

Addressing the Challenge of Delayed Diagnosis Due to Age-related Disparities in Young Women's Breast Cancer Care

Globally, close to 1.2 million adolescents and young adults (AYA) aged 15–39 years were diagnosed with cancer in 2019.^[1] The highest incidence of cancer in young women was attributed to a disproportionate number (close to 170,000) of young women diagnosed with breast cancer.^[1] The highest number (over 43,000) of AYA cancer deaths and close to 2,500,000 disability-adjusted life years were attributed to breast cancer.^[1] This increasing trend in the prevalence of breast cancer in young women, more aggressive disease features, increased recurrence rates, and poorer outcomes makes breast cancer a “rising threat” to young women worldwide.^[2]

Long delays in diagnosis have been identified as one of the characteristics of young women with breast cancer. Age disparities have been well-documented in breast cancer stage-at-diagnosis data. For example, disproportionate numbers of young women in the United States (US) between 1976 and 2009 were reported to have been diagnosed with metastatic breast cancer compared to older women.^[3] Due to patient or physician inaction, young women with a late-stage diagnosis experience adverse outcomes, including distress and a lower chance of survival.^[3] Predictions that more young women will present with advanced breast cancer are a genuine concern for young women who already have a poor prognosis.^[3]

Addressing the late diagnosis, age disparity requires a multifaceted approach targeting a number of stakeholders including, but not limited to, policymakers, society at large, the general AYA population, young women with breast cancer not yet diagnosed, and the health-care providers (HCP) who encounter them in their practice. This commentary will critically review the issue of diagnostic delays of breast cancer in young women, awareness and early detection knowledge barriers for young women, the status of known frontline HCP knowledge barriers, and health promotion strategies to help mitigate early detection knowledge gaps.

YOUNG WOMEN'S EXPERIENCES

Young women with breast cancer have shared their diagnostic delay experiences on a variety of inperson and online platforms (e.g., websites).^[4] Stories about breast cancer knowledge and service barriers have also been formally shared through AYA cancer initiatives and research questionnaires.^[5] For example, young women in the United Kingdom (UK) recently shared their breast cancer risk and experiences with researchers. The results generated three themes, including breast cancer being an older woman's disease (e.g. “Future me's problem”) and uncertainty regarding breast checking (e.g. “I do not know what I am feeling for”).^[5] They also reported missed opportunities

with fundraising campaigns to promote awareness and educate young women about breast cancer symptoms, risk reduction, and prevention.^[5]

Young women's voices are also shared informally through social media posts and blogs and are exemplified by personal communications, such as “Last year... had so many ultrasounds and claimed it was not cancer. If they would have sent me for a biopsy right away I would not be stage 4 right now.” (Savannah Polson, February 10, 2020) and “... some doctors just make you feel like you should not be there or that you look healthy for someone who is sick.” (Maya Gamutilela Mercredi, March 24, 2023).

With no formal routine breast cancer screening available for young women, self-detection is of paramount importance; young women need to know their breasts, check them regularly, watch for changes, and seek a medical assessment when unexplained changes persist.^[2,6] Health promotion strategies can help address breast cancer knowledge gaps in young women, including, but not limited to, facts, risk factors, breast cancer symptoms, and self-care strategies.^[6] Educating young women has the potential to increase breast cancer risk reduction behaviors and earlier detection to help improve outcomes and increase survival rates.

Tailored health promotion initiatives aimed at young women are now emerging to address this identified need for breast health care. For example, the multiyear Team Shan's Breast Cancer in Young Women (Team Shan) campus awareness campaigns on postsecondary school campuses in Canada were successful in reaching young women with their breast cancer risk and increasing breast cancer topic knowledge levels (e.g. “Outside ads lead to website. It [campaign] worked for me.”).^[6] Young women were receptive to learning about their breast cancer risk and breast health information. They responded positively to the marketing campaigns (e.g. “Because I kept seeing the posters/billboards. I downloaded an app that reminds me to check for breast cancer”).^[6] Shan's story resonated with young women on campus (e.g. “The campaign touched because I am the same age as Shan.”).^[6] They appreciated not being forgotten in breast cancer messaging and asked for ongoing awareness and education (e.g. “Keep up the good work raising awareness.”).^[6] Team Shan's long-term goals for earlier detection and improved outcomes have also been reached (e.g. “There is one organization I thank for my life. My early detection was due to Team Shan.”).^[7]

High school initiatives have also successfully increased short-term AYA cancer knowledge levels.^[7] Sustainable

health promotion and education opportunities through public health mandates and school health curriculums can help fill the gap in breast cancer awareness and education for young women. Effective interventions support the engagement of young women in their design, including public health best practices and educational professional expertise.^[7] Targeted health promotion messaging to young women provides an opportunity to empower young women to ask the question, “Could this be cancer?”^[7] Opportunities are being missed, putting young women at an increased risk of late diagnosis and loss of life.

