

# Reimagining Care for Adolescent and Young Adult Cancer Programs: Moving With the Times

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Literature regarding the development of adolescent and young adult (AYA) cancer programs has been dominantly informed by pediatric centers and practitioners. However, the majority of young adults are seen and treated at adult cancer centers, in which cancer volumes afford the development of innovative supportive care services. Although the supportive care services in adult cancer centers are helpful to AYAs, some of the most prominent and distinct issues faced by AYAs are not adequately addressed through these services alone. This article describes how the AYA Program at Princess Margaret Cancer Centre has collaborated with existing supportive care services in addition to supplying its own unique services to meet the comprehensive needs of AYAs in the domains of: symptom management (sexuality and fatigue), behavior modification (return to work and exercise), and health services (advanced cancer and survivorship). These collaborations are augmented by patient education interventions and timely referrals. The objective of this article was to assist other centers in expanding existing services to address the needs of AYA patients with cancer. *Cancer* 2015;000:000-000. © 2015 American Cancer Society.

**KEYWORDS:** adolescent and young adult, exercise, fatigue, palliation, patient education, return to work, sexuality, supportive care.

## INTRODUCTION

Adolescents and young adults (AYAs) with cancer (those aged <39 years) have needs including psychosocial, informational, and medical needs that are distinct from those of their adult and pediatric counterparts.<sup>1</sup> The needs of AYAs are distinct because they are moving through key milestones in their life cycle that are interrupted at the time of diagnosis.<sup>2</sup> Adult cancer centers often deliver care through disease-focused models in which high patient volumes and limited infrastructure challenge the ability to address the specific care needs of AYAs with cancer. In addition, AYA patients represent a small percentage of adult patients with cancer and thus health care teams have less experience and expertise with this population.<sup>1,3</sup> Targeted AYA programming and services should be implemented in adult cancer centers to address the distinct needs of young adults with cancer.<sup>2,4</sup> At the same time, AYAs have needs that overlap with those of adult cancer populations and thus supportive care programs for adult patients can be leveraged for AYAs. This combination of targeted programming complemented by existing supportive care services can address the full spectrum of AYA needs.

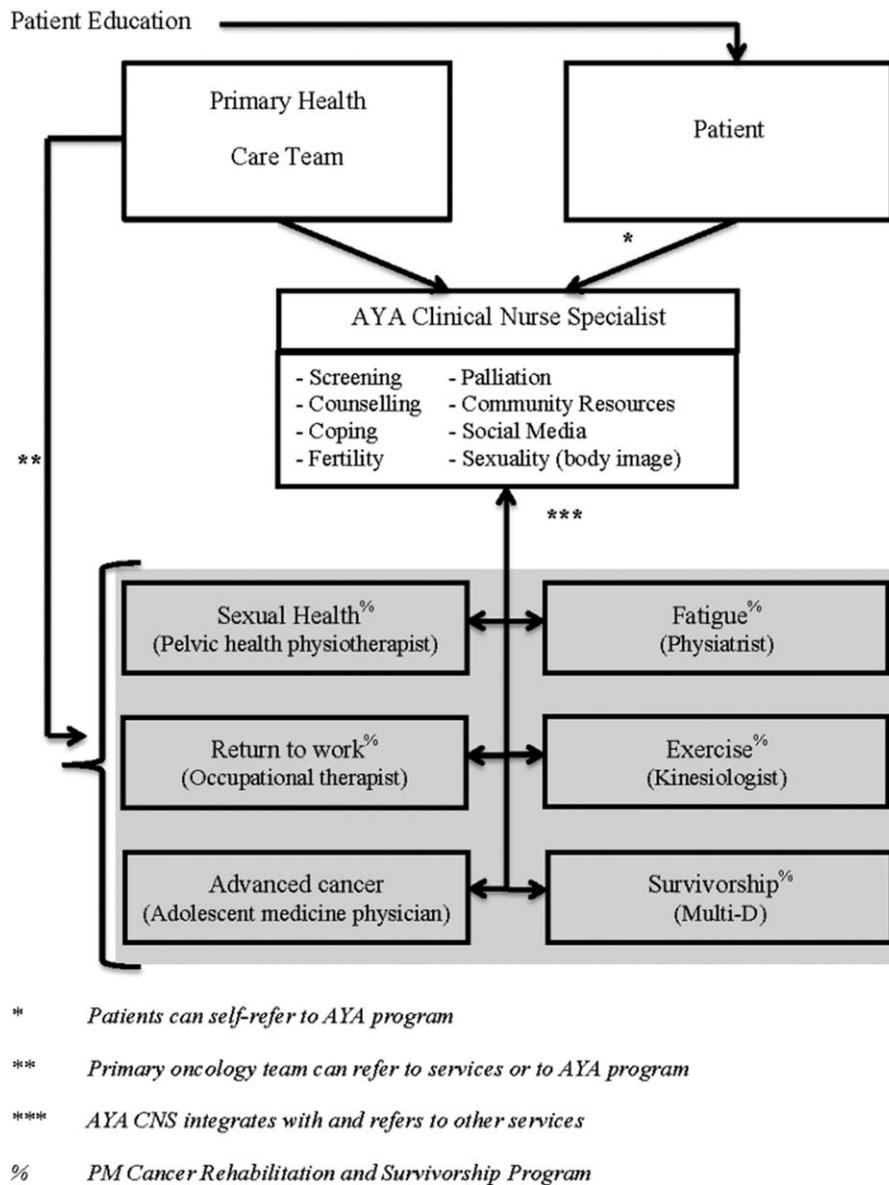
Approximately 1300 new AYAs are diagnosed with cancer annually at the Princess Margaret (PM) Cancer Centre, a large urban adult cancer center. The PM AYA Program was established in 2014 to optimize and standardize supportive care delivery that is tailored to the needs of AYA patients. The PM AYA Program is led by a clinical nurse specialist (CNS) trained in AYA oncology. The CNS meets patients in consultation either through self-referral or referral by a health care provider (HCP). Consultations with the CNS involve a dialogue between the CNS and AYAs to establish an understanding of the informational and supportive care needs of the patients. The CNS offers patient teaching that is augmented

