Published in final edited form as:

Semin Oncol Nurs. 2015 August ; 31(3): 251–259. doi:10.1016/j.soncn.2015.05.005.

Models of Cancer Survivorship Care for Adolescents and Young Adults

Karen E. Kinahan, MS, PCNS-BC,

Clinical Nurse Specialist, Robert H. Lurie Comprehensive Cancer Center of Northwestern University, Chicago, IL

Stacy Sanford, PhD, CBSM,

Assistant Professor, Department of Psychiatry and Behavioral Sciences, Department of Medical Social Sciences, Northwestern University Feinberg Medical School and Robert H. Lurie Comprehensive Cancer Center of Northwestern University, Chicago, IL

Karim T. Sadak, MD, MPH, MSE,

Director, Cancer Survivor Program, Division of Pediatric Hematology/Oncology, Department of Pediatrics University of Minnesota Masonic Children's Hospital, Minneapolis, MN

John M. Salsman, PhD,

Research Associate Professor, Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine and Robert H. Lurie Comprehensive Cancer Center of Northwestern University, Chicago, IL

Karina Danner-Koptik, RN, MSN, APN-CPON®, and

Clinical Nurse Specialist, Ann and Robert H. Lurie Children's Hospital of Chicago, Chicago, IL

Aarati Didwania, MD, MSCI

Assistant Professor, Department of Medicine, Northwestern University Feinberg School of Medicine and Robert H. Lurie Comprehensive Cancer Center of Northwestern University, Chicago, IL

Abstract

Objectives—To review the literature on adolescent and young adult (AYA) oncology, discuss survivorship models of care, and focus on the unique needs of AYA patients with transition of care from treatment to survivorship.

Data Sources—Peer-reviewed literature, workshop summaries, clinical practice guidelines.

Conclusion—Advancements have been made for AYAs with regard to identifying risk factors from cancer treatment and the need for ongoing follow-up care. Survivors face several unique care transitions. Several models of survivorship care are available for AYAs.

Implications for Nursing Practice—The responsibilities of survivorship care for AYA patients fall on clinical providers, researchers, the government, advocacy groups as well as the

survivors and families themselves. Nurses must remain cognizant and educated on AYA survivorship issues.

Keywords

Adolescent and young adult; AYA; oncology nursing; cancer survivorship; transition of care

The evolution of adolescent and young adult (AYA) oncology began nearly 15 years ago with the inception of the AYA Committee followed by the Survivor Transition Task Force (STTF) of the newly formed Children's Oncology Group (COG). The AYA Committee was designed to research the obstacles faced by AYA patients in conjunction with the adult cooperative groups in the United States. The STTF was developed to discuss strategies for caring for a growing number of childhood and adolescent cancer patients as they began to age out of the pediatric clinical arena. Exciting progress has been made over the last decade or more, and AYA cancer has become a recognized discipline of oncology.

One challenge AYAs face is the transition from active cancer treatment to surveillance and lifelong survivorship care. Data from the Childhood Cancer Survivor Study (CCSS) examined the cumulative incidence of severe, disabling, life-threatening, or fatal health conditions among adult survivors of childhood cancer compared with sibling controls as they entered their fourth and fifth decades of their life. The results showed that these conditions were greater among survivors compared with siblings (53.6%; 95% CI, 51.5 to 55.6; vs 19.8%; 95% CI, 17.0 to 22.7) by 50 years of age. The results of this study demonstrate the elevated risk of morbidity and mortality among survivors that increases beyond the fourth decade of life, and impacts the need for ongoing clinical surveillance of these adverse health conditions.¹ The transition can be especially difficult for AYAs treated in pediatric settings who then find themselves transitioning to an adult medical setting for ongoing risk-based follow-up care.² For older young adult patients, who started their journey in the adult cancer arena, transitioning from on-therapy to off-therapy and finding their “new normal” as a cancer survivor is also challenging, and they are often not provided the resources they need to establish and maintain risk-based follow-up care. These transitions raise questions about who will provide care for these patients, which providers have the greatest expertise and how to educate patients and providers about the survivor's cancer history, therapies received and potential or actual risk factors for late effects from therapy. More specifically, how do we best accomplish our goal of optimizing survivor-focused, risk-based care, oftentimes in the general medical setting, as the risk of cancer and other comorbid conditions increases with age?³

