

Adolescents and young adults (AYAs) with cancer aged 15–39 years have unique psychosocial, informational, and medical concerns compared to their older adult and pediatric counterparts. Recognizing the gaps in young adult cancer care, an AYA program was launched at a large tertiary cancer center to optimize the AYA cancer care experience. This article describes the contributions of a clinical nurse specialist in AYA program development.

AT A GLANCE

- The needs of adolescents and young adults (AYAs) with cancer are not routinely identified and addressed in adult cancer care institutions.
- Clinical nurse specialists (CNSs) are particularly suited to influence AYA care through several domains of program development: clinical care, education, leadership, and evaluation.
- The diverse expertise of CNSs can enhance nursing knowledge on key AYA issues and significantly influence AYA care in the areas of fertility, sexual health, social support, and exercise.

KEYWORDS

fertility; adolescents and young adults; clinical nurse specialist

DIGITAL OBJECT

IDENTIFIER

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Adolescents and Young Adults

Addressing needs and optimizing care with a clinical nurse specialist

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Faced with cancer, adolescents and young adults (AYAs) (aged 15–39 years) have different psychosocial and medical needs than their adult counterparts (Ferrari et al., 2010). These needs include information on topics such as fertility, sexuality, body image, nutrition, and exercise (D’Agostino, Penney, & Zebrack, 2011; Gupta, Edelstein, Albert-Green, & D’Agostino, 2013). When these unique needs are not met, AYAs experience higher distress during their cancer journey (Williams, 2013). Recognizing this gap in care, the University Health Network Princess Margaret Cancer Centre (PM) launched an AYA program in 2014 to optimize the AYA cancer care experience and address the needs of this population. The program was led by a clinical nurse specialist (CNS), a medical director, a clinical director, and a project team that provided mentorship to the CNS during the early stages of program development.

CNS practice is balanced between four key competencies: clinical care, education, leadership, and research. The role has been instrumental in developing and integrating the key domains of the AYA program:

- Patient consultations in which AYAs’ unique needs are addressed
- Provider education on important AYA issues (fertility, sexual health, and AYA-specific resources)
- Leadership activities (program awareness, partnership building, and resource development)

- Program evaluation (Canadian Nurses Association [CNA], 2014).

This article describes the unique contributions of the CNS in AYA program development, as well as the roles and preliminary outcomes of the CNS within each domain.

Clinical Nurse Specialist Role in Program Development Clinical Care

The CNS provides consultations using an evidence-based tailored assessment guided by a screening tool created by the PM AYA Program (CNA, 2014) (see Figure 1). This tool triages patient concerns and supports assessment and interventions by the CNS, including education and navigation to hospital- and community-based programming. The CNS offers psychosocial support and makes referrals to other specialized services. AYAs may be referred to the program at any time during their illness trajectory, but the CNS typically encounters them at the time of diagnosis. Those with complex needs are offered follow-up appointments every eight weeks to monitor intervention outcomes (CNA, 2014). Through collaborations with internal psychosocial programming, the CNS is skilled in triaging patients to the appropriate counseling service. The program was initially piloted in the hematology site and has been sequentially rolled out across all disease-specific sites.

Provider Education

To better understand the learning needs of nursing staff on AYA-related issues, baseline

FIGURE 1.
SCREENING TOOL FOR REFERRALS AMONG ADOLESCENTS AND YOUNG ADULTS WITH CANCER

DATE: _____ **PATIENT STATUS:** ___New patient ___On treatment ___Survivorship

Please select the number that best describes you:											
	1	2	3	4	5	6	7	8	9	10	
No concerns with work/school											Significant concern with work/school
No concern with finances											Significant financial concerns
I have excellent social supports.											I do not have individuals in my life that are supporting me.
Not anxious about my future											Very anxious about my future
No concern about my appearance											Significant concern about my appearance
No concerns about my sexual health											Significant concerns about my sexual health
No concerns about my fertility											Significant concerns about my fertility
No difficulty understanding information about my cancer											Significant difficulty understanding information about my cancer
No concerns with diet/nutrition											Significant concern with diet/nutrition
No difficulty navigating the hospital system											Significant difficulty navigating the hospital system
No concerns with physical activity/exercise											Significant concerns with physical activity/exercise
Other area of concern											

