



HHS Public Access

Author manuscript

Clin J Oncol Nurs. Author manuscript; available in PMC 2016 March 17.

Published in final edited form as:

Clin J Oncol Nurs. 2015 December ; 19(6): 675–681. doi:10.1188/15.CJON.19-06AP.

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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Abstract

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

No financial relationships relevant to the content of this article have been disclosed by the independent peer reviewers or editorial staff. The views expressed in this article are those of the authors and do not reflect the official policy or position of the Oncology Nursing Society or the Institute of Medicine, its committees, or its convening activities.

survivors' needs and best practices by conducting much-needed research with this understudied population.

Graphical abstract



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Keywords

adolescent; young adult; cancer; survivor; physical activity; substance abuse

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, & Lucía, 2011; Winter, Müller, Hoffman, 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; Bélanger, 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, McTiernan, & 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; Kuehni 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, Toumbourou, 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 (Frobisher 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, Puleo, 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 (Wetherill & 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, 2014). Therefore, defining responsibility for maintaining or changing health behaviors should be explicitly addressed. Younger AYAs can lack motivation for change, being most responsive to immediate gratification and unable to see long-term consequences. For older AYAs, demands of work, partnerships, and parenting may present challenges to achieving personal health goals. However, AYAs have shown interest in gaining skills to enhance healthy behaviors (Rabin et al., 2013). Acquiring such skills can contribute to independence, self-efficacy, and sense of control over their health. Identifying AYAs' personal values and goals and relating these to desirable health behaviors is essential (Naar-King & Suarez, 2010). Sustained behavior change may require periodic re-evaluation of values and goals as AYAs develop and their priorities change.

The AYA period is often a time of high emotional distress. Adjustment disorders are common in the context of many changes (e.g., education, employment, living situation), new responsibilities, and interpersonal demands of this period. The onset of more serious mental health problems, including anxiety, mood, and substance abuse disorders, is significant

(McGorry, Purcell, Goldstone, & Amminger, 2011). AYA survivors have higher rates of suicidal behavior than the general population (Lu et al., 2013) and are at risk for post-traumatic stress symptoms (Kwak et al., 2013). Identification and treatment of mental health problems is essential to addressing healthy lifestyle behaviors because many AYAs report unmet needs for psychosocial services (Zebrack et al., 2013).

Preliminary efforts have been made to develop and validate health-promoting interventions specific to medically ill AYAs (Kuijpers, Groen, Aaronson, & van Harten, 2013). However, these interventions' theoretical underpinnings and optimal delivery methods, timing, and settings remain important areas to explore. Promising interventions capitalize on the social context of AYAs and include peer mentors and technology for education, monitoring, and social connections.

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 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 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.

Acknowledgments

The authors take full responsibility for the content of the article. The study was supported, in part, by grants from the National Cancer Institute (Nos. 5R25CA057711, R21CA155965, and 5R25CA047888). The content of this article has been reviewed by independent peer reviewers to ensure that it is balanced, objective, and free from commercial bias.

The authors gratefully acknowledge the Livestrong Foundation for generously co-sponsoring the Institute of Medicine (IOM) workshop and Critical Mass: The Young Adult Cancer Alliance for supporting the workshop. The activities of the IOM's National Cancer Policy Forum are supported by its sponsoring members, which currently include the Centers for Disease Control and Prevention, the National Cancer Institute, the Association of American Cancer Institutes, the American Association for Cancer Research, the American Cancer Society, the American Society of Clinical Oncology, the American Society for Radiation Oncology, C-Change, the Cancer Support Community, the CEO Roundtable on Cancer, GlaxoSmithKline Oncology, the Livestrong Foundation, the National Comprehensive Cancer Network, Novartis Oncology, the Oncology Nursing Society, and Sanofi Oncology. The authors thank the planning committee members, speakers, and participants for their contributions to the workshop.

