

# Promoting Healthy Development Among Survivors of Adolescent Cancer

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Cancer-surviving adolescents face significant health challenges including both physical and psychological late effects as they transition to young adulthood. A cancer diagnosis during adolescence, a time of social independence and increased personal decision making, can cause significant social and emotional struggles that may impair the ability of the adolescent to make health-promoting decisions and avoid risky behaviors such as substance use. This article reports on the little studied experiences of adolescents who have survived cancer with a focus on developing programs and policies that address their health-promotion needs in both community and survivorship clinics.

**Key words:** adolescents, cancer, survivor of cancer, health promotion

**S**URVIVAL RATES for childhood cancer have steadily increased in the United States over the past 20 years. With current treatments, nearly 78% of children diagnosed with cancer are expected to become long-term survivors.<sup>1,2</sup> Currently, there are 270,000 survivors of childhood cancer in United States, and by 2010, it is estimated that 1 in every 250 young adults will be a survivor of cancer.<sup>3</sup> However, rates of survival have remained relatively unchanged for the adolescent and young adult (AYA) population—defined as those diagnosed between 15 to 39 years of age.<sup>4</sup> According to the Institute of Medicine (IOM), nearly one third of childhood cancer diagnoses occur during 15 to 21 years of age.<sup>5</sup> Tumors that occur in this age group differ from other age groups and 15- to 21-year-olds have been shown to have lower

participation rates in clinical cancer trials, indicating the need for study of this population.<sup>6,3</sup> Five-year survival rates for adolescents aged 15 to 21 have increased to 77%, with a 90% survival rate or better for some diagnoses.<sup>3</sup> However, most research has been on younger survivors.<sup>4</sup>

Recently, there has been a growing awareness in the medical community that adolescents who receive a cancer diagnosis may be in need of further research and support. In 2006, the National Cancer Institute and the Lance Armstrong Foundation released a report entitled, *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults With Cancer: Report of the Adolescent and Young Adult Oncology Progress Review Group*, that demonstrated the need for further study and support for adolescents who receive a cancer diagnosis.<sup>4</sup> This report found that while there has been significant resources and multidisciplinary support for pediatric oncology patients, adolescents have been notably understudied and are in need of additional support as they face cancer.<sup>4</sup> Furthermore, this report highlighted the specific needs of the survivors of adolescent cancer for health-promotion interventions and programs that provide them with information

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related to their treatment regimen and healthcare risks.<sup>4</sup> The report reinforced that while survivors of adolescent cancer may face some of the same issues as other adolescents with healthcare conditions, cancer is still a potentially life-threatening diagnosis that poses different challenges than other chronic or disabling conditions.<sup>4</sup>

Because adolescence is a critical developmental period, a cancer diagnosis for individuals in this age group can have significant psychological outcomes that can include depression, anxiety, posttraumatic stress disorder, distorted self-image, poor self-esteem, isolation from peers, developmentally incongruent fears of death, reduced social skills, and a foreshortened sense of future.<sup>2,5,7</sup> Survivors of adolescent cancer are often lost to follow-up by their pediatric clinic due to their growing independence and mobility as they enter adulthood. Consequently, this cohort has been grossly understudied.<sup>2</sup> Two reports released in 2004, *Living Beyond Cancer: Finding a New Balance*, prepared by the President's Cancer Panel, and *Childhood Cancer Survivorship: Improving Care and Quality of Life*, by the IOM, recommend increasing research and programmatic attention on adolescent cancer survivorship, with an emphasis on psychosocial issues.

The purpose of this article is to review the needs of survivors of adolescent cancer and to highlight the importance of designing specific programs to address the unique health-promotion and supportive needs of this population. While literature that addresses survivors of childhood cancer is reviewed, this article focuses on survivors who receive a cancer diagnosis during adolescence. I begin with a discussion of the needs of survivors of adolescent cancer as supported by recent research on this underserved population. I have also discussed the current programming availability for survivors of adolescent cancer and legislative efforts to increase funding for services for all children with cancer and survivors of cancer, and discuss the implications of these policy initiatives on adolescents with cancer.

