnosis, Selected Cancer Type, Age Group and Sex*. 2022. Retrieved from: https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310076101

[6] McGoldrick D, Gordon P, Whiteson M, Adams H, Rogers P, Sutcliffe S. Awareness and advocacy for adolescents and young adults with cancer. *Cancer*. 2011;117:2311-2315.

[7] Hubbard G, Macmillan I, Canny A, et al. Cancer symptom awareness and barriers to medical help seeking in Scottish adolescents: a cross-sectional study. *BMC Public Health*. 2014;14:1117.

[8] Bleyer A. CAUTION! Consider cancer: common symptoms and signs for early detection of cancer in young adults. *Semin Oncol.* 2009;36: 207-212.

[9] Kyle RG, Forbat L, Rauchhaus P, Hubbard G. Increased cancer awareness among British adolescents after a school-based educational intervention: a controlled before-and-after study with 6-month follow-up. *BMC Public Health*. 2013;13:190.

[10] Larsen L. "I think it is a powerful campaign and does a great job of raising awareness in young women": findings from breast cancer awareness campaigns targeting young women in Canada. *Can Oncol Nurs J*. 2022; 32:61-67.

[11] Bottorff JL, Struik LL, Bissell LJL, Graham R, Stevens J, Richardson CJ. A social media approach to inform youth about breast cancer and smoking: an exploratory descriptive study. *ScienceDirect* 2014;21:159-168.

[12] Semple A. *When "Thank You" Isn't Enough*. 2015. Available from: https://teamshan.ca/when-thank-you-isnt-enough. Accessed November 23, 2022.