References

- Badr H, Chandra J, Paxton RJ, Ater JL, Urbauer D, Cruz CS, Demark-Wahnefried W. Health-related quality of life, lifestyle behaviors, and intervention preferences of survivors of childhood cancer. *Journal of Cancer Survivorship*. 2013; 7:523–534. [PubMed: 23749663]
- Badr H, Paxton RJ, Ater JL, Urbauer D, Demark-Wahnefried W. Health behaviors and weight status of childhood cancer survivors and their parents: Similarities and opportunities for joint interventions. *Journal of the American Dietetic Association*. 2011; 111:1917–1923. [PubMed: 22117669]
- Ballard-Barbash R, Friedenreich CM, Courneya KS, Siddiqi SM, McTiernan A, Alfano CM. Physical activity, biomarkers, and disease outcomes in cancer survivors: A systematic review. *Journal of the National Cancer Institute*. 2012; 104:815–840. [PubMed: 22570317]

- Bauer UE, Briss PA, Goodman RA, Bowman BA. Prevention of chronic disease in the 21st century: Elimination of the leading preventable causes of premature death and disability in the USA. *Lancet*. 2014; 384:45–52. [PubMed: 24996589]
- Bauld C, Toumbourou JW, Anderson V, Coffey C, Olsson CA. Health-risk behaviours among adolescent survivors of childhood cancer. *Pediatric Blood and Cancer*. 2005; 45:706–715. [PubMed: 16007604]
- Baumann FT, Zopf EM, Bloch W. Clinical exercise interventions in prostate cancer patients—A systematic review of randomized controlled trials. *Supportive Care in Cancer*. 2012; 20:221–233. [PubMed: 21989678]
- Bechard, L.; Duggan, C. Cancer treatment. In: Watkins, JB.; Duggan, C.; Walker, WA., editors. *Nutrition in pediatrics: Basic science and clinical applications*. 3rd. Ontario: BC Decker: Hamilton; 2008. p. 607-616.
- Bélangier LJ, Plotnikoff RC, Clark A, Courneya KS. Physical activity and health-related quality of life in young adult cancer survivors: A Canadian provincial survey. *Journal of Cancer Survivorship*. 2011; 5:44–53. [PubMed: 20857227]
- Booth FW, Roberts CK, Laye MJ. Lack of exercise is a major cause of chronic diseases. *Comprehensive Physiology*. 2012; 2:1143–1211. [PubMed: 23798298]
- Casey BJ, Tottenham N, Liston C, Durston S. Imaging the developing brain: What have we learned about cognitive development? *Trends in Cognitive Science*. 2005; 9:104–110.
- Clarke SA, Eiser C. Health behaviours in childhood cancer survivors: A systematic review. *European Journal of Cancer*. 2007; 43:1373–1384. [PubMed: 17459696]