Navigating the health-care system can also be a challenge for young women, including, but not limited to, access to medical care (e.g. no primary care provider and transportation challenges), lack of insurance or treatment funding, and other practical issues (e.g. time off from school and work).^[7] Service challenges may vary from jurisdiction to jurisdiction but need to be addressed.

HEALTH-CARE PROVIDER BARRIERS AND CHALLENGES

Diagnosis of breast cancer in young women is relatively rare and may be delayed due to a “low pretest probability of cancer.” AYAs report more frequent visits than controls to their HCP 3 months before diagnosis. This behavior may reflect the need for further investigation and referral to obtain an accurate diagnosis. Despite the low risk, the seriousness of the disease and early treatment options support further investigation.^[8] HCP knowledge barriers of AYA cancer types, common symptoms, and health service challenges to a timely diagnosis have been documented for several years. Identified professional barriers include, but are not limited to, the rarity of the disease, the perception that young women are too young for breast cancer, limited patient exposure, low suspicion, and being less familiar with symptoms in young women.^[9] For example, “What makes this disease so scary is that its victims are otherwise healthy young adults in whom we least expect to find something seriously wrong.”^[10] Other contributing factors to a diagnostic delay have been reported, including, but not limited to, symptoms dismissed as benign issues, lack of screening programs, lack of understanding of breast cancer biology, and confusion over self-care for young women compared to older women.^[9] Understanding the local medical landscape can help identify the information needs and challenges of HCPs who encounter young women in their practice. Improved clinical awareness of AYA cancer types, signs, and symptoms can help prevent diagnostic delays and reduce morbidity and mortality.

Historically, the US AYA Oncology Progress Review Group “Closing the Gap: A Strategic Plan” recommended awareness strategies targeting HCPs to increase early recognition of AYA cancers and referrals to appropriate specialists by penetrating the consciousness of frontline providers with the message to “Consider Cancer.”^[11] This message and the awareness and training strategies outlined are still relevant today.

HCP survey results from New Zealand found HCPs were receptive to professional education on recognized knowledge gaps, particularly about symptoms and diagnostic pathways for cancer in AYA.^[12] Recent priority setting in the UK included the following research priority for teenage and young adult cancer: “What General Practitioner or young person strategies, such as awareness campaigns and education, improve early diagnosis for young people with suspected cancer?”^[13] Addressing these identified knowledge and research priorities can assist in improving early detection and outcomes.

The CAUTION symptoms list can assist practitioners in recognizing the manifestations of cancer to help expedite and accurately diagnose AYAs with cancer.^[14] Common symptoms of breast cancer include, but are not limited to, breast lump, nipple discharge, and skin changes. The “mnemonic-friendly” list of seven symptoms, each represented by a letter in CAUTION, can be demonstrated with breast cancer symptoms:^[14] change in breast size, skin texture, redness, warmth; abnormal discharge from the nipple, nipple changes; unilateral breast pain, swelling; tumor (breast lump); increasing lymph gland involvement; obstinate fatigue, weight loss; and neurologic deficit.^[14] Further diagnostic aids include seven significant sites (e.g. breasts) on physical examination of cancer signs with the letter B: brain, breast, belly, bones, blood, and bare (birth canal), and seven human orifices (e.g. nipples) where abnormal discharge may also signify cancer.^[14] These early detection aids can help HCPs accurately diagnose young women presenting in their practice. Addressing identified HCP knowledge deficits through tools and resources to meet their information needs and offering professional development opportunities can help mitigate HCP barriers and challenges to an earlier breast cancer diagnosis. Further strategies include, but are not limited to, medical school education, diagnostic guidelines, screening strategies, appropriate imaging, community partnerships, and breast health care have also been recommended to increase awareness and early detection and help improve quality of life and survivorship for young women diagnosed.^[9]

CONCLUSIONS

Young women with breast cancer are frequently misdiagnosed and diagnosed later than older women. Late diagnosis negatively impacts the breast cancer journey, quality of life, and chance of survival. As breast cancer incidence rates continue to increase worldwide and survivorship rates lag behind other age groups, addressing late diagnosis in young women is both needed and vital in improving outcomes. Health promotion approaches designed to reach young women with crucial breast cancer information and the message “Could this be Cancer?” have the potential to expedite time to an earlier diagnosis and appropriate treatment.

Early detection of young women is an issue of public health importance. Implications for policymakers include the inclusion of young women’s needs in breast cancer early

detection guidelines. Public health expertise should be engaged, and researchers should be encouraged to investigate targeted health promotion awareness initiatives and outcome monitoring. HCP awareness and education opportunities play a vital role in increasing knowledge levels and also building a body of professional expertise.

Knowledgeable HCPs who encounter young women with presenting symptoms and “Consider Cancer” have the potential to accurately diagnose and expedite time to treatment. A timely diagnosis can help decrease distress, improve patient outcomes, and reduce the current breast cancer survivorship disparities. Setting early detection as a priority, with meaningful action on recommendations, will be crucial to influence positive change and sustain improved outcomes for young women diagnosed in the future.

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