In July of 2013, LIVESTRONG and The Institute of Medicine (IOM) hosted a workshop, inviting key investigators in AYA cancer including clinicians, health advocates, and AYA cancer survivors to discuss gaps and challenges in AYA care and identify plans for improvement.⁴ Improving AYA survivorship care was one agenda item, with emphasis on developing new models for transition into survivorship, working more closely with Primary Care Providers (PCP) and providing tiered care based on long-term risks and psychosocial needs.⁴ The report from the workshop states that promotion of education, training and communication are underway in an effort to increase the national focus of AYA cancer and

promote resources for patients and providers. Recognizing that provider education is essential, the American Society of Clinical Oncology (ASCO) and AYA partner organizations have developed “Focus Under 40” educational programs for oncology professionals, nurses and nurse practitioners, fellows, Physician Assistants, and PCPs. These programs were designed to increase awareness and enhance the understanding of care issues and challenges associated with the AYA patient population. They are free of charge, offer continuing medical education credits and are available on-line at <http://university.asco.org/focus-under-forty>.⁵

Promotion and distribution of educational and clinical resources like Focus Under Forty and the COG Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers (<http://www.survivorshipguidelines.org>) are paramount in effort to bridge the follow-up and knowledge gaps in AYA cancer survivor care.⁴⁻⁷

Over the last 15 years we have moved from not only identifying common issues of the AYA cancer patient and survivor, to promotion and planning for improvements in transition, survivorship care and patient outcomes. The IOM report previously mentioned provides a comprehensive overview of the needs of this patient population. This manuscript will aim to provide detail on the unique needs AYA patients face with regard to transition from cancer treatment to long-term follow-up care. Additionally, we will discuss models of cancer survivorship programs and an overview of components for a successful AYA survivor program.

Transition of Care

Several unique challenges exist in care transitions faced by AYA cancer survivors. Adolescence and young adulthood, in general, are times of great personal and professional change and this often amplifies the challenges faced by cancer patients when they transition from care focused on treatments aimed at cure to long-term follow-up care that is survivor-focused. This shift in emphasis can not only lead to anxiety from both AYA cancer survivors as well as their parents/caregivers, but it can also provide an opportunity to develop and/or instill life-long health practices that minimize the risk of developing late effects. The following is a review of the current state of knowledge on the challenges faced by AYA cancer survivors related to transitions in their care.

A fundamental challenge in AYA cancer survivorship care is ensuring continued follow-up even when the focus is no longer on curing the oncologic diagnosis as remission has been achieved. Much of the long-term survivorship data available is based on childhood cancer survivors who only overlap with the youngest segment of the AYA population but serve as a valuable resource for understanding and expanding the knowledge of AYA cancer survivorship issues.⁸⁻¹⁰ Several studies of long-term childhood cancer survivors have examined this transition and report low participation rates for AYA-aged survivors in survivor-focused care. The CCSS, a retrospective cohort of survivors (n = 9,434) with a mean age of 26.8 years (range, 18 to 48 years), reported that only 19.2% of survivors had visited a cancer center in the preceding 2 years.¹¹ This is concerning as most survivorship programs are housed within a cancer center. In this same group, less than half (41.9%) had a

cancer-related visit. In another CCSS report where the mean age of survivors was 31.4 years, only 31.5% of survivors indicated receiving care that focused on their prior cancer and 17.8% reported survivor-focused care that included advice and risk reduction or discussion or ordering of screening tests.¹² These findings confirmed the challenge in transitioning survivors from treatment-focused care to long-term follow-up care.

A hope existed that these AYA-aged survivors were receiving survivor-focused care from their PCP as 88% reported receiving some form of medical care.¹² Only 71.4% reported receiving care that included a general physical examination.¹¹ In addition, a cross-sectional survey study of general internists in the US (n = 1,110) found that most providers seem unfamiliar with available guidelines and would prefer to follow patients in collaboration with a cancer center.¹³ This finding was echoed in a similar survey study of family physicians in both the US and Canada.¹⁴ Even in a population of pediatric oncologists, many appeared unfamiliar with long-term follow-up surveillance guidelines.¹⁵ From a programmatic and systems level, a COG study published in 2011 found that not all institutions provided dedicated survivorship care or care plans, or had databases for tracking outcomes.¹⁶ These findings collectively suggested that providers and health care systems might also contribute barriers when transitioning care for AYA to survivor-focused clinical programs. Another potential barrier to transition is employment. It has been shown that adult survivors of childhood cancer are twice as likely as healthy controls to be unemployed.¹⁷ A report from the CCSS showed that adult survivors of childhood cancer are employed in lower skilled jobs than siblings, who were used as a control group. This same study revealed that those survivors with certain treatment history traits are at a higher risk to attain lower skilled jobs and may need vocational assistance throughout adulthood.¹⁸