## SURVIVORS OF ADOLESCENT CANCER

The end of cancer treatment does not indicate the end of the effects of cancer. Survivors diagnosed as adolescents may experience a variety of physical and psychological late effects that can include poor peer relations, difficulty transitioning to adult care, significant physical disability, issues with reduced growth, obesity, and fertility, risks of secondary cancers, developmental delays, learning difficulties, social stigma, depression, anxiety, posttraumatic stress disorder, and difficulty integrating their cancer experience into their current life.<sup>2,5,8</sup> Because there has been little direct study of survivors of cancer diagnosed during adolescence, I begin with a review of the studies of all survivors of childhood cancer.

The National Cancer Institute estimates that survivors of childhood cancer are 5 times as likely as their siblings to experience adverse health events. While half of all survivors of childhood cancer report 1 late effect, nearly 1 in 4 experience serious late effects.<sup>2</sup> In 1993, the National Cancer Institute began funding the Childhood Cancer Survivor Study, a long-term, retrospective cohort study taking place at 27 participating research centers in North America and Canada. Survivors of childhood cancer originally diagnosed between 1970 and 1986 were identified, and more than 14,000 survivors were initially surveyed and followed for long-term health outcomes. The Childhood Cancer Survivor Study has found that survivors of childhood cancer were significantly more likely to report adverse general health, mental health, activity limitations, and functional impairments than their siblings.<sup>9,10</sup> Data indicate that 44% of survivors reported adverse affects in at least 1 health domain.<sup>10</sup> Adverse effects were influenced by being female, being a racial or ethnic minority, having an annual income lower than \$20,000, and not completing high school education.<sup>10</sup> Physical late effects can include damage to kidney, lungs, heart, and other vital organs, increased risks of secondary malignancies, chronic obesity, infertility, learning impairments, speech and hearing

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difficulties, neurocognitive deficits, and mild to severe physical impairment. In addition, these survivors may also be at risk for unknown consequences of new and experimental therapies.

In addition to the aforementioned late effects, adolescents diagnosed with cancer report that their cancer experience removed them from experiencing a "normal" adolescence.<sup>4,8</sup> Treatment protocols force adolescents to have lengthy hospital stays, significant isolation, and physical pain and suffering. This is a particularly difficult set of circumstances for a developmental stage marked by peer relationships, physical and cognitive maturation, and social identity formation. While their peers are experiencing the normal developmental milestones of adolescence, this population is hospitalized or homebound, often under the watchful eyes of parents and physicians and significantly removed from their peer group. Adolescents with cancer describe treatment as disruptive and often emphasize the lack of privacy, constant supervision, and isolation from peers. Ultimately, adolescents battling cancer are unable to experience a "normal" adolescence.<sup>8,11</sup> After the cancer, survivors may yearn to return to the developmental stage they were at upon diagnosis to move through their adolescent experience.<sup>4,8,11</sup>

While 10% to 20% of survivors of adolescent cancer show signs of psychological distress or impairment, recent research suggests that many survivors of cancer also display incredible resiliency and strength in the face of their experience.<sup>4,8-10</sup> A recent study of survivors of AYA cancers reported only moderate negative effect of illness and treatment on social adjustment and educational/vocational status.<sup>12</sup> Karian et al<sup>13</sup> reported themes of optimism, increased feelings for the value of life, and an expansion of consciousness in a qualitative study of survivors of adolescent cancer. Woodgate<sup>8</sup> found that resilience in survivors of adolescent cancer was facilitated by key protective factors such as self-concept, meaning, coping, social support, and external support. Parry and Chesler<sup>14</sup> found that some sur-

vivors of childhood cancer, including those diagnosed during adolescence, may actually be *thriving* in the aftermath of the traumatic experience. Thriving in the population of survivors of childhood and adolescent cancers is positively influenced by meaning making, coping, and psychospiritual growth.<sup>15</sup> Hollen et al<sup>15</sup> found that cancer-surviving adolescents who displayed traits of resiliency (even temperament, high self-esteem, social support, and resistance to social pressure) and good decision making were less likely to engage in risky behaviors. These studies suggest that positive growth and resiliency are also possible outcomes of surviving childhood and adolescent cancers that can serve as a protective function for survivors.