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**Figure 1.** A roadmap of the structure of the Adolescent and Young Adult (AYA) Program at the Princess Margaret (PM) Cancer Centre, including referral pathways. Multi-D indicates multidisciplinary; CNS, clinical nurse specialist.

by patient education resources developed to address the specific needs of AYAs, especially in the areas of fertility preservation, community-based resources, peer support, and coping. After consultation, the CNS triages AYA patients to further resources as needed (see Fig. 1 for team structure). Substantial time also has been dedicated to developing and delivering education modules on AYA issues to front-line nursing staff at PM.

Although significant attention has been dedicated to improving access to and information regarding fertility and counseling in the PM AYA Program and others, to the best

of our knowledge little attention has been paid to other domains of need that warrant similar attention within the AYA cancer experience. These needs include: 1) sexual health and fatigue (symptom management); 2) return to work and exercise (behavior modification); and 3) patient education, advanced cancer, and survivorship (health services) (Table 1). The interprofessional team of the PM AYA Program presents this review with the objective of highlighting the concerns within each domain followed by collaborative strategies to assist other centers in understanding the possibilities for expanding their own AYA programs.

**TABLE 1.** Princess Margaret AYA Program Approach to Common Problems

The Problem	Our Strategy
<ul style="list-style-type: none"> <li>• AYA CNS offers consultation that includes screening and counseling</li> <li>• Specific focus on fertility preservation, sexuality/body image, community-based resources</li> <li>• Triage patients to further services or continue to see patients on longitudinal basis</li> <li>• Leverage and collaborate with other services at PM</li> <li>• Develop education modules for nursing staff regarding AYA issues</li> <li>• Liaise with community programs and international organizations</li> </ul>	
<i>Symptom management</i>	
Sexual health	<ul style="list-style-type: none"> <li>• Counseling with AYA CNS including advice regarding lubricating gels</li> <li>• Normalizing discussions regarding sexuality</li> <li>• Pelvic health physiotherapist with specialized training in pelvic floor muscle manual therapy</li> </ul>
Fatigue	<ul style="list-style-type: none"> <li>• Fatigue clinic led by a physiatrist who discusses symptom etiology; recommends intervention including exercise, counseling, and pharmacotherapy</li> </ul>
<i>Behavior modification</i>	
Return to work	<ul style="list-style-type: none"> <li>• Occupational therapist who discusses issues with patient and employer and reviews contracts, legal aspects, employee rights, and insurance</li> <li>• AYA CNS facilitates early referral</li> </ul>
Exercise	<ul style="list-style-type: none"> <li>• Counseling with AYA CNS regarding importance of physical activity; referral to community-based programs</li> <li>• Kinesiologist with expertise in oncology</li> <li>• Formal activity assessments and prescriptions for physical activity</li> </ul>
<i>Health services</i>	
Patient education	<ul style="list-style-type: none"> <li>• AYA education materials reviewed for design and readability</li> <li>• Materials distributed online and into AYA-populated clinics</li> <li>• Facilitate development of nursing education modules</li> </ul>
Advanced cancer	<ul style="list-style-type: none"> <li>• Counseling with AYA CNS regarding understanding of disease, prognosis, symptom management, and supportive care</li> <li>• Adolescent medicine physician with expertise in oncology, psychotherapy, and psychopharmacology for additional longitudinal assessments and counseling</li> </ul>
Survivorship	<ul style="list-style-type: none"> <li>• Transdisciplinary team (social work, occupational therapy, physiotherapy, nursing, massage therapy, and physiatry)</li> <li>• Development of disease site-specific care plans</li> <li>• Education and information provided by AYA CNS</li> </ul>

Abbreviations: AYA, adolescent and young adult; CNS, clinical nurse specialist; PM, Princess Margaret Cancer Centre.