- Cohen J, Wakefield CE, Fleming CA, Gawthorne R, Tapsell LC, Cohn RJ. Dietary intake after treatment in child cancer survivors. *Pediatric Blood and Cancer*. 2012; 58:752–757. [PubMed: 21850679]
- Collett B, Acosta A, Whitsett S, McTiernan A, Friedman D. Exercise intervention for pediatric cancer survivors: Feasibility and preliminary efficacy. *Journal of Clinical Oncology*. 2007; 18(Suppl.): 20013.
- Courneya KS. Exercise in cancer survivors: An overview of research. *Medicine and Science in Sports and Exercise*. 2003; 35:1846–1852. [PubMed: 14600549]
- Cox CL, McLaughlin RA, Rai SN, Steen BD, Hudson MM. Adolescent survivors: A secondary analysis of a clinical trial targeting behavior change. *Pediatric Blood and Cancer*. 2005; 45:144–154. [PubMed: 15770636]
- Demark-Wahnefried W, Werner C, Clipp EC, Guill AB, Bonner M, Jones LW, Rosoff PM. Survivors of childhood cancer and their guardians. *Cancer*. 2005; 103:2171–2180. [PubMed: 15812823]
- de Moor JS, Puleo E, Butterfield RM, Li FP, Emmons KM. Availability of smoking prevention and cessation services for childhood cancer survivors. *Cancer Causes and Control*. 2007; 18:423–430. [PubMed: 17297556]
- Emmons K, Li FP, Whitton J, Mertens AC, Hutchinson R, Diller L, Robison LL. Predictors of smoking initiation and cessation among childhood cancer survivors: A report from the childhood cancer survivor study. *Journal of Clinical Oncology*. 2002; 20:1608–1616. [PubMed: 11896111]
- Emmons KM, Butterfield RM, Puleo E, Park ER, Mertens A, Gritz ER, Li FP. Smoking among participants in the childhood cancer survivors cohort: The Partnership for Health Study. *Journal of Clinical Oncology*. 2003; 21:189–196. [PubMed: 12525509]
- Ferrer RA, Huedo-Medina TB, Johnson BT, Ryan S, Pescatello LS. Exercise interventions for cancer survivors: A meta-analysis of quality of life outcomes. *Annals of Behavioral Medicine*. 2011; 41:32–47. [PubMed: 20931309]
- Frobisher C, Winter DL, Lancashire ER, Reulen RC, Taylor AJ, Eiser C, Hawkins MM. Extent of smoking and age at initiation of smoking among adult survivors of childhood cancer in Britain. *Journal of the National Cancer Institute*. 2008; 100:1068–1081. [PubMed: 18664655]
- Fuemmeler BF, Pendzich MK, Clark K, Lovelady C, Rosoff P, Blatt J, Demark-Wahnefried W. Diet, physical activity, and body composition changes during the first year of treatment for childhood acute leukemia and lymphoma. *Journal of Pediatric Hematology/Oncology*. 2013; 35:437–443. [PubMed: 23211695]