Many AYA cancer patients receive care through pediatric institutions. Eventually, an age-appropriate setting is desired and survivorship care may be transitioned from pediatric providers to adult-care settings. This transition has been extensively studied in several chronic illnesses of childhood but few studies have examined the facilitators and barriers to the transition of survivorship care for AYA cancer survivors. Much of the findings summarized here are from research on childhood cancer survivors who have aged out of the pediatric setting and must transition to adult providers. As opposed to the survivor who is still a child, an AYA survivor typically is an independent decision-maker and plays an integral role in the decision to transition their survivorship care. Therefore, clinical programs for AYA cancer survivors must acknowledge and address the needs and desires of AYA survivors as they make this transition. Disease prevention and management of AYA cancer survivors depends on the transition to and adherence to stay in the adult health care home. Therefore, as clinicians we must be vigilant in our education of the AYA and steadfast in continuing the transition process, over time, as we care for them.

A study in the UK reported on 112 survivors of childhood cancer with a mean age of 28.2 years. This population preferred oncology-led follow-up versus a model of care that utilized a PCP or nurse-directed tele-medicine encounters.¹⁹ Clinical components of survivorship care were also favored over psychosocial/supportive care options. A similar study of Washington, DC childhood cancer survivors reported that issues related to insurance, clinical team composition, and scheduling appeared to be most important for AYA survivors making

the decision to transition their survivorship care to adult-care settings.²⁰ In this study, 75% of the study population was between the ages of 16 and 24 years. A Delphi study of 20 AYA survivors of childhood cancer showed that they desired information regarding their medical histories, psychosocial support, and social advocacy.²¹ A larger study of 47 AYA survivors of childhood cancer, as well as their parents, was published in 2008 and reported that participants desired comprehensive care, access to resources, and opportunities to know that they were not alone and to network with other adult survivors.²² Lastly, a cohort of Latino AYA survivors of childhood cancer in southern California and their parents were studied by Casillas et al in 2009.²³ Barriers to survivorship care included cancer stigma for both the patient and the nuclear family. This highlighted the importance of the nuclear family in survivorship discussions within this particular population.

Many factors must be considered when developing health care systems for survivors of AYA cancer. The natural transitions in life during adolescence and young adulthood mirror the challenges faced in the transition of survivorship care. By incorporating input from survivors, parents/caregivers and all providers will likely ensure that new clinical programs targeted at this population will be most successful.

Models of Survivorship Care

AYAs are treated in a wide variety of academic and community-based clinics and they are a highly mobile population that can pose significant challenges for maintaining continuity of care. The importance of establishing long-term follow-up care for AYA survivors is paramount, regardless of where they received their initial cancer treatment. AYA survivors have potential for decades more life to live and, over time, a significant number of long-term AYA cancer survivors will suffer from chronic, debilitating medical conditions, such as endocrine disorders, cardiomyopathy, pulmonary fibrosis, and second malignant neoplasms as a result of their cancer and treatment.^{8,24,25} Our current understanding of these outcomes comes from the CCSS, which provides us with extensive outcome data about patients treated under the age of 21.²⁶ Many recommendations are based on our knowledge from this group and may not generalize to older young adults (eg, 30 to 39 years old). Large cohort studies of older young adults are needed to better understand the late and long-term effects of surviving cancer as an AYA, and to develop AYA survivorship programs that are responsive to these needs.

At present, national standards provide important recommendations and suggest resources for both generic and AYA-specific cancer survivorship care. In 2015, the American College of Surgeons Commission on Cancer will require accredited programs to implement treatment summaries and survivorship care plans.²⁷ These standards aim to improve communication, quality, and coordination of care for survivors. As cancer centers across the country strive to meet these new standards, ASCO has developed online resources to help guide program development via the ASCO Cancer Survivorship Compendium (available at <http://www.asco.org/practice-research/asco-cancer-survivorship-compendium>).²⁸ These online resources include a list of eight long-term follow-up care models and acknowledge that multiple factors, such as the patient population and available resources, will dictate which model is most appropriate at any particular institution. Models differ most notably in terms

of where and who is providing the survivorship care. The characteristics and limitations of each model are provided for optimizing the success of the model chosen.