## SYMPTOM MANAGEMENT

### *Sexual Health*

#### The problem

Alterations in sexuality and sexual function may be caused by the cancer itself, the treatments,<sup>5</sup> or associated psychological distress,<sup>6</sup> and can occur irrespective of age, sex, and type of cancer.<sup>7</sup> Despite sexuality being an integral part of being human, and the knowledge that AYAs want information and guidance about their sexual health, our impression is that discussions do not routinely occur among HCPs and patients. Barriers to communication regarding sexuality cited by HCPs include lack of time as well as lack of knowledge about and comfort with the topic.<sup>8</sup> Sexuality (including oral contraception, fertility, function, body image, etc) should be routinely discussed openly and as part of routine oncology care with all AYA oncology patients.<sup>9</sup>

#### PM AYA Program strategy

We developed an education strategy to address issues regarding sexuality, including an approach to building HCP knowledge and comfort level with the topic. The AYA CNS offers preliminary counseling regarding body image and sexual dysfunction and, through collaboration

with the PM Survivorship Program, can leverage the expertise of a physiotherapist specialized in pelvic floor muscle (PFM) strategies for women experiencing dyspareunia secondary to treatment-induced premature ovarian failure. Manual or “hands-on” therapy applied directly to the PFM is used to 1) promote relaxation and restore normal tone; 2) increase elasticity of the vaginal opening; and 3) desensitize painful areas in the PFM.<sup>10</sup> To the best of our knowledge, the majority of studies investigating the effectiveness of pelvic floor physiotherapy in the cancer population focus on increasing the strength of the PFM (eg, in the treatment of urinary incontinence)<sup>11</sup> and not in the treatment of sexual pain. There is increasing evidence to support the involvement of pelvic floor physiotherapy principles in the multidisciplinary management of sexual pain,<sup>12</sup> and thus PFM warrants further investigation in the AYA oncology population.

The physiotherapist at the study institution also has worked with experts in patient education (and other clinical experts) to develop several pamphlets to address vaginal stenosis, dryness, and pelvic floor exercises. Kits have been assembled that are available in every clinic as part of Education Stations to facilitate the conversation. The physiotherapist also delivers regular classes concerning

sexuality for patients of all ages. Although these resources are not only for AYAs, this is cited as an important issue for these patients.

## **Fatigue**

### **The problem**

Regardless of age or sex, fatigue is a highly prevalent symptom as a result of cancer and cancer-related treatments.<sup>13,14</sup> As per the National Comprehensive Cancer Network (NCCN), cancer-related fatigue has been described as a “persistent, subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning.”<sup>15</sup> A recent systematic literature review examining AYA patients with cancer demonstrated mixed findings and characterized fatigue as prevalent, often severe, and distressing.<sup>16</sup>

Fatigue can result from multiple etiologies, thereby adding to management challenges.<sup>17</sup> It is often difficult to distinguish whether fatigue is a result of cancer, its treatment, and/or other causes. Symptom clustering can occur when a patient has overlapping issues such as pain, insomnia, depression, and/or dyspnea, all of which can contribute to fatigue. Other factors also can impact the fatigue picture, such as disease stage, infection, hormonal issues (such as with testicular cancer treatment), poor nutrition, and current physical activity levels.

### **PM AYA Program strategy**

The PM AYA Program leverages the expertise of the PM Fatigue Clinic, which is staffed by an interdisciplinary team including rehabilitation medicine (physiatry), occupational therapy, and physiotherapy. The goal of the PM Fatigue Clinic is to educate patients and to facilitate the adoption of behavioral strategies to manage fatigue, including energy conservation and relaxation, changes to lifestyle (including diet and exercise), and obtaining support. The development of each aspect of clinic intervention was guided by the NCCN guidelines and the Edmonton Fatigue Framework and is principally underpinned by a chronic care self-management model based on the research and theory of stress, active coping strategies, self-regulation, and social learning. AYA patients have found this clinic to be useful in validating their symptoms of fatigue and understanding a systematic approach to its treatment.

Although exercise is reported to have at least a moderate effect on reducing cancer-related fatigue, sleep disturbance, and depression,<sup>18,19</sup> a recent systematic review demonstrated mixed findings regarding whether structured exercise programs are beneficial to treat fatigue in AYA patients.<sup>16</sup> Depending on the specific clinical

scenario, we will either suggest and encourage general exercise strategies or refer onward to the exercise program (see below).

Psychosocial interventions also are an important consideration for managing fatigue.<sup>20</sup> Interventions such as cognitive behavioral therapy, counseling, supportive expressive therapy, and educational models have a small to moderate effect on improving feelings of vigor and vitality in adults, and this is comparable to the effect that exercise can have on fatigue.<sup>16</sup> A psychosocial intervention using a self-coping strategy in AYA patients demonstrated no clear benefit with regard to fatigue.<sup>21</sup> We see AYA patients in regular follow-up to reiterate the cognitive behavioral therapy approach.

Pharmacologic strategies for cancer-related fatigue also deserve attention. The current evidence for psychostimulants, including methylphenidate, suggests short-term use and a possible benefit in adults.<sup>22</sup> To the best of our knowledge, the use of psychostimulants for cancer-related fatigue in AYA patients has not yet been explored, but is a reasonable consideration based on our experience.

