Needs and Lifestyle Challenges of Adolescents and Young Adults With Cancer: Summary of an Institute of Medicine and Livestrong Foundation Workshop

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**Background:** Among adolescents and young adults (AYAs) in the United States, cancer is the leading cause of disease-related death. AYA survivors face numerous short- and long-term health and psychosocial issues, as well as increased risk for behavioral and lifestyle challenges, including poor diet, low physical activity (PA), and substance abuse. Many of these behaviors are modifiable, but gaps in care serve as barriers for AYA survivors.

**Objectives:** The purpose of this article is to (a) raise awareness of AYAs’ increased risk for poor diet, low PA, and substance abuse; (b) examine previous interventions addressing these issues; and (c) provide recommendations for future directions.

**Methods:** This article summarizes a workshop coordinated by the Institute of Medicine and the Livestrong Foundation to address AYA survivors’ needs and ways to enhance their quality of care.

**Findings:** Oncology nurses can promote the inclusion of lifestyle behaviors in survivorship care plans of AYA patients and serve as a valuable resource in improving AYA care on a larger scale. In addition, oncology nurse researchers may offer greater understanding of AYA patients’ and survivors’ needs and best practices by conducting much-needed research with this understudied population.

Cancer is the leading cause of disease-related death among adolescents and young adults (AYAs) (National Cancer Institute [NCI], 2014). An estimated 70,000 AYAs aged from 15–39 years are diagnosed with cancer annually, which is eight times more than children younger than age 15 years (Zebrack, Mathews-Bradshaw, & Siegel, 2010). AYA survivors face numerous short- and long-term health and psychosocial issues (Oeffinger et al., 2006; Robison et al., 2005). These individuals are also at increased risk for many behavioral and lifestyle challenges, such as low physical activity (PA), poor diet, and substance abuse (Klosky et al., 2012). However, these challenges can be addressed through educational and behavioral interventions.

Unfortunately, a significant gap exists for AYA patients because few cancer treatment and survivorship programs tend to their needs. NCI has recognized this as a health disparity requiring special attention (Zebrack et al., 2010). A key challenge is that AYAs do not fit neatly into either adult or pediatric oncology.
settings. In addition, these patients need, but often do not receive, individualized long-term follow-up care by physicians aware of the numerous late effects for which AYAs are at risk. To address these challenges, the Institute of Medicine (IOM) and Livestrong Foundation coordinated a workshop about the needs of AYA survivors and potential strategies to improve their quality of care (Nass & Patlak, 2013). The current article summarizes key issues discussed in the workshop regarding poor diet, low PA, and substance abuse, which are issues that oncology care nurses are uniquely positioned to address. The article emphasizes AYAs’ increased risk for these negative behaviors, potential contributing factors, previous interventions addressing these issues and lessons learned, and recommendations for future directions.

**Lifestyle Challenges**

**Diet**

Because AYAs with cancer are at increased risk for current and future health problems and premature death, fostering the development of health-promoting behaviors that may ameliorate some of these risks is important (Tai et al., 2012). Specific attention has been focused on weight status, diet, and PA because these behaviors can be directly controlled by survivors, and ample evidence exists in the general population of the benefits of these preventive strategies (Hewitt, Weiner, & Simone, 2003; U.S. Department of Agriculture & U.S. Department of Health and Human Services, 2010). Adolescence and young adulthood are critical periods when lifelong habits are established; these behaviors contribute significantly to physical development and body habitus. These developments subsequently influence body image, self-esteem, and future socialization (Steinberg, 2008).

During normal adolescence, a flood of growth, thyroid, and sex hormones spurs muscle and skeletal development. Bone mass increases in volume and density; the heart and lungs increase in size and capacity (Susman & Rogol, 2004). To achieve optimal physical growth and development, adolescents require adequate nutrition and PA (Sallis & Patrick, 1994; Story, 1992). When cancer occurs in adolescents, the cancer and its treatment can disrupt normal growth and development, as well as heighten nutritional needs (Bechard & Duggan, 2008). Despite increased need for adequate nutrition, estimates suggest that 39%-94% of survivors of early cancers do not meet national recommendations for the intake of several nutrients (Badr, Paxton, Ater, Urbauer, & Demark-Wahnefried, 2011; Cohen et al., 2012; Demark-Wahnefried et al., 2005). A review by Stolley, Restrepo, and Sharp (2010) concluded that young cancer survivors have unhealthy diets, with high fat intakes and low fruit and vegetable intakes. Common deficiencies include calcium, vitamin D, folate, and iron, which are nutrients important for cardiovascular health and bone development (Badr et al., 2011; Cohen et al., 2012; Demark-Wahnefried et al., 2005; Stolley et al., 2010). Demark-Wahnefried et al. (2005) reported that cancer survivors aged younger than 18 years were more likely to meet calcium guidelines and eat five or more daily servings of fruits and vegetables compared to cancer survivors who were in the age group from 19-39 years, suggesting that AYAs may be at particular risk because most are aged 18 years or older.