Note. Tool courtesy of University Health Network Princess Margaret Cancer Centre. Used with permission.

surveys were distributed by the CNS to each disease-specific clinic prior to the launch of the program. The results confirmed a moderate to high need for additional nursing education on AYA issues at each disease site clinic with a larger proportion of AYA patients (leukemia, lymphoma, breast, brain, head and neck/thyroid, gynecology, gastrointestinal, testes, and sarcoma). The survey asked participants to rate their specific AYA educational needs using a five-point Likert-type scale that ranged from 1 (no additional education needed) to 5 (high additional education needed). A total of 165 surveys were completed, with a response rate of 82%. In response, the CNS created nursing

education sessions on fertility risks and preservation options, the impact of cancer treatment on sexual health and interventions for management, and an overview of community programs for AYA (CNA, 2014). The content for these sessions incorporated information from the survey responses, evidence from the literature (Katz, 2007; Loren et al., 2013), and feedback from relevant experts, including a reproductive endocrinologist, nurse practitioner specializing in fertility preservation, and a CNS with expertise in oncology sexual health counseling. The fertility experts were identified through a partnering fertility clinic, and the CNS is well known internationally for her

work. The CNS developed and delivered lectures on these topics to nurses across all cancer disease sites. The number of participants varied in each session; 75 nurses attended the fertility lecture, 84 attended the sexual health lecture, and 99 attended the community programs for AYA lecture. More than 30 one-hour education sessions have been delivered by the CNS to about 84 nurses throughout PM. The lectures were evaluated by participants for effectiveness and revised based on feedback. The lectures were further supplemented by CNS mentorship in practice settings (CNA, 2014). To build capacity, the CNS created resource kits for all clinic areas that included

pamphlets and referral information for relevant programming (CNA, 2014).

Leadership

An environmental scan was conducted by the CNS in the first six months of program implementation and revealed that 40 meetings with pertinent programs were held. The CNS further shadowed in oncology clinics populated by AYAs to learn more from patients and providers what additional supports and resources were required from the AYA program. The CNS developed partnerships with fertility specialists and sexual health experts, including urologists, a gynecologist, an endocrinologist, and sexuality counselors to streamline the referral processes and ensure that programming met the needs of patients. The CNS also visited Seattle Children's Hospital in Washington and the University of Southern California in Los Angeles to learn about the experiences of established AYA programs. These visits affected the decision to create an AYA consultation service and provided insight into the development of a referral pathway for fertility preservation.

To facilitate implementation and integration of the AYA program, a communication strategy was successfully developed and implemented by the CNS with support from the AYA team (CNA, 2014). The communication goals included sharing program information and learning how the AYA team could support providers and patients. The CNS acted as a content expert to develop a consultation documentation tool. The tool included patient concerns, referrals, and details on interventions. The consultation note was then uploaded into the patient's chart. As a result, patient interactions were communicated to oncology teams in a timely manner and encouraged ongoing targeted supportive care for AYAs.

Evaluation

To evaluate the need for improvement in AYA consultation delivery, the CNS collected email consent from patients and,

at the conclusion of the consultation, they were emailed a survey on their experience (CNA, 2014). To date, the survey has been distributed to 293 patients. This feedback assisted in quality-assurance mechanisms by ensuring that the CNS was providing effective care. Additional strategies included ad hoc patient focus groups in which participants had the opportunity to provide feedback on their experience and to evaluate resources created by the program.