## **BEHAVIOR MODIFICATION**

### **Return to Work**

#### **The problem**

Navigating the return to work (RTW) after a leave of absence for cancer treatment is a significant challenge for patients. Failure to navigate RTW is an important predictor of long-term quality of life (QOL).<sup>23,24</sup> However, despite the importance of work, to our knowledge, little attention has been paid to developing interventions to support a patients' reentry into the workforce.<sup>23,25</sup> Survivors report a desire and need to reengage in paid employment to address financial needs, affirm a sense of productivity, suggesting a sign of recovery and return to normal life.<sup>23,24,26</sup> Adults survivors are 1.4 times more likely to be unemployed than individuals without health concerns<sup>26</sup> and similarly, fewer AYAs are employed compared with age-matched, healthy peers.<sup>27</sup> AYAs are in the prime of their work lives, and the inability to RTW poses a significant risk of financial losses at the individual, family, and societal levels.

AYAs face additional challenges because younger AYAs are either trying to complete a degree at school or are searching for their first job and older AYAs are usually at a stage in their careers in which they are trying to get promoted and build a reputation that allows them to excel.<sup>28</sup> An extended leave of absence from the workforce can be detrimental to this preliminary phase of one's career trajectory. The greater the number of years one has

been employed, the easier the transition back to work<sup>29</sup>; this poses a challenge to AYAs who may have no to limited work experience preceding their cancer diagnosis. AYAs are more likely to have short-term contract positions, which lack substantial insurance/benefits packages.

### **PM AYA Program strategy**

In all adults, a lack of communication between survivors, HCPs, and employers is cited as one of the most prominent barriers to a successful RTW after treatment of cancer.<sup>30</sup> Conversely, the ability of these parties to work collaboratively to establish workplace accommodations that are in keeping with survivors' abilities has been shown to improve the RTW experience and employment outcomes.<sup>31</sup> Furthermore, although many patients want to wait to RTW or school until all their treatment is finished and they are back to "100%," our own experience has suggested that early RTW on a part-time basis may facilitate the transition to full-time employment/school and should be encouraged. The PM Survivorship Clinic has established a consultancy service with an occupational therapist to promote clear communication among stakeholders involved in the RTW process. This helps patients reenter the workforce or go back to school with supports that empower them to request appropriate accommodation to facilitate reentry. The PM AYA Program collaborates with the Survivorship Program through early recognition of medical and psychosocial factors that may contribute to a delayed RTW and facilitates referrals in this regard.

Employers and school administrators are often very willing to support individuals returning to work or school after cancer treatment; however, patients and HCPs must be able to express their concerns and necessary adjustments, respectively.

### **Exercise**

#### **The problem**

Information regarding exercise is a need commonly identified by AYAs both during and after the completion of cancer therapy.<sup>2</sup> Exercise provides numerous benefits across the cancer continuum, from prevention to survival.<sup>32</sup> For survivors, strong evidence has demonstrated that exercise can improve physical and cognitive function, psychosocial well-being, and overall QOL.<sup>33</sup> A majority of this research has been conducted in survivors of breast, prostate, and colon cancer; however, research is accumulating rapidly across all cancer sites and treatments. Survivorship resources that emphasize routine physical activity (PA) tailored for AYAs are needed given their vulnerabil-

ity to additional cancers, morbidity, and compromised QOL over many years.<sup>34</sup>

AYAs are advised to avoid physical inactivity; however, the recommended doses of moderate-to-vigorous PA differ between groups because survivors aged 15 to 18 years are recommended to achieve 60 minutes per day and those aged  $\geq 19$  years are recommended to achieve 150 minutes per week.<sup>35</sup> Unfortunately, only 35% to 50% of AYAs are meeting these PA guidelines,<sup>36</sup> despite evidence describing their interest, motivation, and self-perceived ability to engage in PA programs.<sup>37</sup> Noted barriers to PA counseling and services in oncology include insufficient resources, expertise in exercise for cancer survivors, and physician support/awareness of benefits.<sup>38</sup> However, cancer rehabilitation programs are becoming more prevalent and position exercise at their foundation.<sup>39</sup> HCP involvement in the delivery of PA services tailored for AYA cancer survivors is essential to ensure program participation and effectiveness for this group.

### **PM AYA Program strategy**

We have established a consultative service with a kinesiologist who has specialized training in oncology. Exercise interventions with AYAs have focused on improving engagement and adherence in age-appropriate ways. For example, exercise and PA counseling are best received by AYAs when it acknowledges and facilitates their independence and autonomy (ie, supportive rather than controlling), employs a respectful and nonjudgmental tone, and focuses on their abilities rather than disabilities.<sup>40</sup> Moreover, AYAs prefer interventions that include social support and incorporate technology for remote access/participation.<sup>41</sup> Early research in exercise with AYA patients has embraced these principles with varying degrees of success.<sup>42-44</sup> When AYAs are seen in consultation by our service, exercise prescriptions are tailored to the clinical context of the patient (ie, type of cancer and treatment, comorbidities, etc), with an emphasis on adapting the program to engage these patients in age-appropriate activity. HCPs should continue to advocate and "prescribe" exercise to AYAs with cancer.