Although AYAs have suboptimal nutrient intakes, their calorie consumption is often excessive. Research shows that most AYA survivors consume 10% more energy than they expend daily, promoting weight gain and obesity risk (Cohen et al., 2012). Consequently, more than one-third of AYA survivors who are a normal weight before diagnosis become overweight by the end of treatment (Love et al., 2011). As a result, AYAs develop several risk factors for metabolic syndrome, including higher body mass index, enlarged waist circumference, elevated triglycerides, and low-density lipoprotein cholesterol levels. This precipitates downstream health events, such as cardiovascular disease, hypertension, and poor general physical health (Steinberger et al., 2012).

Despite an increased need for dietary interventions among AYA survivors, efforts to address this need have been limited. To date, two studies have been done—one aimed at improving diet quality (n = 251), which produced disappointing results (Cox, McLaughlin, Rai, Steen, & Hudson, 2005; Hudson et al., 2002), and one aimed at increasing calcium consumption (n = 75), which effectively increased calcium supplement use but not dietary calcium intake (Mays, Gerfen, Mosher, Shad, & Tercyak, 2012). Therefore, more research is needed to craft and evaluate interventions that include not only educational and behavioral components, but also take into account setting; timing; familial, social, and environmental contexts; and developmental stage (Gilliam et al., 2012).

**Physical Activity**

Sedentary lifestyle and lack of PA are risk factors for numerous health problems, including diabetes, cardiovascular disease, obesity, hypertension, osteoporosis, and depression (Bauer, Briss, Goodman, & Bowman, 2014; Booth, Roberts, & Laye, 2012; Hamlin & Paterson, 2014). Because AYA cancer survivors are already vulnerable to many of these health problems (Tai et al., 2012), they are highly encouraged to maintain active lifestyles (San Juan, Wolin, & Lucia, 2011; Winter, Müller, Hoffmann, Boos, & Rosenbaum, 2010).

Although not extensively studied, research from clinical cohorts suggests that adult survivors of childhood and AYA cancer report lower levels of PA than their counterparts (Badr et al., 2013; Belanger, Plotnikoff, Clark, & Courneya, 2011; Demark-Wahnefried et al., 2005; Rabin & Politi, 2010). Childhood Cancer Survivor Study data show that 52% of adult childhood cancer survivors (CCSs) report not meeting Centers for Disease Control and Prevention guidelines of 20 minutes of vigorous activity three or more days per week or 30 minutes of moderate activity five or more days per week, and 23% were inactive (Ness et al., 2009). Population-based data from the U.S. Behavioral Risk Factor Surveillance Survey (BRFSS) suggest that 31% of AYA survivors report no leisure-time PA (Tai et al., 2012).

Many clinical issues relevant to cancer treatment create challenges for patients to maintain active lifestyles. For example, treatment regimens during childhood and adolescence may affect lean muscle development so that participation in PA results in increased fatigue, diminished coordination, or injury (Fuemmeler et al., 2013). However, PA has many potential benefits for survivors, such as reduced fatigue, improved mood, greater quality of life, and improved survival (Ballard-Barbash et al., 2012; Courneya, 2003; Holmes, Chen, Feskanich, Kroenke,
& Colditz, 2005; Meyerhardt et al., 2006). These findings may extend to AYA survivors, but lack of data makes such generalization speculative.

Few PA interventions have targeted AYA survivors. Intervention programs requiring participant program attendance at hospitals have been marred by high attrition (Collett, Acosta, Whitsett, McTernan, & Friedman, 2007; Takken et al., 2009). Therefore, interventions planned for AYA survivors should accommodate life changes they are undergoing and offer remote delivery (Rabin, Simpson, Morrow, & Pinto, 2013). For example, a 12-week pilot study showed that AYA survivors randomized to websites that featured a PA intervention (n = 8) versus general information on cancer (n = 10) reported a higher degree of satisfaction and increased self-reported PA (Rabin, Dunsiger, Ness, & Marcus, 2011). Another pilot study used social media (Facebook) to deliver a PA intervention called FITNET aimed at increasing moderate-to-vigorous PA using an intervention and self-help comparison group (Valle, Tate, Mayer, Allicock, & Cai, 2013). Although both groups increased in PA during the intervention period, no relative advantage of FITNET was found. However, results demonstrated the feasibility of social media to recruit, enroll, and disseminate a PA intervention to this population. Because this age cohort is native to digital media, interventions using mobile phone applications for promoting PA and healthy diet may also be appealing (Fuemmeler, Stroo, Clark, Ostbye, & Cox, 2012). Although supervised PA interventions are likely to have a larger effect on changes in PA, distance-based approaches show the greatest promise at reaching this highly mobile and geographically dispersed population (Baumann, Zopf, & Bloch, 2012; Ferrer, Huedo-Medina, Johnson, Ryan, & Pescatello, 2011). Continued efforts are needed to refine and develop distance-based programs for AYA survivors.