#### HEALTH-PROMOTION NEEDS AND RISKY BEHAVIORS OF SURVIVORS OF ADOLESCENT CANCER

Receiving a cancer diagnosis during adolescence, a developmental stage marked by independence and experimentation, can impede normal developmental tasks. Adolescent survivors report feeling simultaneously mature and delayed socially and developmentally.<sup>16</sup> These delays can cause adolescents who receive a cancer diagnosis to engage in risk behaviors that may impair their health in the future.<sup>17</sup> Survivors of AYA cancers may initiate drug use and sexual experimentation long after their peers have done so. Risky experimentation, physical and psychological late effects, and reduced physical activity and health-promoting behaviors make adolescent survivors vulnerable to ongoing health issues into adulthood.<sup>2,17</sup>

Survivors of adolescent cancer may be at particular risk for substance use and abuse and related problems due to physical and psychological late effects. Physical late effects of childhood cancer can include obesity, growth deficiency, organ damage, physical abnormalities, and risk of secondary cancers.<sup>18</sup> Compounding these physical late effects for survivors are the psychological late effects that

have been previously discussed in this article. Together, physical and psychological effects of cancer may be emotionally challenging enough to increase the risk of substance use and abuse for survivors of childhood cancer.

Risk factors for adolescent substance use and abuse in general include, low commitment to school, peer rejection in early grades, "alienation and rebelliousness," and increased stressors.<sup>19</sup> For adolescents with cancer these factors are almost always present. Studies of adolescents with other chronic health conditions have shown substance use rates similar to or higher than their peers.<sup>20</sup> Health conditions impact adolescent development in a variety of ways: body image and sexual development may be affected, peer relationships are often interrupted, the ability to understand consequences of risky decisions are often impaired, and parents may become overly protective.<sup>20,21</sup> Data from adolescents facing other chronic conditions offer a window into understanding why survivors of adolescent cancer are at risk for substance abuse. For instance, adolescents with cancer who are focused on the diagnosis and treatment of cancer are less engaged in school and may experience social isolation and loneliness. In addition, recent studies of survivors of childhood cancer have found that worry about the effects of the disease is prevalent within this population. Zebrack and Chesler<sup>7</sup> found that worries of survivors of childhood cancer about their health were associated with low self-esteem and poor life outlook. Low self-esteem, peer rejection, and alienation are known risk factors for substance use among teens.<sup>19</sup> A recent study found that the strongest predictors of substance abuse for survivors of childhood cancer were perception of susceptibility to late effects, higher grade in school, and worry.<sup>22</sup> This finding implies that a diagnosis during adolescence may predict a higher likelihood of substance abuse.

Hollen and Hobbie<sup>23</sup> found comparable levels of substance use among survivors of teen cancer and nondiagnosed peers. In fact, the

distribution of initiation of drinking alcohol was similar for teen survivors as it was for peers (10-19 and 11-21 years of age, respectively). Perhaps, the most illuminating and alarming finding was that experimentation for teen survivors occurred at postdiagnosis for 95% of the survivors in the sample.<sup>15</sup> Survivors of adolescent cancer who engage in substance use often compound their risks for late effects of treatment.<sup>22,23</sup> The Children's Oncology Group recently released long-term follow-up guidelines for survivors of childhood and adolescent cancers that state that alcohol use may increase the risk of secondary cancers.<sup>1</sup>

Health-promotion activities are needed for adolescents diagnosed with cancer so that they may increase their knowledge of health risks.<sup>2</sup> Survivors of adolescent cancer should learn to identify psychosocial factors that may put them at risk for substance use and abuse.<sup>2</sup> Studies of AYAs facing chronic conditions such as diabetes and cystic fibrosis have shown that this population is in need of transitional health programs that address the common issues of adolescents such as sexuality, growth and development, substance use, and relationships but with a special emphasis on how illness interacts with adolescence and young adulthood.<sup>24</sup> Adolescents diagnosed with cancer must also face the developmentally incongruent fears of immediate death that accompany with the diagnosis of cancer. Survivors of adolescent cancer also need increased physical activity and exercise and attention to healthy diet and nutrition.<sup>2,25</sup> Cox et al<sup>22</sup> found that substance abuse risk was reduced in survivors of childhood and adolescent cancers by an intervention that included components of counseling on risk, enhancing knowledge of treatment and the disease, promoting realistic expectations of the efficacy of health behaviors, and communicating ways to reduce the risks of late effects. The intervention of risk counseling was effective in leading to an increased desire to change, which then led to changing behavior. Therefore, more programming is needed to assess health-risk behaviors and intervene