## **HEALTH SERVICES**

### **Health Literacy and Patient Education**

#### **The problem**

Low health literacy is associated with less use of preventative health services,<sup>45</sup> problems completing medical forms, an inability to understand instructions for prescription medications, difficulty comprehending provider instructions,<sup>46</sup> and poorer health status.<sup>47</sup> Low health literacy is

defined as “the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions” (<http://www.nald.ca/library/research/ccl/health/health.pdf> and <http://www.nap.edu/catalog/10883/health-literacy-a-prescription-to-end-confusion>). Many AYAs are likely to have low health literacy because health literacy skills develop during adolescence and young adults have less experience with health care because they are generally healthier than older adults and as such are less exposed to and knowledgeable of the health care system.<sup>48</sup> Consequently, AYAs may need more information and support than their older adult counterparts to help them navigate these complexities.

AYAs have significant information needs and many seek this information online, but to the best of our knowledge most AYA informational needs remain unmet.<sup>49</sup> It is important to ensure that the provision of information is part of cancer care delivery for these individuals. Although this would contribute to better health service delivery and outcomes for AYAs, it is a challenge to accomplish. Some health literacy scholars argue that there should be a separate definition for cancer health literacy because the cancer knowledge and skills required of lay individuals is sufficiently complex to warrant a separate conceptualization.<sup>50,51</sup> Given the complexities of information needs among AYAs and the scarcity of relevant tailored resources, the health care system is challenged to consider how to meet the needs of this underserved population.

### **PM AYA Program strategy**

The study center has established an education strategy for AYA that includes the development of patient education resources tailored to the known and unmet informational needs of AYAs. Each resource undergoes plain language review and adheres to principles of clear design to optimize readability.<sup>52</sup> AYA information packages are distributed in clinics throughout the PM Cancer Centre to ensure that AYAs obtain this information. In addition, the strategy includes the development of an online repository of resources dedicated to AYAs to facilitate access to this information. We have also developed short courses to educate HCPs about the unique needs and issues faced by AYAs.

### **Dealing with Advanced/Metastatic Cancer The problem**

Despite advances in cancer care, between 10% to 40% of AYAs will eventually progress to palliation,<sup>53</sup> yielding to

an increase in overall need. Metastatic disease often necessitates further loss of independence, with near-complete reliance on others physically, financially, and emotionally. Existential issues become more pressing, evoking questions of meaning and concerns related to death. Moreover, AYAs with young families frequently worry about their children’s ability to cope. Rather than reflecting back on life as older adults might, AYAs often have anticipatory grief about a life they will never be able to live. These individuals must have the opportunity to explore their feelings confidentially to minimize their fear of upsetting family or partners.<sup>54</sup>

Advanced disease can remove AYAs from their usual social network, leading to debilitating isolation. Care goals in patients with advanced disease are similar across the age spectrum: provision of expert symptom management, appraisal of spiritual and emotional needs, sensitive communication including advance care planning, and family bereavement care.<sup>55</sup> However, the developmental, psychosocial, and ethical differences in AYAs call for a distinct approach.<sup>54</sup>

### **PM AYA Program strategy**

AYAs value nonjudgmental, compassionate, and honest communication styles in their providers, and their autonomy should continue to be respected when cancer is advanced.<sup>1,56,57</sup> To complement the counseling provided by our AYA CNS, we have added a pediatrician trained in adolescent medicine, psychotherapy, and psychopharmacology to help address the needs of AYA patients with advanced disease. This individual has become an embedded psychosocial care provider within oncology clinics, but also connects with patients separately in person, by telephone, or by E-mail, depending on the preferences of the patient. Our team complements and closely collaborates with the palliative care team, a service that should ideally be introduced soon after diagnosis to avoid potential distress resulting from referral during a crisis.<sup>54,58</sup>

We have found that one of the most important consequences of our AYA Program has been the secondary effect on HCPs. Caring for young individuals with advanced cancer can be highly stressful and emotionally draining and therefore being mindful of countertransference toward AYAs is vital. Providers that are close in age may at times view an AYA patient as a peer, and older staff may respond to AYAs as if they were their own children.<sup>59</sup> Our AYA CNS has become involved in complex cases of young adults dying in the hospital and has acted as an important conduit between the patient, the family, and the palliative care and oncology health care teams. Adequate

supports should be available to help staff recognize responses within themselves and their team to avoid compassion fatigue and staff burnout.<sup>54,60</sup>

## Survivorship

### The problem

The transition from primary cancer treatment to follow-up care presents survivors with significant challenges to restoring and sustaining their health and overall well-being.<sup>61</sup> Cancer treatments can result in side effects that may persist for years after treatment ends and pose a life-long risk of late effects,<sup>62</sup> which can impair physical and psychosocial functioning and overall QOL and be further complicated by comorbidities, genetic risks, and behavioral and lifestyle factors.<sup>34,63</sup>

Regardless of whether it is provided in the community or at an academic center, posttreatment follow-up for AYAs should be risk-based and take a wellness-centered approach that includes surveillance for secondary cancers and the late effects of prior treatment.<sup>64</sup> The goals of follow-up care for AYAs should include education, supported self-management, and psychosocial support and also address pertinent age-specific issues such as body image, sexuality and fertility, and vocation/education<sup>65</sup> and be informed by guidelines issued by the Children's Oncology Group<sup>66</sup> and NCCN.<sup>67</sup>

