

Adolescents and young adults (AYAs) with cancer aged 15–39 years have unique medical, psychosocial, and informational needs. At the time of diagnosis, they are often going through important life milestones, such as establishing their independence, attending school or work, and maintaining romantic and/or family relationships. This article describes some of the critical time points for AYAs with cancer and the resources available to support the nursing profession in meeting the unique care needs of this population.

#### AT A GLANCE

- AYAs with cancer have unique care needs throughout their illness trajectory (diagnosis, survivorship, clinical trial enrollment, and palliation) that require the attention of their healthcare providers.
- Tools and resources have been established to screen for and intervene on AYA-specific concerns.
- Nurses are well positioned to assess the unique care needs of young people and to work with an interprofessional team to optimally address these concerns.

#### KEYWORDS

adolescents and young adults; AYAs; oncology nursing; informational needs

#### DIGITAL OBJECT IDENTIFIER

10.1188/18.CJON.483-486

# Crucial Conversations

## Addressing informational needs of adolescents and young adults diagnosed with cancer

Laura Mitchell, RN, MN, CON(C)<sup>®</sup>, Seline Tam, BMSc, BScN, and Abha A. Gupta, MD, MSc, FRCPC

**S**arah is 29 years old and has been recently diagnosed with hormone-sensitive breast cancer. Her oncology team informed her that she will require gonadotoxic chemotherapy treatment, followed by surgery and endocrine therapy. Sarah's oncology team facilitated a referral to the clinical nurse specialist (CNS) involved in their cancer center's adolescent and young adult (AYA) program for additional support.

During the consultation, the CNS asked Sarah to complete a screening tool used to identify common concerns among young adults with cancer. Sarah identified several areas of concern: fertility, body image, coping support, and work. When exploring Sarah's responses to the screening tool, the CNS learned that Sarah is not in a romantic relationship but would like to have children in the future. In addition, Sarah is trying to decide between having a lumpectomy or a mastectomy, both of which are acceptable for managing her cancer. She feels isolated by her body image concerns and hopes to connect with other young women regarding their decision making for breast cancer surgery. Sarah also shared that she is employed in a marketing industry but does not have private benefits to pay for medication and is worried about having an income during her cancer treatment.

The CNS played an important role in Sarah's care by offering a tailored AYA assessment and by further offering education, resources, and navigation

to specialty services specific to Sarah's needs.

### Defining the Population

The National Cancer Institute ([NCI], 2018) defines AYAs as individuals aged 15–39 years with a cancer diagnosis in North America. In the United States, about 70,000 AYAs are newly diagnosed with cancer each year, and this population is known to have different needs than children and older adults (Gupta, Edelstein, Albert-Green, & D'Agostino, 2013; NCI, 2018).

A cancer diagnosis is experienced differently for the AYA population because they are at a stage when they are establishing independence from their family, completing school, pursuing careers, starting romantic relationships, building financial stability, and/or planning a family (Quinn, Gonçalves, Sehovic, Bowman, & Reed, 2015). AYAs with cancer have many unique needs, which include fertility, sexual health, coping, diet and nutrition, school and work, exercise, life goals, palliative care, and finances, which require the attention of healthcare providers (Gupta et al., 2013; Ramphal et al., 2016; Tsangaris et al., 2014).

### Customized Care

To optimally address the care of young people with cancer, healthcare providers should be knowledgeable about unique AYA concerns, provide relevant information, be flexible in care delivery, and further involve patients in

decision-making processes (D'Agostino, Penney, & Zebrack, 2011). To guide care delivery for AYAs, the National Comprehensive Cancer Network (2018) developed guidelines considering medical and psychosocial domains of care. In addition, the use of a screening tool can be an effective approach for identifying the care needs of AYAs and for initiating difficult conversations. To the authors' knowledge, only one validated AYA screening tool exists, which was created in Australia (Can Teen, 2011). However, many cancer programs assess AYAs with alternate distress screening tools (Mitchell et al., 2017).

Dedicated programs have been established around the world to overcome the gaps in care delivery for AYAs with cancer (Mitchell, Stuart-McEwan, Panet, & Gupta, 2017; Reed, Block, & Johnson, 2014). The makeup of these programs varies among countries; the United Kingdom defines AYAs as individuals aged 13–24 years, whereas Australia defines them as individuals aged 12–25 years (Rogers, De Pauw, Schacter, & Barr, 2013; Teenage Cancer Trust, 2018; Youth Cancer Service, 2018).