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with survivors of adolescent cancer. Studies of adolescents with chronic health conditions have shown a need for understanding and programmatic efforts to reduce risky health behaviors.<sup>21,26,27</sup>

For survivors of adolescent cancer, risky health behaviors can potentially compromise their health more than that of their peers. Even use, not only abuse, of alcohol or other substances puts this population at greater risk physically and psychologically because of late effects of treatment of cancer and the risks of secondary cancers. Efforts at increasing the health-promotion activities of survivors of adolescent cancer are an essential part of mitigating these risks. The growing number of survivors of adolescent cancer and the potential complications they face posttreatment highlight the importance of developing health-promotion programs to meet their unique needs.<sup>2,5</sup>

#### HEALTHCARE AND INFORMATION NEEDS OF SURVIVORS OF ADOLESCENT CANCER

One of the factors that may impair progress in addressing the needs of survivors of AYA cancers is that cancer is often misdiagnosed in this population.<sup>4</sup> Low clinical suspicion combined with low general public awareness makes this population vulnerable to delayed or incorrect diagnoses. In addition, AYAs are not all treated in the same setting: adolescents may be treated by pediatric oncologists, adult oncologists, community healthcare clinics, designated cancer centers, or children's hospitals.<sup>4</sup> These patients are caught in between the worlds of pediatric and adult oncology. Consequently, diagnosis, treatment protocols, data collection, and supportive services are not uniform. Where an adolescent is treated may also influence their treatment protocol and access to information. Control of information and treatment decisions are important to adolescents diagnosed with cancer if they are to transition to independent healthcare decision making.<sup>4,28</sup> For those younger than 18 at the time of diagnosis, they likely

had most of their healthcare decisions made by parents or adult healthcare surrogates. Ideally, the adolescents would have been asked to give assent to their treatment choices but the ultimate responsibility for their treatment information would rest with the adults in their lives.

After cancer, this population of now young adults must suddenly face the adult healthcare and insurance system as they come to an understanding of how cancer treatment affects them physically and psychologically. Numerous studies have pointed to the lack of adequate insurance and healthcare financial support in the AYA population.<sup>4</sup> Progress in the treatment and follow-up of survivors of AYA cancers is hindered by a number of factors that are closely related: significantly low participation in clinical trials; delayed diagnosis due to low provider suspicion of cancer; and the highest uninsured rate of any population in the country.<sup>4</sup> Therefore, the transition to assuming control of their own healthcare is complicated for AYAs as they finish treatment and move toward medical independence.

#### GUIDELINES AND RESEARCH ON HEALTH PROMOTION AND RISK REDUCTION FOR SURVIVORS OF ADOLESCENT CANCER

Since cure rates for childhood and adolescent cancers have only recently reached 78%, specific programming for this unique group of survivors is still beginning. In 2003, the IOM released a report, *Childhood Cancer Survivorship: Improving Care and Quality of Life*, that provided recommendations for meeting the often underserved needs of this vulnerable population.<sup>5</sup> This report made the following 5 recommendations to improve care:

1. Develop evidence-based clinical practice guidelines for the care of survivors of childhood and adolescent cancers.
2. Define a minimum set of standards for systems of comprehensive, multidisciplinary follow-up care that links primary and specialty care.

3. Improve awareness of psychological and physical late effects of cancer and their impact on long-term health of survivors of childhood and adolescent cancers.
4. Improve professional education and training of late effects of cancer.
5. Support the implementation of *Healthy People 2010* goals for children and adolescents with special healthcare needs.

