

# Providing Developmentally Appropriate Psychosocial Care to Adolescent and Young Adult Cancer Survivors\*

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To deliver developmentally appropriate psychosocial care, the key developmental tasks facing adolescents and young adults (AYA) need to be taken into consideration. These include establishing autonomy from parents; a personal set of values and identity; strong peer relationships, including intimate and sexual relationships; and obtaining adequate preparation to join the workforce. To minimize the amount of disruption caused by the cancer experience and to maximize the health-related quality of life of AYA patients, young individuals with cancer need opportunities to participate as much as possible in typical AYA activities and to master the developmental tasks of this life stage. Promoting a sense of normalcy is essential. To achieve this, the health care environment must be flexible and recognize the important role of peers. Informational and practical supports also are necessary for AYA to stay on track developmentally in the context of coping with cancer. Critical elements of effective AYA psychosocial services should include access to AYA-specific information and support resources, fertility and sexuality counseling, programs to maximize academic and vocational functioning, and financial support. *Cancer* 2011;117(10 suppl):2329–34. © 2011 American Cancer Society.

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In recent years, there has been growing recognition around the world that adolescent and young adults (AYA) who are diagnosed with and treated for cancer have distinctive psychosocial concerns that set them apart from pediatric and older adult populations.<sup>1–4</sup> In March 2010, the Canadian Task Force on Adolescent and Young Adults with Cancer held a workshop with various stakeholders, including AYA, to discuss priority issues in advancing oncologic care for this age-specific group. The current article focuses on “how” to address the health care needs of AYA patients (age 15–29 years). It includes comments and recommendations from AYA who participated in the workshop and reflects published literature suggesting important features of developmentally appropriate AYA psychosocial care. To deliver developmentally appropriate care, health care professionals caring for this population need to have an appreciation for “emerging adulthood,”<sup>5</sup> a phase in life when AYA are developing their own social and financial responsibilities; autonomy from parents; a personal set of values and identity; strong peer relationships, including intimate and sexual relationships; and obtaining adequate preparation to join the workforce.<sup>5,6</sup> To minimize the amount of disruption caused by the cancer experience and to maximize the health-related quality of life of AYA, young individuals with cancer need opportunities to participate as much as possible in typical AYA activities<sup>3,6–8</sup> and to master the developmental tasks of emergent adulthood. New and emerging resources for AYA focus on *promoting a sense of normalcy*. They emphasize the importance of flexibility in health care

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delivery<sup>6,9,10</sup> and the role and value of peers.<sup>3,11</sup> Informational and practical supports also are necessary for AYA to stay on track developmentally in the context of coping with cancer.<sup>12,13</sup>

### **Creating Flexibility in Health Care Delivery**

Traditionally, AYA with cancer have been cared for either in a pediatric hospital or in adult medical oncology centers. The average pediatric oncology patient is aged 4 or 5 years, whereas the average oncology patient in the adult system is at least aged 60 years.<sup>14</sup> Recognition that neither system is particularly suited to care for AYA with cancer has sparked the creation or reorganization of services and the formation of AYA oncology programs to address the unmet needs of this population. AYA programs are in development in numerous countries, and there is considerable variability in how these programs are structured.<sup>14,15</sup> Some of these AYA oncology programs are comprehensive, free-standing or independent units, such as those of the Teenage Cancer Trust in the United Kingdom. Others are multidisciplinary team-based programs housed either in pediatric or adult oncology hospitals (eg, The University of Texas MD Anderson Cancer Centre in Houston and Boston's Dana-Farber Cancer Institute in the United States; McGill University Hospital in Montreal, Canada; the Oncology Referral Center in Aviano, Italy; Aarhus University Hospital in Aarhus, Denmark; and Radboud University Nijmegen Medical Center in Nijmegen, the Netherlands). In Australia, the onTrac@PeterMac program operates within the Peter MacCallum Cancer Center in Melbourne and has provided dedicated supportive care, but not medical services, to AYA since 2004 by combining adult and pediatric expertise. The 2 most common services offered by the various AYA programs were identified as AYA-specific psychosocial/educational support and fertility services.<sup>14</sup> This is in line with research reporting the importance placed by AYA patients on having access to psychosocial support throughout the cancer journey and having adequate information on the potential impact of the cancer and its treatment on future fertility.<sup>9</sup>