Although there has been a call to develop effective treatment models to maximize posttreatment care, the reality is that many AYA survivorship issues continue to be relatively neglected and poorly understood.<sup>28,68</sup> Traditionally, follow-up care for AYAs has been provided primarily by oncology specialists. However, intensive oncology specialist follow-up is likely not sustainable and for many patients is unnecessary.<sup>69</sup>

### PM AYA Program strategy

The PM Cancer Rehabilitation and Survivorship Program is built on principles of self-management to support survivors living with late and long-term effects of cancer treatment and provides comprehensive, ongoing care across the age spectrum. Care is provided by a transdisciplinary team (social work, occupational therapy, physiotherapy, nursing, massage therapy, and psychiatry). Patients referred to this program receive a comprehensive assessment and treatment plans are tailored to the needs of patients. Within the specific disease site clinics, integrated survivorship initiatives also have been developed. For example, a tailored survivorship care plan has been established for men with testicular cancer, encouraging HCPs to promote a standardized and comprehensive approach to fertility, sexuality, late effects

of therapy, cancer surveillance, psychosocial well-being, and overall function. In addition, the AYA CNS has been integrated into the disease site clinics and plays an important role in patient education regarding survivorship issues and works collaboratively with the Cancer Rehabilitation and Survivorship team to refer patients for specific interventions.

## Conclusions

The most important aspect of the PM AYA Program is the AYA CNS, who acts as a fulcrum between the primary team, the patient, and other supportive services. Leveraging the services and expertise available within the PM Cancer Centre has been monumental in channeling the bidirectional transfer of knowledge regarding issues specific to AYAs with cancer. It would be difficult for any individual HCP to develop the expertise in all the aforementioned domains, and external or philanthropic funding is often essential to support the teams and infrastructure required for such a comprehensive program. The PM AYA Program remains nascent in development and continued targeted programs and quality improvement initiatives documenting the benefit of these interventions remain the top priority.

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The authors made no disclosures.

## REFERENCES

1. Ferrari A, Thomas D, Franklin AR, et al. Starting an adolescent and young adult program: some success stories and some obstacles to overcome. *J Clin Oncol*. 2010;28:4850-4857.
2. Gupta AA, Edelstein K, Albert-Green A, D'Agostino N. Assessing information and service needs of young adults with cancer at a single institution: the importance of information on cancer diagnosis, fertility preservation, diet, and exercise. *Support Care Cancer*. 2013;21:2477-2484.
3. Tsangaris E, Johnson J, Taylor R, et al. Identifying the supportive care needs of adolescent and young adult survivors of cancer: a qualitative analysis and systematic literature review. *Support Care Cancer*. 2014;22:947-959.
4. Reed D, Block RG, Johnson R. Creating an adolescent and young adult cancer program: lessons learned from pediatric and adult oncology practice bases. *J Natl Compr Canc Netw*. 2014;12:1409-1415.
5. Ofman US, Auchincloss SS. Sexual dysfunction in cancer patients. *Curr Opin Oncol*. 1992;4:605-613.
6. Tierney DK. Sexuality: a quality-of-life issue for cancer survivors. *Semin Oncol Nurs*. 2008;24:71-79.
7. Hordern AJ, Street AF. Constructions of sexuality and intimacy after cancer: patient and health professional perspectives. *Soc Sci Med*. 2007;64:1704-1718.
8. Park ER, Norris RL, Bober SL. Sexual health communication during cancer care: barriers and recommendations. *Cancer J*. 2009;15:74-77.
9. Murphy D, Klosky JL, Termuhlen A, Sawczyn KK, Quinn GP. The need for reproductive and sexual health discussions with adolescent and young adult cancer patients. *Contraception*. 2013;88:215-220.