Subsequent to the IOM report, the Children's Oncology Group developed a risk-based set of clinical guidelines, *Long-term Follow-up Guidelines for Survivors of Adolescent and Young Adult Cancers*, that provide recommendations for assessment and management of late effects of AYA cancers.<sup>29</sup> These guidelines are now being used in practice by pediatric oncology survivorship clinics. To bring the guidelines into practice, an interdisciplinary group of pediatric oncology practitioners recently demonstrated their clinical applicability to specific cases of survivors.<sup>30</sup>

Despite recent guidelines, there has been little empirical research on evidence-based practices to improve care for survivors of AYA cancers. One study of an educational health-promotion intervention for adolescent survivors found that this population does display knowledge deficits about their treatment and their health-risk factors.<sup>31</sup> This pilot study supported the feasibility of health-promotion education in long-term follow-up clinics for survivors of adolescent cancer.<sup>31</sup> Subsequent analysis of this multicomponent behavioral intervention showed that knowledge of cancer risks, health perceptions, and health practices of survivors of adolescent cancer can be modified with interventions that focus on education and risk counseling and that this effect may be greater for females.<sup>32</sup> Interventions must be designed that address specific health goals, incorporate differential focus based on gender, and consider optimal timing.<sup>32</sup>

Cox et al<sup>33</sup> found *health-risk* and *health-protective* behaviors to be separate constructs of health for adolescent survivors that may have an inverse relationship. They defined *health-risk behaviors* as smoking, alcohol

use, driving under influence of alcohol, use of smokeless tobacco, and junk food consumption, whereas *health-protective behaviors* as dental hygiene, balanced diet or good nutrition, seatbelt and sunscreen use, sleep, exercise, and breast self-examination and testicular self-examination. Researchers used a multicomponent intervention that comprised standard care plus written and oral guidance for modification of health goals, encouragement of commitment to health goals, and reinforcement at 3 and 6 months to attempt to modify health-risk and health-protective behaviors.<sup>33</sup> For survivors of adolescent cancer in this study, the health behavior intervention affected girls and boys differently: girls reduced smoking more than did boys, whereas boys reduced drinking more than girls.<sup>33</sup> Late effect counseling increased adolescent motivation for health behavior change and perception of risk in both treatment and control groups.<sup>33</sup> However health-protective behaviors, such as sleep, exercise, seatbelt and sunscreen use, were unaffected by the intervention regardless of gender.<sup>33</sup> Overall, the researchers concluded that *health-risk and health-protective* behaviors must be targeted separately; interventions must be tailored for boys and girls differently; studies of the actual clinical encounters are warranted to understand the relationship and communication strategies that affect behavior change; and finally that patient motivation can be affected by intervention.<sup>33</sup>

#### PROMISING PROGRAMS AND POLICIES

Decreasing risk behaviors and promoting health behaviors in survivors of adolescent cancer are the strongest approaches to reducing secondary malignancies and ameliorating the late effects of cancer.<sup>29,33</sup> However, there are few examples of evidence-based practice models to achieve this goal. In a review of the literature of evidence-based interventions for survivors of childhood cancer, Kazak<sup>34</sup> found notable areas of neglect in intervention research, such as a lack of focus of the strength of the child and family; the need for inclusion

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of fathers in family-based research; a lack of interventions designed specifically for cultural relevance and sensitivity to ethnic minority groups; inconsistency in care models across settings; and a lack of intervention research that focuses on the needs of survivors of cancer.

The needs of survivors of adolescent cancer may be addressed in designated cancer centers, by primary care physicians, or in a variety of nonprofit programs designed to address them. Many children's hospitals have developed pediatric oncology survivorship follow-up clinics. In 1983, The Children's Hospital of Philadelphia, under the direction of Dr Anna T. Meadows, started the first program to care for and track survivors of long-term childhood cancer. According to the Association of Cancer Online Resources, there are now 41 active pediatric oncology survivor follow-up clinics in the United States. The following criteria are used to add an institution to the list<sup>35</sup>:

- Has a dedicated time and place for survivor clinic.
- Meets at least twice a month.
- Staffed by a physician with experience in the late effects of childhood cancer.
- Has a nurse coordinator.
- Provides state-of-the-art screening for individual's risks of late effects.
- Provides referrals to specialists.
- Provides wellness education.

However, children and adolescents with cancer are seen in 244 Children's Oncology Group-affiliated children's hospitals in this country, which means there are more than 200 pediatric oncology centers without long-term follow-up clinics. Moreover, when they do exist, they may not have a specific program that incorporates the needs of those survivors who received their diagnosis during adolescence.