- Fuemmeler, BF.; Stroo, M.; Clark, KA.; Ostbye, T.; Cox, L. Designing a health promoting smartphone app for adolescent cancer survivors: Mila celestial bloom; Paper presented at the 33rd Annual Meeting of the Society for Behavioral Medicine; New Orleans, LA; 2012 Apr.
- Gilliam MB, Madan-Swain A, Whelan K, Tucker DC, Demark-Wahnefried W, Schwebel DC. Social, demographic, and medical influences on physical activity in child and adolescent cancer survivors. *Journal of Pediatric Psychology*. 2012; 37:198–208. [PubMed: 22004885]
- Graham H, Inskip HM, Francis B, Harman J. Pathways of disadvantage and smoking careers: Evidence and policy implications. *Journal of Epidemiology and Community Health*. 2006; 60(Suppl. 2):7–12. [PubMed: 17708005]
- Hamlin M, Paterson A. Sedentary behaviour and chronic disease. *Perspectives in Public Health*. 2014; 134:131–132. [PubMed: 24816416]
- Hewitt, M.; Weiner, SL.; Simone, JV. Childhood cancer survivorship: Improving care and quality of life. Washington, DC: National Academics Press; 2003.
- Holmes MD, Chen WY, Feskanich D, Kroenke CH, Colditz GA. Physical activity and survival after breast cancer diagnosis. *JAMA*. 2005; 293:2479–2486. [PubMed: 15914748]
- Hudson MM, Tyc VL, Srivastava DK, Gattuso J, Quargnenti A, Crom DB, Hinds P. Multi-component behavioral intervention to promote health protective behaviors in childhood cancer survivors: The protect study. *Medical and Pediatric Oncology*. 2002; 39(1):2–1. [PubMed: 12116072]
- Klosky JL, Howell CR, Li Z, Foster RH, Mertens AC, Robison LL, Ness KK. Risky health behavior among adolescents in the childhood cancer survivor study cohort. *Journal of Pediatric Psychology*. 2012; 37:634–646. [PubMed: 22427699]
- Kuehni CE, Rueegg CS, Michel G, Rebholz CE, Strippoli MP, Niggli FK, von der Weid NX. Cohort profile: The Swiss childhood cancer survivor study. *International Journal of Epidemiology*. 2012; 41:1553–1564. [PubMed: 22736394]
- Kuijpers W, Groen WG, Aaronson NK, van Harten WH. A systematic review of web-based interventions for patient empowerment and physical activity in chronic diseases: Relevance for cancer survivors. *Journal of Medical Internet Research*. 2013; 15:e37. [PubMed: 23425685]
- Kwak M, Zebrack BJ, Meeske KA, Embry L, Aguilar C, Block R, Cole S. Prevalence and predictors of post-traumatic stress symptoms in adolescent and young adult cancer survivors: A 1-year follow-up study. *Psycho-Oncology*. 2013; 22:1798–1806. [PubMed: 23135830]
- Love E, Schneiderman JE, Stephens D, Lee S, Barron M, Tsangaris E, Nathan PC. A cross-sectional study of overweight in pediatric survivors of acute lymphoblastic leukemia (ALL). *Pediatric Blood and Cancer*. 2011; 57:1204–1209. [PubMed: 21319284]
- Lu D, Fall K, Sparén P, Ye W, Adami HO, Valdimarsdóttir U, Fang F. Suicide and suicide attempt after a cancer diagnosis among young individuals. *Annals of Oncology*. 2013; 24:3112–3117. [PubMed: 24169626]
- Mays D, Gerfen E, Mosher RB, Shad AT, Tercyak KP. Validation of a milk consumption stage of change algorithm among adolescent survivors of childhood cancer. *Journal of Nutrition Education and Behavior*. 2012; 44:464–468. [PubMed: 22770832]
- McGorry PD, Purcell R, Goldstone S, Amminger GP. Age of onset and timing of treatment for mental and substance use disorders: Implications for preventive intervention strategies and models of care. *Current Opinion in Psychiatry*. 2011; 24:301–306. [PubMed: 21532481]
- Meyerhardt JA, Giovannucci EL, Holmes MD, Chan AT, Chan JA, Colditz GA, Fuchs CS. Physical activity and survival after colorectal cancer diagnosis. *Journal of Clinical Oncology*. 2006; 24:3527–3534. [PubMed: 16822844]
- Naar-King, S.; Suarez, M. Motivational interviewing with adolescents and young adults. New York, NY: Guilford Press; 2010.
- Nass, SJ.; Patlak, M. Identifying and addressing the needs of adolescents and young adults with cancer; Paper presented at the National Cancer Policy Summit; Washington, DC. 2013 Nov.
- National Cancer Institute. A snapshot of adolescent and young adult cancers. 2014. Retrieved from <http://www.cancer.gov/research/progress/snapshots/adolescent-young-adult>
- Ness KK, Leisenring WM, Huang S, Hudson MM, Gurney JG, Whelan K, Oeffinger KC. Predictors of inactive lifestyle among adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Cancer*. 2009; 115:1984–1994. [PubMed: 19224548]

- Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows AT, Robison LL. Chronic health conditions in adult survivors of childhood cancer. *New England Journal of Medicine*. 2006; 355:1572–1582. [PubMed: 17035650]
- Phillips-Salimi CR, Lommel K, Andrykowski MA. Physical and mental health status and health behaviors of childhood cancer survivors: Findings from the 2009 BRFSS survey. *Pediatric Blood and Cancer*. 2012; 58:964–970. [PubMed: 22012636]
- Rabin C, Dunsiger S, Ness KK, Marcus BH. Internet-based physical activity intervention targeting young adult cancer survivors. *Journal of Adolescent and Young Adult Oncology*. 2011; 1:188–194. [PubMed: 23610737]
- Rabin C, Politi M. Need for health behavior interventions for young adult cancer survivors. *American Journal of Health Behavior*. 2010; 34:70–76. [PubMed: 19663754]
- Rabin C, Simpson N, Morrow K, Pinto B. Intervention format and delivery preferences among young adult cancer survivors. *International Journal of Behavioral Medicine*. 2013; 20:304–310. [PubMed: 22328444]
- Reed-Knight B, Blount RL, Gilleland J. The transition of health care responsibility from parents to youth diagnosed with chronic illness: A developmental systems perspective. *Families, Systems and Health*. 2014; 32:219–234.
- Robison LL, Green DM, Hudson M, Meadows AT, Mertens AC, Packer RJ, Zeltzer LK. Long-term outcomes of adult survivors of childhood cancer. *Cancer*. 2005; 104(Suppl.):2557–2564. [PubMed: 16247780]
- Sallis J, Patrick K. Physical activity guidelines for adolescents: Consensus statement. *Pediatric Exercise Science*. 1994; 6:302–314.
- San Juan AF, Wolin K, Lucía A. Physical activity and pediatric cancer survivorship. *Recent Results in Cancer Research*. 2011; 186:319–347. [PubMed: 21113771]
- Steinberg, LD. *Adolescence*. Boston, MA: McGraw-Hill; 2008.
- Steinberger J, Sinaiko AR, Kelly AS, Leisenring WM, Steffen LM, Goodman P, Baker KS. Cardiovascular risk and insulin resistance in childhood cancer survivors. *Journal of Pediatrics*. 2012; 160:494–499. [PubMed: 21920542]
- Stolley MR, Restrepo J, Sharp LK. Diet and physical activity in childhood cancer survivors: A review of the literature. *Annals of Behavioral Medicine*. 2010; 39:232–249. [PubMed: 20559768]
- Story, M. Nutritional requirements during adolescence. In: McAnarney, ER.; Kreipe, RE.; Orr, DP.; Comerci, GD., editors. *Textbook of adolescent medicine*. Philadelphia, PA: Saunders; 1992. p. 75-84.
- Susman, E.; Rogol, A. Puberty and psychological development. In: Lerner, RM.; Steinberg, L., editors. *Handbook of adolescent psychology*. New York, NY: John Wiley and Sons; 2004. p. 15-44.
- 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. [PubMed: 22688896]
- Takken T, van der Torre P, Zwerink M, Hulzebos EH, Bierings M, Helders PJ, van der Net J. Development, feasibility and efficacy of a community-based exercise training program in pediatric cancer survivors. *Psycho-Oncology*. 2009; 18:440–448. [PubMed: 19242926]
- U.S. Department of Agriculture & U.S. Department of Health and Human Services. *Dietary guidelines for Americans 2010*. 2010. Retrieved from <http://health.gov/dietaryguidelines/dga2010/dietaryguidelines2010.pdf>
- Valle CG, Tate DF, Mayer DK, Allicock M, Cai J. A randomized trial of a Facebook-based physical activity intervention for young adult cancer survivors. *Journal of Cancer Survivorship*. 2013; 7:355–368. [PubMed: 23532799]
- Wetherill R, Tapert SF. Adolescent brain development, substance use, and psychotherapeutic change. *Psychology of Addictive Behaviors*. 2013; 27:393–402. [PubMed: 22732057]
- Winter C, Müller C, Hoffmann C, Boos J, Rosenbaum D. Physical activity and childhood cancer. *Pediatric Blood and Cancer*. 2010; 54:501–510. [PubMed: 19743298]
- World Cancer Research Fund & American Institute for Cancer Research. *Food, nutrition, physical activity, and the prevention of cancer: A global perspective*. 2007 Retrieved from http://www.aicr.org/assets/docs/pdf/reports/Second_Expert_Report.pdf.

- Zebrack B, Mathews-Bradshaw B, Siegel S. Quality cancer care for adolescents and young adults: A position statement. *Journal of Clinical Oncology*. 2010; 28:4862–4867. [PubMed: 20855821]
- Zebrack BJ, Block R, Hayes-Lattin B, Embry L, Aguilar C, Meeske KA, Cole S. Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. *Cancer*. 2013; 119:201–214. [PubMed: 22744865]

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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.

American Cancer Society

Article on the unique needs of children and adolescents with cancer
<http://bit.ly/1J9G6p9>

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/1isg23z>

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_gls/f_guidelines.asp#age

FIGURE 1.

Resources for Oncology Nurses Developed for Adolescent and Young Adult (AYA) Patients and Survivors of Cancer