Substance Abuse

Data are limited on the prevalence of AYA substance use, with almost no systematic efforts to address substance use in survivorship care. In the general population, substance use trajectories suggest peak tobacco and alcohol use from ages 21–25 years and illicit drug use, although less prevalent, from ages 18–20 years. Studies of substance use prevalence among AYA survivors have focused on CCSs, and have been largely cohort-based studies of patients treated at academic medical centers. Substance abuse is particularly concerning among AYAs because almost all substances with abuse potential interact with cancer and treatment effects (Clarke & Eiser, 2007). For example, alcohol is associated with an increased risk of aerodigestive cancers in adult survivors and may increase the risk of myocardial dysfunction, liver damage, osteoporosis, and breast cancer (World Cancer Research Fund & American Institute for Cancer Research, 2007).

In CCS cohort studies, prevalence of tobacco use ranges from 16%–24% (Emmons et al., 2002; Kuechni et al., 2012). However, studies examining smoking among cancer survivors in the general population (using BRFSS data) found a smoking prevalence of 37% among CCSs; the age-matched prevalence among individuals without cancer was 21% (Phillips-Salimi, Lommel, & Andrykowski, 2012). Rates of alcohol consumption are generally high, with 50%–90% of AYAs reporting at least some alcohol use. The prevalence of drinking in the survivorship cohorts appears to be higher (Klosky et al., 2012) than among CCSs and AYA survivors in the population-based BRFSS (Phillips-Salimi et al., 2012). Prevalence of drug use is difficult to ascertain because of limited data. Among U.S. CCSs, about 12% report use of cannabis (Klosky et al., 2012), compared to about 20% of CCSs younger than age 18 years and 49% of CCSs older than age 18 years in Australia (Bauld, Toubourou, Anderson, Coffey, & Olsson, 2005). Illicit drug use in CCS cohorts in the United States is reported to be less than 1%, compared with 7%–24% among Australian CCSs.

Factors associated with increased substance use among CCSs and AYAs are similar to those in the general population. For tobacco use, factors include having less education and lower income, as well as being Caucasian (Emmons et al., 2002, 2003). For alcohol, factors include being male, as well as having higher self-reported stress levels and lower mental health scores (Froebisher et al., 2008). This may indicate that survivors engage in substance use to cope with life stressors, reflecting a pattern of social determinants in which populations with lower resources and higher demands are more likely to smoke and use other addictive substances (Graham, Inskip, Francis, & Harman, 2006).

Little emphasis has been placed on substance use among CCSs and AYA survivors; almost no intervention research has been conducted outside of tobacco use. Therefore, several key research questions exist that need to be addressed to provide comprehensive health care to future CCSs and AYA survivors, including the following.

• How important are survivor-focused interventions?
• What is the best way to address mental health issues in the context of prevention and treatment?
• What is the best way to address risky health behaviors in CCSs and AYA survivors in the healthcare delivery system?

Once identified, significant efforts are needed to ensure incorporation of these strategies into cancer treatment and follow-up care delivery (de Moor, Pulco, Butterfield, Li, & Emmons, 2007). In addition, an evaluation is needed to explore substance use among survivors who are not part of survivorship cohorts. Data suggest that significant differences may exist in population characteristics between these groups (Phillips-Salimi et al., 2012).

Challenges of Addressing Lifestyle Risks

Addressing lifestyle risks for AYAs presents particular challenges because of distinct developmental issues during this phase of life. Individuals in the AYA period develop socially, emotionally, and cognitively at unique rates, often affected by changing family and social contexts. In addition, neurologic development is not complete until the mid-20s (Casey, Tottenham, Liston, & Durston, 2005), so these young people may not yet have full access to higher order abstract thinking, affect regulation, or impulse control necessary to consistently integrate health behaviors (Wetherell & Tapert, 2013).