Cancer-surviving adolescents may also find support, information, and advocacy in camp-based programs, online groups, or survivorship conferences. A few examples of these programs include *Planet Cancer*, an online community of young survivor of adult cancer founded by a young survivor of adult cancer,

which uses empowerment, support, and humor to help survivors gain control, support, and perspective.<sup>36</sup> Planet Cancer also hosts survivorship retreats that help young adult survivors and their partners deal with the effects of cancer. Another example of retreat-based support for survivors of adolescent cancer is the Young Adult Survivor Conference (YASC)—a 4-day retreat designed to provide education and support for survivors diagnosed as children, adolescents, and young adults.<sup>28</sup> The goals of this program are to address survivorship issues, provide cancer education, and tools for self-advocacy and support. A recent evaluation of the YASC program showed that survivors reported increased knowledge, skills, and support as a result of participating in the YASC program.<sup>28</sup>

Because AYAs face unique and often unrecognized challenges, there has been a growing advocacy movement to meet their needs. In 2006, the National Cancer Institute, in collaboration with the Lance Armstrong Foundation, convened prominent members of the scientific, medical, and advocacy communities to create a national agenda for AYA oncology. The subsequent report entitled, *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults With Cancer*, included 5 overarching recommendations to guide the work of the AYA advocacy community:

1. Identify the characteristics that distinguish the unique cancer burden in patients of AYA cancers.
2. Provide education, training, and communication to improve awareness, prevention, access, and quality cancer care for AYAs.
3. Create the tools to study the AYA cancer problem.
4. Ensure excellence in service delivery across the cancer control continuum.
5. Strengthen and promote advocacy and support for patients of AYA cancers.

As a follow-up to this AYA Progress Review Group, The Lance Armstrong Foundation hosted an inaugural meeting of the Live-STRONG Young Adult Alliance in Austin, Tex,

on November 10-12, 2006. This meeting brought together organizations, advocates, funders, and survivors to strategize about the implementation of the AYA report. The LiveSTRONG Adolescent/Young Adult Alliance is now a coalition of organizations with the goal to improve the survival rates and quality of life for 15- to 40-year-old young adults with cancer. According to the LiveSTRONG Web site, the alliance is committed to promoting research and the investigation of the problem, serving as a voice for the issue and promoting effective solutions.<sup>37</sup>

Advocacy for survivors of adolescent cancer is also occurring in the form of federal legislation. Two bills were recently introduced to 107th Congress that address the needs of survivors of adolescent cancer. The Conquer Childhood Cancer Act of 2006 would "amend the Public Health Service Act to advance medical research and treatments into pediatric cancers, ensure patients and families have access to the current treatments and information regarding pediatric cancers, establish a population-based national childhood cancer database, and promote public awareness of pediatric cancers."<sup>38</sup> The second bill, The Cancer Survivorship Research and Quality of Life Act of 2006<sup>39</sup> would expand and coordinate the activities of the National Institutes of Health and the Centers for Disease Control and Prevention to focus on research and programs on cancer survivorship including childhood and adolescent survivors. Included in this bill are provisions to increase funding, guidance, research, and professional training, and study of model programs. The bill stipulates a special focus on identification of risk and protective factors related to late effects, identification of predictors of neurocognitive and psychosocial outcomes including quality of life, development of intervention studies including those that would promote health be-

haviors, and interventions to improve health utilization and access to long-term follow-up care.

**CONCLUSIONS**

Cancer in adolescents is an important healthcare problem that has received less study in comparison with other childhood cancers. The number of survivors of adolescent cancer is continuing to grow and yet providers and researchers are only beginning to understand what the long-term health promotion needs of this population may be. Programs and policies must be developed that strengthen protective factors, enhance resiliency, and reduce risk for survivors of adolescent cancer. Policy initiatives that fund programs, research, and healthcare financing for survivors of adolescent cancer are critically needed. While there are few empirically based models of health-promotion interventions for this group, there is near unanimous consensus that programs must be developed that will create opportunities for survivors of adolescent cancer to reduce their risk of secondary cancers, deal with the complicated late effects of treatment, appropriately reintegrate into their social groups without risking their health, and enter their early adulthood with an understanding of their treatment and the ability to protect their future health. Health-promotion efforts for cancer-surviving adolescents must include skills building, knowledge of health risks, access to treatment information, psychosocial support by peers and professionals, adequate healthcare financing and insurance, ongoing psychosocial and physical assessments by competent practitioners, appropriate age- and life-stage-based information, coordinated service provision, and empowerment.

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