Impact of the Clinical Nurse Specialist

Clinical Care

In current practice, the CNS assesses about 25 patients for consultation and 25 patients for follow-up each month. The patient population reflects the volume of AYAs within disease site clinics, so patients most often seen have leukemia, lymphoma, or breast

education, nurses reported having a better understanding of fertility (and its preservation), sexual health, and AYA community resources. For example, following the ambulatory fertility education sessions, 43 of 52 participants strongly agreed or agreed to having a better understanding of how cancer affects fertility and 49 strongly agreed or agreed that they have more knowledge on fertility preservation options, indicating that the CNS has played an important role in enabling AYA-focused nursing care (CNA, 2014). Based on the completed AYA patient satisfaction surveys (n = 26), patients gave an average rating of 9 in terms of the AYA program being helpful, with 0 indicating not helpful and 10 indicating extremely helpful. Anecdotal feedback from patients demonstrated that the program plays a key role in all stages of an AYA's illness trajectory.

"Adolescents and young adults most commonly were referred for fertility counseling and coping resources."

cancer. From October 2014 to November 2015, 91 referrals were documented. The most common reasons for referral included fertility counseling (n = 38), coping resources (n = 34), and sexual health counseling (n = 10), and the most common referrers were physicians or nurses (n = 69) and self-referred patients (n = 14). From October 2014 to November 2015, the CNS facilitated referrals for 53 AYAs to social work (n = 25) and psychology and psychiatry services (n = 28) because of complex psychosocial needs. The CNS's ability to provide specialized care for this vulnerable population has contributed to optimal clinical care delivery (CNA, 2014).

Provider Education

AYA education is now integrated into nursing orientation and annual inpatient nursing skills laboratories. Following AYA

Leadership

To increase patient and provider access to fertility information and services, the CNS worked with a local fertility clinic to develop referral pathways for clinicians. The CNS and AYA team also created fertility brochures that were identified as a need at PM and outside centers. The AYA program conducted a large environmental scan of other cancer centers in the region. Almost all centers identified this resource as a gap in their patient education materials. The brochures are now used at several cancer centers and have been distributed to these centers through email. They can also be uploaded on the program's website (Tam et al., 2016). The CNS has played an influential role in increasing awareness of AYA issues by delivering presentations on programmatic initiatives at several North American meetings (CNA, 2014; Mitchell,

Gupta, & Hendershot, 2015; Mitchell, Panet, D'Agostino, Stuart-McEwan, & Gupta, 2014; Mitchell, Panet, Stuart-McEwan et al., 2014). The CNS has lectured at hospital rounds and community events. An article with other nursing experts, including nurse practitioners specializing in fertility preservation, breast cancer, and childhood cancer survivorship, was published describing their roles in fertility preservation (Hendershot et al., 2016).

Evaluation

The feedback collected from the surveys was reviewed by the CNS. One of the identified areas in which AYAs require additional clinical intervention relates to sexual health concerns, particularly menopausal symptoms, decreased libido, and contraception. To address this gap, the CNS and AYA team initiated an AYA sexual health symposium held at the Global AYA Cancer Congress in Edinburgh, Scotland, with the goal of developing AYA sexual health clinical care guidelines (CNA, 2014).

To evaluate the significance of the CNS role in AYA clinical care and provider education, the CNS contributed to a qualitative research study looking at patient and provider satisfaction. Preliminary findings revealed that the consultations delivered by the CNS had a significant impact on patient participants in the areas of social support (85%), sexual health (76%), exercise (74%), and fertility (73%) (Gupta et al., 2013).

Lessons Learned

The four key competencies of the CNS role have been critical for AYA program implementation. The CNS's ability to identify where gaps in care exist was necessary for designing a program that would be effective at meeting patient and provider needs. In addition, the CNS's ability to develop specific skill sets through self-directed learning enabled the delivery of comprehensive patient consultations. The CNS's contributions to creating program awareness through education and resource development was also important for increasing patient access to appropriate services. Finally,

the development of evaluation measures by the CNS and AYA team to assess program metrics longitudinally was necessary to ensure the delivery of quality assurance.

Conclusion

To make the AYA program more robust, several goals have been established for the future. The development of AYA sexual health guidelines will be pursued by the AYA team to enhance their skills in addressing the sexuality needs of AYAs with cancer. The CNS will continue to liaise with other disciplines to streamline services. Finally, research collaborations will be explored to facilitate more publications so that other centers have the opportunity to learn from this experience.

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