Although disciplines involved in the AYA clinical care team vary, the mission of these programs is similar: to address the specific information and service needs of the defined AYA population. When assessing the value of AYA programming, the Princess Margaret Cancer Centre in Toronto, Ontario, demonstrated that younger adults with cancer who access AYA-specific programming are more satisfied with care related to fertility, social support, school or work, and sexual health and body image, all of which are known to be important concerns among young people (Mitchell, Tam, et al., 2018).

### Crucial Conversations

AYAs have specific informational and care needs at critical time points along the illness trajectory, such as diagnosis, survivorship, clinical trial (CT) enrollment, and palliation.

### Diagnosis

As highlighted by Sarah's case, AYAs with cancer wish to receive information on fertility risks and preservation options (Gupta et al., 2013). When asked how they would like to receive fertility information (conversations with a healthcare provider, written information, and/or online), AYAs preferred to receive information from a healthcare provider supplemented by a brochure or other written material (Tam et al., 2018). Important considerations for fertility conversations with AYAs include cost of the fertility procedure and the type of procedure required. This may require a more in-depth explanation for young women given the procedure's complexity. Sexual health conversations at diagnosis should be considered because cancer and its treatment can significantly affect

of normalcy, receive cancer-related information, and reduce developmental disruption with their diagnosis (Stupid Cancer, n.d.; Warner et al., 2016). Digital tools are also important for information delivery, and AYAs benefit from health-care provider assistance in navigating evidence-based web pages (Warner et al., 2016).

### Survivorship

Following treatment, emotional care of young adults with cancer should be a priority because as many as 20% are at risk for post-traumatic stress symptoms. Counseling and/or peer support can be beneficial for this population (Samson-Daly & Wakefield, 2013). In the survivorship phase, AYAs can encounter distress related to continuing with academic, career, and personal goals to achieve life

---

"Adolescents and young adults have specific informational and care needs at critical time points along the illness trajectory."

---

younger adults, making it necessary for healthcare providers to inform patients and assess for potential sexual side effects (Mitchell, Tam, et al., 2018).

The authors' AYA program hosted an AYA sexual health symposium at the first Global AYA Cancer Congress in Edinburgh, United Kingdom, where experts recommended that AYAs be assessed particularly for climacteric symptoms (hot flashes), sexual dysfunction, contraception use, and the psychological impact of sexuality and body image changes (Mitchell, Lewin, et al., 2018). In addition, peer support and the use of technology are important psychosocial considerations for AYAs. Some young adults benefit from peer support programming to maintain a sense

of milestones at a similar pace as their peers (Overholser, Kilbourn, & Liu, 2017). It is crucial that healthcare providers guide AYAs by encouraging slower transitions and establishing realistic goals when reengaging in normal life. Referrals to rehabilitation services, such as cancer-specific exercise programming and neuropsychology for management of cognitive changes (i.e., brain fog), may be helpful to ensure successful transitions in this population (Gupta et al., 2016).

### Clinical Trial Enrollment

With the ongoing development of new cancer treatment therapies, younger adults may be offered enrollment to a CT at various time points in their illness trajectory. Evidence shows that AYAs have low

CT enrollment rates (Roth et al., 2016). Several factors known to influence AYA decision making around CT enrollment include family or peer opinions, impact on daily life (school, family planning), illness severity, and psychosocial readiness (Gupta et al., 2017). When healthcare providers communicate with young people about CT decision making, it is important to explore the patient's understanding of the treatment's purpose, as well as the patient's values and priorities beyond medical care, to ensure this is an appropriate approach for him or her (Gupta et al., 2017).

### Palliation

Little is known about the specific palliative care needs of AYAs with cancer; however, early palliative care involvement is encouraged (Donovan, Knight, & Quinn, 2015). To understand the priorities of AYAs with advanced cancer, a validated tool for advance care planning has been established (Wiener et al., 2012). *Voicing My Choices* is a guide that assists AYAs with serious illnesses to communicate their needs to caregivers, family, and friends (Wiener et al., 2012). Because these conversations are very challenging, healthcare providers may use this approach to bring up the topic to AYAs and ensure they are effectively meeting the needs of young patients.