10. Bergeron S, Lord MJ. The integration of pelvi-perineal re-education and cognitive-behavioural therapy in the multidisciplinary treatment of the sexual pain disorders. *Sex Relation Ther.* 2003;18:135-141.
11. Rutledge TL, Rogers R, Lee SJ, Muller CY. A pilot randomized control trial to evaluate pelvic floor muscle training for urinary incontinence among gynecologic cancer survivors. *Gynecol Oncol.* 2014;132:154-158.
12. Weijmar Schultz W, Basson R, Binik Y, Eschenbach D, Wesselmann U, Van Lankveld J. Women's sexual pain and its management. *J Sex Med.* 2005;2:301-316.
13. Baggott C, Gibson F, Coll B, Kletter R, Zeltzer P, Miaskowski C. Initial evaluation of an electronic symptom diary for adolescents with cancer. *JMIR Res Protoc.* 2012;1:e23.
14. Yeh CH, Wang CH, Chiang YC, Lin L, Chien LC. Assessment of symptoms reported by 10- to 18-year-old cancer patients in Taiwan. *J Pain Symptom Manage.* 2009;38:738-746.
15. Mock V, Atkinson A, Barsevick A, et al; National Comprehensive Cancer Network. NCCN Practice Guidelines for Cancer-Related Fatigue. *Oncology (Williston Park).* 2000;14:151-161.
16. Spathis A, Booth S, Grove S, Hatcher H, Kuhn I, Barclay S. Teenage and young adult cancer-related fatigue is prevalent, distressing, and neglected: it is time to intervene. A systematic literature review and narrative synthesis. *J Adolesc Young Adult Oncol.* 2015;4:3-17.
17. Atay S, Conk Z, Bahar Z. Identifying symptom clusters in paediatric cancer patients using the Memorial Symptom Assessment Scale. *Eur J Cancer Care.* 2012;21:460-468.
18. Cramp F, Byron-Daniel J. Exercise for the management of cancer-related fatigue in adults. *Cochrane Database Syst Rev.* 2012;11:CD006145.
19. Tomlinson D, Diorio C, Beyene J, Sung L. Effect of exercise on cancer-related fatigue: a meta-analysis. *Am J Phys Med Rehabil.* 2014;93:675-686.
20. Kangas M, Bovbjerg DH, Montgomery GH. Cancer-related fatigue: a systematic and meta-analytic review of non-pharmacological therapies for cancer patients. *Psychol Bull.* 2008;134:700-741.
21. Hinds PS, Quargnenti A, Bush AJ, et al. An evaluation of the impact of a self-care coping intervention on psychological and clinical outcomes in adolescents with newly diagnosed cancer. *Eur J Oncol Nurs.* 2000;4:6-17; discussion 18-19.
22. Yennurajalingam S, Bruera E. Review of clinical trials of pharmacologic interventions for cancer-related fatigue: focus on psychostimulants and steroids. *Cancer J.* 2014;20:319-324.
23. Kennedy F, Haslam C, Munir F, Pryce J. Returning to work following cancer: a qualitative exploratory study into the experience of returning to work following cancer. *Eur J Cancer Care.* 2007;16:17-25.
24. de Boer AG, Verbeek JH, Spelten ER, et al. Work ability and return-to-work in cancer patients. *Br J Cancer.* 2008;98:1342-1347.
25. de Boer AG, Taskila TK, Tamminga SJ, Frings-Dresen MH, Feuerstein M, Verbeek JH. Interventions to enhance return-to-work for cancer patients. *Cochrane Database Syst Rev.* 2015;9:CD007569.
26. Boyer LE, Williams M, Callister LC, Marshall ES. Hispanic women's perceptions regarding cervical cancer screening. *J Obstet Gynecol Neonatal Nurs.* 2001;30:240-245.
27. Tai E, Buchanan N, Townsend J, Fairley T, Moore A, Richardson LC. Health status of adolescent and young adult cancer survivors. *Cancer.* 2012;118:4884-4891.
28. Nass SJ, Beaupin LK, Demark-Wahnefried W, et al. Identifying and addressing the needs of adolescents and young adults with cancer: summary of an Institute of Medicine workshop. *Oncologist.* 2015;20:186-195.
29. Mehnert A. Employment and work-related issues in cancer survivors. *Crit Rev Oncol Hematol.* 2011;77:109-130.
30. Bains M, Yarker J, Amir Z, Wynn P, Munir F. Helping cancer survivors return to work: what providers tell us about the challenges in assisting cancer patients with work questions. *J Occup Rehabil.* 2012;22:71-77.
31. Lindbohm ML, Viikari-Juntura E. Cancer survivors' return to work: importance of work accommodations and collaboration between stakeholders. *Occup Environ Med.* 2010;67:578-579.
32. Courneya KS, Friedenreich CM. Physical activity and cancer control. *Semin Oncol Nurs.* 2007;23:242-252.
33. Galvao DA, Newton RU. Review of exercise intervention studies in cancer patients. *J Clin Oncol.* 2005;23:899-909.
34. Quinn GP, Goncalves V, Sehovic I, Bowman ML, Reed DR. Quality of life in adolescent and young adult cancer patients: a systematic review of the literature. *Patient Relat Outcome Meas.* 2015;6:19-51.
35. Schmitz KH, Courneya KS, Matthews C, et al; American College of Sports Medicine. American College of Sports Medicine roundtable on exercise guidelines for cancer survivors. *Med Sci Sports Exerc.* 2010;42:1409-1426.
36. Badr H, Chandra J, Paxton RJ, et al. Health-related quality of life, lifestyle behaviors, and intervention preferences of survivors of childhood cancer. *J Cancer Surviv.* 2013;7:523-534.
37. Belanger LJ, Plotnikoff RC, Clark A, Courneya KS. Physical activity and health-related quality of life in young adult cancer survivors: a Canadian provincial survey. *J Cancer Surviv.* 2011;5:44-53.
38. Santa Mina D, Petrella A, Currie K, et al. Enablers and barriers in cancer exercise program delivery: the Canadian experience. *Curr Oncol.* 2015. In press.
39. Midtgaard J, Hammer NM, Andersen C, Larsen A, Bruun DM, Jarden M. Cancer survivors' experience of exercise-based cancer rehabilitation-a meta-synthesis of qualitative research. *Acta Oncol.* 2015;54:609-617.
40. Wurz AJ, Brunet J. Promoting physical activity in adolescent cancer survivors. *Univ Ottawa J Med.* 2015;5:1-4.
41. Zebrack B, Isaacson S. Psychosocial care of adolescent and young adult patients with cancer and survivors. *J Clin Oncol.* 2012;30:1221-1226.
42. Belanger LJ, Mummery WK, Clark AM, Courneya KS. Effects of targeted print materials on physical activity and quality of life in young adult cancer survivors during and after treatment: an exploratory randomized controlled trial. *J Adolesc Young Adult Oncol.* 2014;3:83-91.
43. Keats MR, Culos-Reed SN. A community-based physical activity program for adolescents with cancer (project TREK): program feasibility and preliminary findings. *J Pediatr Hematol Oncol.* 2008;30:272-280.
44. Rosipal NC, Mingle L, Smith J, Morris GS. Assessment of voluntary exercise behavior and active video gaming among adolescent and young adult patients during hematopoietic stem cell transplantation. *J Pediatr Oncol Nurs.* 2013;30:24-33.
45. Miller DP Jr, Brownlee CD, McCoy TP, Pignone MP. The effect of health literacy on knowledge and receipt of colorectal cancer screening: a survey study. *BMC Fam Pract.* 2007;8:16.
46. Baker DW, Parker RM, Williams MV, et al. The health care experience of patients with low literacy. *Arch Fam Med.* 1996;5:329-334.
47. Health literacy: report of the Council on Scientific Affairs. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association. *JAMA.* 1999;281:552-557.
48. Manganello JA. Health literacy and adolescents: a framework and agenda for future research. *Health Educ Res.* 2008;23:840-847.
49. DeRouen MC, Smith AW, Tao L, et al; AYA HOPE Study Collaborative Group. Cancer-related information needs and cancer's impact on control over life influence health-related quality of life among adolescents and young adults with cancer. *Psychooncology.* 2015;24:1104-1115.
50. Diviani N, Schulz PJ. Association between cancer literacy and cancer-related behaviour: evidence from Ticino, Switzerland. *J Public Health Res.* 2014;3:295.
51. Dumenci L, Matsuyama R, Riddle DL, et al. Measurement of cancer health literacy and identification of patients with limited cancer health literacy. *J Health Commun.* 2014;19(suppl 2):205-224.
52. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med.* 2011;155:97-107.
53. Schrijvers D, Meijnders P. Palliative care in adolescents. *Cancer Treat Rev.* 2007;33:616-621.
54. Wiener L, Weaver MS, Bell CJ, Sansom-Daly UM. Threading the cloak: palliative care education for care providers of adolescents and young adults with cancer. *Clin Oncol Adolesc Young Adults.* 2015;5:1-18.
55. Himelstein BP, Hilden JM, Boldt AM, Weissman D. Pediatric palliative care. *N Engl J Med.* 2004;350:1752-1762.