Given the variation in settings in which AYA receive oncology care, from large, comprehensive cancer centers to private, individual physician practices, there is not a single, clear, ideal model of care for these patients. What is crucial is that health care providers working with this population are sensitive and responsive to each patient's level of maturity and independence and use a flexible interaction style and approach.<sup>14</sup> For example, delaying

morning medical rounds to a time when the AYA are more likely to be awake, removing the white coat before entering an AYA patient's room, adjusting treatment dates so that AYA are not missing important social events (eg, milestone birthdays, school dances, graduation ceremonies), and asking AYA directly about their concerns related to their exposures to sex, drugs, and alcohol can enhance health care providers' credibility<sup>6</sup> when dealing with a population for whom questioning authority is typical.

Establishing open communication with AYA is critical and, on a case-by-case basis, must account for the individual's level of cognitive and emotional development.<sup>14</sup> Even up to age 25 years, young adult's cognitive and emotional capabilities still are forming, and their abilities to reason are not quite fully concretized.<sup>16</sup> Thus, what may appear to adult health care providers as irrational judgment or poor decision-making on the part of a young cancer patient, in fact, may be perceived by the AYA as reasonable. Missing a doctor's appointment to attend a friend's party is not necessarily a function of the AYA's lack of understanding about the importance of adhering to therapeutic protocols; instead, their actions may be influenced largely by their feelings and social influences.<sup>17</sup> In their still-forming minds, young individuals may believe they have fully rational or justifiable reasons for their behavior, and their decisions are not solely a function of weighing the relative risks and consequences of their behaviors.<sup>17</sup> Communication that corrects misperceptions and reinforces the importance of adhering to therapy is necessary; a punitive tone, however, most likely will cause a young patient to reject an authority figure's sound advice.<sup>18</sup>

Questioning (but not disrespecting) authority is a normal developmental task at this age.<sup>19</sup> AYA do understand the risks of infection and can and will accept the limitations placed on their social activities, but they prefer that this information be communicated in a manner that is positive, respectful, and nonjudgmental.<sup>8</sup> Indeed, studies indicate that AYA patients express dissatisfaction with staff who deliver information in what is perceived as a cold, aloof, or patronizing manner.<sup>6,8</sup> AYA survivors attending the workshop reported having negative reactions to being told what they "cannot" do rather than what they "can" do. An example they provided was that being told that they *cannot* spend time with friends going to the movies or the mall because of a high risk for exposure to infection would be received negatively unless balanced with concrete instructions about what they *can* do.

AYA participants in the workshop also emphasized the importance of health care providers having a conversation with them about when these restrictions are no longer needed. They want to know when they are no longer at risk and have "permission" to re-engage in physical and social activities.

Research suggests that over-controlling relationships with treating teams have a negative impact on treatment adherence<sup>20</sup> and that having a less restrictive and more balanced communication style actually may increase the likelihood that AYA patients will adhere to treatment protocols. Palmer and colleagues<sup>9</sup> suggest that interacting in an age-appropriate manner with AYA involves 1) providing information directly to the patient, 2) asking them to repeat back information as a way of demonstrating comprehension, 3) allowing time for the processing of information, 4) not assuming that the patient feels confident to ask questions, 5) not assuming that parents' concerns are the same as theirs, and 6) delivering information in a caring manner. Communication skills can be honed through advanced training and experience.