### Implications for Practice

Given the diverse needs of the AYA population, interprofessional collaboration is critical for optimizing the care of younger people with cancer. Because they often work in clinical areas with higher volumes of AYAs or have developed expertise with this vulnerable population, nurses are instrumental in assessing the needs of AYAs with cancer and engaging in crucial conversations at various points throughout the illness trajectory (Teenage Cancer Trust, 2014). In addition, as members of the interprofessional team (medicine, rehabilitation, psychosocial, external programs), nurses can provide AYAs with

relevant information and direct them to appropriate resources and services necessary to enhance their care experience (Gupta et al., 2016; Mitchell et al., 2017).

### Conclusion

Although AYAs with cancer are only a small proportion of the total oncology population, they have distinguishable medical and psychosocial needs. Healthcare providers must be aware of these needs. Oncology nurses are particularly well positioned to assess and intervene on AYA issues, positively affecting the cancer experiences of young people.

**Laura Mitchell, RN, MN, CON(C)**<sup>®</sup>, is a clinical nurse specialist in the Lawrence S. Bloomberg Faculty of Nursing, **Seline Tam, BMSc, BScN**, is a research analyst, and **Abha A. Gupta, MD, MSc, FRCPC**, is a staff oncologist, all in the Princess Margaret Cancer Centre at the University of Toronto in Canada. Mitchell can be reached at [laura.mitchell@uhn.ca](mailto:laura.mitchell@uhn.ca), with copy to [CJONEditor@ons.org](mailto:CJONEditor@ons.org).

The authors take full responsibility for this content and did not receive honoraria or disclose any relevant financial relationships.

### REFERENCES

Can Teen. (2011). *AYA oncology psychosocial care manual*. Retrieved from <https://www.canteen.org.au/health-professionals/research-and-evaluation/guidelines/aya-oncology-psychosocial-care-manual>

D'Agostino, N.M., Penney, A., & Zebrack, B. (2011). Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer, 117*, 2329–2334. <https://doi.org/10.1002/cncr.26043>

Donovan, K.A., Knight, D., & Quinn, G.P. (2015). Palliative care in adolescents and young adults with cancer. *Cancer Control, 22*, 475–479. <https://doi.org/10.1177/107327481502200413>

Gupta, A.A., Bell, J.A.H., Wang, K., Forcina, V., Tam, S., Lin, Y.-C., . . . Lewin, J. (2017, May). *Evaluation of adolescents and young adults (AYA) attitudes towards participation in cancer clinical trials*. Poster presented at the American Society of Clinical Oncology Conference, Chicago, Illinois.

Gupta, A.A., Edelstein, K., Albert-Green, A., & D'Agostino, N. (2013). Assessing information and service needs of young adults with cancer at a single institution: The importance of information on cancer diagnosis, fertility preserva-

tion, diet, and exercise. *Supportive Care in Cancer, 21*, 2477–2484. <https://doi.org/10.1007/s00520-013-1809-4>

Gupta, A.A., Papadakos, J.K., Jones, J.M., Amin, L., Chang, E.K., Korenblum, C., . . . Giuliani, M.E. (2016). Reimagining care for adolescent and young adult cancer programs: Moving with the times. *Cancer, 122*, 1038–1046. <https://doi.org/10.1002/cncr.29834>

Mitchell, L., Lewin, J., Dirks, J., Wang, K., Tam, S., Katz, A., . . . Gupta, A.A. (2018). Sexual health issues for the young adult with cancer: An international symposium held during the first global adolescents and young adults cancer congress (Edinburgh, United Kingdom). *Journal of Adolescent and Young Adult Oncology, 7*, 153–163. <https://doi.org/10.1089/jayao.2017.0067>

Mitchell, L., Stuart-McEwan, T., Panet, H., & Gupta, A. (2017). Adolescents and young adults: Addressing needs and optimizing care with a clinical nurse specialist. *Clinical Journal of Oncology Nursing, 21*, 123–126. <https://doi.org/10.1188/17.CJON.123-126>

Mitchell, L., Tam, S., Lewin, J., Srikanthan, A., Heck, C., Hodgson, D., . . . Gupta, A. (2018). Measuring the impact of an adolescent and young adult program on addressing patient care needs. *Journal of Adolescent and Young Adult Oncology*. Advance online publication. <https://doi.org/10.1089/jayao.2018.0015>

National Cancer Institute. (2018). Adolescents and young adults with cancer. Retrieved from <https://www.cancer.gov/types/aya>

National Comprehensive Cancer Network. (2018). *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®): Adolescent and young adult (AYA) oncology* [v.2.2018]. Retrieved from [https://www.nccn.org/professionals/physician\\_gls/pdf/aya.pdf](https://www.nccn.org/professionals/physician_gls/pdf/aya.pdf)