Addressing behavior change through clinical interventions among AYAs must be informed by changing medical contexts and AYAs’ current capacities and limitations. This is a transitional period from pediatric to adult health care; responsibility for health care also shifts from being shared with parents to being more independent (Reed-Knight, Blount, & Gilleland,
clinical nurse specialists are critical for managing transitions in care and engaging experts from other disciplines. They can also advocate for the inclusion of lifestyle behaviors in survivorship care plans.

The IOM and Livestrong Foundation workshop summarized reveals that less research has been conducted with AYAs than children or adults. This presents an opportunity for nurse scientists, particularly those in the early stages of building research careers and those with interests in interprofessional research. Nursing has always advocated for holistic approaches in caring for patients, including assessing and counseling on lifestyle behaviors. Discovering effective approaches to use with AYAs requires nurse researchers who integrate knowledge of patients’ developmental stages and age-appropriate educational and behavioral interventions. That often means employing technology and social media. In addition, studies of interventions to reduce obesity, smoking, and sedentary behavior in the general population could be adapted to AYA populations.

The unique developmental issues for patients with cancer aged from 15–39 years present a complex scenario for dealing with lifestyle behaviors. However, oncology nurses can and should initiate discussions regarding these important preventive health issues and provide resources for patients.

Conclusion

Although at high risk for numerous behavioral and lifestyle challenges, the needs of AYA survivors are still unmet. A gap

Implications for Practice

Limited programs that are focused on caring for AYA patients exist nationally, and they are mostly housed at major cancer centers. Therefore, many AYAs may not have access to these programs. Oncology nurses in pediatric and adult settings may find themselves caring for patients who fall outside of typical age ranges during treatment, follow-up, and survivorship. During treatment, lifestyle issues, such as diet, exercise, and substance abuse, may not be considered, but extant research shows these issues should not be ignored. Therefore, oncology nurses have a critical role in providing education and behavior change reinforcement for AYA patients and collaborating with colleagues from other healthcare disciplines to meet patients’ needs.

In the practice setting, oncology nurses spend ongoing and intimate time with patients. Therefore, they are well positioned to listen to patients’ concerns and to educate and support them. Figure 1 shows educational resources developed specifically for AYAs to guide oncology nurses in such discussions. Oncology nurse practitioners specializing in AYA care can also serve as resources for colleagues unfamiliar with AYAs’ needs. Oncology clinical nurse specialists are critical for managing transitions in

American Cancer Society
Article on the unique needs of children and adolescents with cancer

CanTeen
Guidelines, resources, and professional development for health professionals of young people living with cancer
http://bit.ly/1Kcy8x9

Children’s Oncology Group
Long-term follow-up guidelines for AYA survivors
www.survivorshipguidelines.org

Institute of Medicine
Workshop summary on the needs of AYAs with cancer
http://bit.ly/1dDgQ1K

Livestrong Foundation
Information and documentary video on AYAs living with cancer
http://bit.ly/1isdg23z

National Cancer Institute
Research related to AYAs with cancer
www.cancer.gov/cancertopics/aya/research
Resources and information about AYAs with cancer
www.cancer.gov/cancertopics/aya

National Comprehensive Cancer Network
Guidelines for AYA oncology
www.nccn.org/professionals/physician_glsf_guidelines.asp#age

FIGURE 1. Resources for Oncology Nurses Developed for Adolescent and Young Adult (AYA) Patients and Survivors of Cancer
Implications for Practice

- Understand the developmental differences and life priorities that exist for the wide range of ages in the adolescent and young adult (AYA) population and that patients in this grouping may be cared for on pediatric or adult units depending on the treatment regimen.

- Foster health-promoting behaviors by discussing diet, exercise, and substance abuse for all ages of AYA patients, as well as by referring patients to colleagues who specialize in those areas.

- Encourage accessing the programs that are directed to the AYA population because many are online and offer a support community.

is recognized for these patients who do not fully meet the criteria of being either pediatric or adult patients but, instead, somewhere in between. Most cancer and survivorship centers do not have programs specifically designed for AYAs, creating many challenges for these individuals as they transition into survivorship and from childhood to adulthood.

However, many of the lifestyle risks that AYAs face have the potential to be addressed and ameliorated through interventions. Oncology nurses hold a unique and critical position in the delivery of such interventions because they spend more time face-to-face with AYA patients. Oncology nurses may be the key to delivering educational resources and support regarding risk behaviors, such as poor nutrition, low PA, and substance abuse. These healthcare professionals may also be instrumental in coordinating need-based interventions, having greater insight into AYA concerns and communication preferences. In pediatric and adult settings, oncology nurses who care for AYA patients should use all opportunities to provide developmentally appropriate educational resources and support to assist AYAs in promoting lifestyles that emphasize good nutrition, adequate PA, and no substance abuse.

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