### ***Recognizing the Important Role of Peers***

A salient aspect of AYA autonomy and identity development is the importance placed on peer group acceptance and peer relationships.<sup>21</sup> A cancer diagnosis and its associated treatment impose increased dependency on parents and sets AYA apart from their healthy peers. To minimize developmental disruption caused by cancer and its treatment and to maintain a sense of normalcy, AYA need to sustain a sense of connection to their peers. Opportunities both to participate in typical socialization experiences with healthy peers and to meet other AYA cancer survivors reportedly have been helpful.<sup>8</sup>

The health care environment can support the maintenance of connections with healthy peers by having accessible visiting hours and a welcoming environment that encourages visiting with the hospitalized AYA. Ideally, AYA patients should have a dedicated space where they can spend time with friends and engage in activities typical of daily life outside of the hospital, such as watching television or movies, playing games, listening to music, or just sitting quietly and talking.<sup>14</sup> In addition, attending school or retaining hours at paid work during treatment also will decrease prolonged separations from peers and the loss of friendships.<sup>6</sup>

It has been observed that support received from other AYA survivors is invaluable for this age group in helping them cope with their illness.<sup>22</sup> In 1 study, AYA

survivors reported that the opportunity to meet other survivors of similar age was more important than the support they received from family and friends.<sup>23</sup> AYA support groups that have been developed to date have used several different peer-support formats, including face-to-face weekly meetings, online groups, weekend retreats, conferences, and adventure therapy trips.<sup>11</sup> Peer-support interventions offer opportunities for AYA to connect, share experiences, learn from each other, and feel genuinely understood in an atmosphere that encourages age-appropriate activities.<sup>24</sup> These activities promote the successful achievement of age-related developmental tasks and positive psychosocial growth,<sup>11</sup> and AYA should be offered access to and opportunities to participate in these programs.

### ***Providing Developmentally Appropriate Information About Cancer and Cancer-Related Health Risks***

For many AYA, their cancer diagnosis may be their first experience with a serious illness and interaction with the medical system. Therefore, they view the challenge of negotiating the cancer care system as a harsh introduction into the medical world. Information delivered in an age-appropriate manner is critical in helping AYA learn to cope with their illness and negotiate the health care system. Research indicates that nearly 90% of adults with cancer desire maximal information at each stage of their care from diagnosis to post-treatment survivorship.<sup>25</sup> AYA are no different. They also have a strong desire for comprehensive information to inform decision-making at the time of diagnosis and to fully understand their treatment.<sup>9</sup> In addition, AYA patients highlight the importance of being well informed about the potential impact of their cancer diagnosis and treatment on their future physical and emotional health. AYA participants at the international workshop also wanted guidance and resources to help pass this information on to their parents, siblings, spouses, friends, and their young children if they had any.

Effective methods for delivering information to cancer patients include face-to-face contact with the health care team and patient educational materials, such as booklets, pamphlets, brochures, video tapes, or DVDs, that have been produced specifically for AYA. Now, the Internet also is a prominent source of health information, and younger cancer patients are more likely than older adult patients to use it for information and support.<sup>26</sup> Web resources for AYA are emerging<sup>12</sup> and include

information related to 1) appropriate medical care, 2) medical information, 3) financial assistance, 4) wellness and disease prevention, and 5) psychosocial and quality-of-life issues and advocacy. Providing AYA patients with prescreened lists of recommended and reliable websites will help them sift through the wealth of information available on the Internet and to know that they are accessing information from trustworthy sources.

### ***Providing Resources to Deal With Concerns About Fertility and Sexuality***

AYA perceive information about future fertility as a priority, yet they often are dissatisfied with how this topic is addressed (or not) by health care providers.<sup>9,27</sup> Forming a sexual identity and establishing reproductive capacity are key developmental tasks for AYA. Although a cancer diagnosis may cause a shift in priorities and temporarily decrease the emphasis placed on sexual and reproductive issues, it is important to recognize that interest and concern around sex, fertility, and family planning will resurface once the shock of the diagnosis has lessened. AYA need to be informed about the potential risks of infertility early on so that they can make informed decisions about treatment choices and retain the option to engage in fertility preservation procedures. In conjunction with their physicians, AYA need assistance in balancing the need to think about the future and not compromising the initiation of therapy. Referral to a reproductive specialist for information and counseling should be made available to AYA.<sup>28</sup>

In addition to fertility, open and frank discussions about sexuality, sexual practices, and intimacy are relevant and appropriate areas of psychosocial assessment when working with AYA cancer patients.<sup>6</sup> The cancer experience may disrupt, delay, and complicate the process of psychosexual development,<sup>29</sup> but it does not bring it to a halt. Sexual identities, desires, and practices continue. AYA with cancer need clear and concrete details on the impact cancer treatment may have on their body image, sexual desire, and sexual function, and they need to know that these disruptions most often are temporary.