Overholser, L., Kilbourn, K., & Liu, A. (2017). Survivorship issues in adolescent and young adult oncology. *Medical Clinics of North America, 101*, 1075–1084. <https://doi.org/10.1016/j.mcna.2017.06.002>

Quinn, G.P., Gonçalves, V., Sehic, I., Bowman, M.L., & Reed, D.R. (2015). Quality of life in adolescent and young adult cancer patients: A systematic review of the literature. *Patient Related Outcome Measures, 6*, 19–51. <https://doi.org/10.2147/PROM.S51658>

Ramphal, R., Aubin, S., Czaykowski, P., De Pauw, S., Johnson, A., McKillop, S., . . . Rogers, P. (2016). Adolescent and young adult cancer: Principles of care. *Current Oncology, 23*, 204–209. <https://doi.org/10.3747/co.23.3013>

Reed, D., Block, R.G., & Johnson, R. (2014). Creating an adolescent and young adult cancer program: Lessons learned from pediatric and adult oncology practice bases. *Journal of the National Cancer Comprehensive Network, 12*, 1409–1415.

- Rogers, P.C., De Pauw, S., Schacter, B., & Barr, R.D. (2013). A process for change in the care of adolescents and young adults with cancer in Canada. "Moving to Action": The second Canadian international workshop. International perspectives on AYAO, Part 1. *Journal of Adolescent and Young Adult Oncology, 2*, 72–76. <https://doi.org/10.1089/jayao.2012.0034>
- Roth, M.E., O'Mara, A.M., Seibel, N.L., Dickens, D.S., Langevin, A.-M., Pollock, B.H., & Freyer, D.R. (2016). Low enrollment of adolescents and young adults onto cancer trials: Insights from the community clinical oncology program. *Journal of Oncology Practice, 12*, e388–e395. <https://doi.org/10.1200/JOP.2015.009084>
- Samson-Daly, U.M., & Wakefield, C.E. (2013). Distress and adjustment among adolescents and young adults with cancer: An empirical and conceptual review. *Translational Pediatrics, 2*, 167–197.
- Stupid Cancer. (n.d.). Stupid cancer: Get busy living. Retrieved from <http://stupidcancer.org/about/index.shtml>
- Tam, S., Puri, N., Stephens, D., Mitchell, L., Giuliani, M., Papadakos, J., & Gupta, A.A. (2018). Improving access to standardized fertility preservation information for older adolescents and younger adults with cancer: Using a user-centered approach with young adult patients, survivors, and partners to refine fertility knowledge transfer. *Journal of Cancer Education, 33*, 528–535. <https://doi.org/10.1007/s13187-016-1108-0>
- Teenage Cancer Trust. (2014). *Competencies: Caring for teenagers and young adults with cancer: A competence and career framework for nursing*. Retrieved from <https://www.teenagecancertrust.org/sites/default/files/Nursing-framework.pdf>
- Teenage Cancer Trust. (2018). About us. Retrieved from <https://www.teenagecancertrust.org/about-us>
- Tsangaris, E., Johnson, J., Taylor, R., Fern, L., Bryant-Lukosius, D., Barr, R., . . . Klassen, A. (2014). Identifying the supportive care needs of adolescent and young adult survivors of cancer: A qualitative analysis and systematic literature review. *Supportive Care in Cancer, 22*, 947–959. <https://doi.org/10.1007/s00520-013-2053-7>
- Warner, E.L., Kent, E.E., Trevino, K.M., Parsons, H.M., Zebrack, B.J., & Kirchhoff, A.C. (2016). Social well-being among adolescents and young adults with cancer: A systematic review. *Cancer, 122*, 1029–1037.
- Wiener, L., Zadeh, S., Battles, H., Baird, K., Ballard, E., Osherow, J., & Pao, M. (2012). Allowing adolescents and young adults to plan their end-of-life care. *Pediatrics, 130*, 897–905. <https://doi.org/10.1542/peds.2012-0663>
- Youth Cancer Service. (2018). About cancer in young people. Retrieved from <https://www.canteen.org.au/youth%20-cancer/health-professionals/cancer-young-people>

**DO YOU HAVE AN INTERESTING TOPIC TO SHARE?**

Supportive Care provides readers with information on symptom management and palliative care issues. If you are interested in writing for this department, contact Associate Editor Joseph D. Tariman, PhD, RN, ANP-BC, FAAN, at [phdjinseattle@gmail.com](mailto:phdjinseattle@gmail.com).