56. D'Agostino NM, Penney A, Zebrack B. Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer*. 2011;117:2329-2334.
57. Palmer S, Mitchell A, Thompson K, Sexton M. Unmet needs among adolescent cancer patients: a pilot study. *Palliat Support Care*. 2007;5:127-134.
58. Rosenberg AR, Wolfe J. Palliative care for adolescents and young adults with cancer. *Clin Oncol Adoles Young Adults*. 2013;3:41-48.
59. Joint Working Party on Palliative Care for Adolescents and Young Adults. Palliative Care for Young People Aged 13–24. ACT: Bristol. 2007.
60. Palmer S, Thomas DA. Adolescent and young adult cancer program, a best practice framework for working with 15–25 year-old cancer patients treated within the adult health sector. Melbourne, Australia: Peter MacCallum Cancer Centre. 2008.
61. Nathan PC, Hayes-Lattin B, Sisler JJ, Hudson MM. Critical issues in transition and survivorship for adolescents and young adults with cancers. *Cancer*. 2011;117(suppl 10):2335-2341.
62. Oeffinger KC, Tonorezos ES. The cancer is over, now what?: understanding risk, changing outcomes. *Cancer*. 2011;117(suppl 10):2250-2257.
63. Hudson MM, Ness KK, Gurney JG, et al. Clinical ascertainment of health outcomes among adults treated for childhood cancer. *JAMA*. 2013;309:2371-2381.
64. McCabe MS, Bhatia S, Oeffinger KC, et al. American Society of Clinical Oncology statement: achieving high-quality cancer survivorship care. *J Clin Oncol*. 2013;31:631-640.
65. Keegan TH, Lichtensztajn DY, Kato I, et al; AYA HOPE Study Collaborative Group. Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. *J Cancer Surviv*. 2012;6:239-250.
66. Children's Oncology Group; Children's Oncology Group Nursing Discipline Clinical Practice Subcommittee/Survivorship in collaboration with the Late Effects Committee. Establishing and Enhancing Services for Childhood Cancer Survivors: Long-Term Follow-Up Program Resource Guide. Location: Children's Oncology Group (USA); 2007.
67. Coccia PF, Pappo AS, Altman J, et al. Adolescent and young adult oncology, version 2.2014. *J Natl Compr Canc Netw*. 2014;12:21-32; quiz 32.
68. Keegan TH, Tao L, DeRouen MC, et al. Medical care in adolescents and young adult cancer survivors: what are the biggest access-related barriers? *J Cancer Surviv*. 2014;8:282-292.
69. Singer S, Gianinazzi ME, Hohn A, Kuehni CE, Michel G. General practitioner involvement in follow-up of childhood cancer survivors: a systematic review. *Pediatr Blood Cancer*. 2013; 60:1565-1573.