### ***Providing Resources to Support Academic and Vocational Functioning***

AYA often suffer interruptions and setbacks in their educational or vocational ambitions. Delays in achieving educational, employment, or career goals contribute to increased social isolation and decreased self-esteem.<sup>6</sup> In addition, physical, cognitive, or emotional late effects

associated with cancer treatment may interfere with the ability to reintegrate or perform in academic or work settings. In some instances, AYA will need to redefine their academic and vocational goals, taking into consideration any limitations resulting from their cancer therapy or late effects. Interventions have been developed to help pediatric cancer survivors re-enter the school environment<sup>30</sup> and transition to postsecondary education and/or the workforce.<sup>31</sup> Efforts should be made to create similar support programs for AYA. Specifically, AYA cancer survivors need 1) support and advice to set appropriate education and employment goals, 2) assistance with job searches for the unemployed, and 3) assistance advocating for workplace accommodations. Practical support that promotes re-entry into school or work is essential in sustaining a sense of normalcy and fostering adjustment to the cancer experience by AYA.<sup>8</sup>

### ***Providing Resources to Address Financial Concerns***

AYA are in the early stages of confronting independent financial challenges. Some may still be financially dependent on parents at the time of diagnosis, whereas others may be independent with mortgages, dependents, or debts of their own. For dependent AYA, the economic burden falls on the family as they face out-of-pocket expenses incurred during therapy, including transportation costs associated with traveling for treatment, parking, long-distance telephone calls, meals and accommodations while away from home, childcare for siblings left at home, wigs or prostheses not covered by insurance, medical copayments, and unreimbursed medication expenses.<sup>13</sup> Even in nationalized health care systems, families incur costs and financial obligations beyond what health insurance pays.<sup>32</sup> For financially independent AYA on treatment, in addition to the out-of-pocket expenses mentioned above, they are burdened by loss of income because of inability to work during treatment. Once treatment is over, AYA may continue to experience financial challenges associated with debts incurred during therapy as well as difficulties obtaining or retaining employment, extended health benefits, and life insurance. Although research findings are mixed, there is evidence to suggest that nearly 25% of adult cancer survivors who were aged <35 years at diagnosis had experienced a variety of cancer-related employment problems, including unfair bias and discrimination.<sup>33</sup> A pre-existing cancer history can disqualify survivors from obtaining extended health benefits



and life insurance; or, if approved, the premiums charged may be cost prohibitive.<sup>34</sup>

Attention to financial issues constitutes an important part of caring for AYA, and financial assistance needs to be integrated into survivorship plans for them, because they often need to be able to secure funding for health care expenses, insurance, and possibly disability income assistance. AYA who participated in the workshop also reported the importance of taking into consideration the financial burden associated with making healthy life-style choices. Fresh, nonprocessed foods, especially organic varieties, are expensive, as are vitamins and supplements and gym memberships. Although they recognize the importance of making healthy choices, AYA may not have the financial means to do so. The AYA participants argued that programs should be established to allow cancer survivors to receive discounts on groceries and on exercise programs and equipment.

### Conclusion

The quality of care for AYA with cancer must be based on the availability and accessibility of health care providers who understand the developmental tasks associated with this life stage and who are willing to be flexible in their approach to creating a health care environment that promotes a sense of normalcy.<sup>35</sup> Critical elements of effective AYA psychosocial support services should include access to AYA-specific information and educational resources, fertility and sexuality counseling, programs to maximize academic and vocational functioning, and concrete financial support. Access to age-appropriate resources and support needs to be incorporated into standard care procedures and offered throughout the complete continuum of care that begins at diagnosis and continues through treatment, and subsequent transitions to off-treatment survival or end-of-life care. Ultimately, the goal of supportive care for AYA with cancer is to facilitate their achievement as self-reliant, independent, and productive members of society.

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