The National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Adolescent and Young Adult (AYA) Oncology address issues specific to the AYA population, recommend interventions unique to this population, educate physicians and nurses regarding the prevalence of cancer in the AYA population, and explain special considerations related to cancer management in AYA patients.²⁹ The NCCN AYA Guidelines cite the larger NCCN Guidelines for Survivorship and provide adapted screening recommendations based on the COG Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers found at <http://www.survivorshipguidelines.org>.⁶ The NCCN AYA Guidelines also highlight three more broad long-term follow-up models for care compared with the eight cited by the ASCO Cancer Survivorship Compendium.²⁸

These models are informed, to varying degrees, by “risk-based” medical care, an essential component of survivorship care for all AYAs. Risk-based care has become a benchmark for quality survivorship care recommended by the IOM.² It is complex and involves a systematic plan of cancer screening, surveillance, and prevention based on the survivor's personal treatment history, comorbid health conditions, family history, and lifestyle behaviors.^{2,30} The model best suited for an individual AYA survivor will depend on variables such as the availability of resources and risk-stratification (eg, actual and potential late effects from therapy; risk for cancer recurrence or second malignant neoplasms).^{2,30,31} See Table 1 for an overview of AYA survivorship models of care.

In the first model, cancer center follow-up, an oncology team, or a specialized survivorship clinic within an oncology setting leads survivorship care.^{3,31} This broad model encompasses multiple models from the ASCO Cancer Survivorship Compendium's list.²⁸ Examples might range from follow-up visits with the primary oncologist to specialty clinics that are specific to disease (eg, breast cancer) or specific to AYA survivors. Each has its advantages and disadvantages. The ASCO Cancer Survivorship Compendium cites potential disadvantages, such as discouraging survivors from establishing a PCP and the time intensive nature of multidisciplinary programs.²⁸ However, a growing number of academic medical institutions around the US are developing multidisciplinary, long-term follow-up survivorship programs. Each program is unique and some of the leaders for these programs include nurses and pediatric oncologists who have experience in building survivorship programs.³⁰ If available, this type of model would be a good option for those survivors with the highest risk for adverse long-term outcomes, such as those treated for central nervous system tumors or hematopoietic stem cell transplant.³

A second survivorship model is follow-up care that occurs exclusively within the scope of primary care and is provided by the patient's PCP, nurse practitioner, or family practice physician. PCPs and nurse practitioners currently play an important role in cancer survivor care. Their comfort and expertise with this growing population of patients will be even more important as the number of medical oncologists decreases in the next decade because of an aging workforce and also an aging population of survivors.^{32,33} This model may be a better

fit for survivors who are assessed to be at lower risk for late effects from therapy.² The disadvantages of this model were alluded to earlier, including some providers' low comfort level with independently providing survivorship care and assuring the appropriate and up-to-date knowledge about late effects and survivorship is maintained over time.¹³

The third model, a “shared-care” model, captures the patient's need for regular engagement with a team of providers, both oncologist and PCP. When patients are on therapy or recently off therapy, they will have close contact with their team of oncology providers. However, when patients have completed therapy and the frequency of follow-up visits lapse, patients can become what is termed “lost in transition.”³⁴ Thus, a cancer survivorship model that includes care from both a PCP and an oncologist throughout the cancer journey can reduce the potential for patients becoming lost in transition. Important components of this model include ongoing points of communication between providers during the cancer patient's treatment phase and off-treatment phase (see Fig. 1) so that both providers stay informed about medical or psychological issues the patient is having, and ensuring that the patient stays in contact with both physicians.^{2,30} One potential disadvantage is the extensive resources necessary to establish and maintain this model. However, the feasibility of this model has been tested successfully in a pilot study of adult survivors of childhood cancers.³⁵

Several factors about the coordination of care, how it is implemented, and attitudes of providers have been investigated. In 2009, the NCI and American Cancer Society sponsored the Survey of Physician Attitudes Regarding the Care of Cancer Survivors (SPARCCS).³⁶ This survey represents 2,202 practicing US physicians regarding survivorship care, and it was designed to examine and compare the attitudes, knowledge, roles, and usual practices of PCPs and oncologists regarding different components of follow-up care for survivors of breast and colon cancer. Results from the study show that there are significant differences in PCPs' and oncologists' thoughts and behaviors with regard to the care of cancer survivors. For example, PCPs and oncologists disagreed regarding the “ideal” model of care for cancer survivors. Most oncologists favored an oncologist-led model, while nearly half of PCPs favored a shared-care model or one led by the PCPs.³⁶ Future studies are needed to assess the efficacy of various models of care for AYA survivors. Ultimately, the goal of care for AYA cancer patients and survivors must be consistent with the specific needs of this population of patients and should include education and guidance with fertility, sexuality, contraception, self-management, and psychosocial/emotional risk factors. It must also provide guidance from providers on how to maintain effective access to insurance and health care for the remainder of their lives.⁴

Conclusion and Future Direction

The current state of knowledge in AYA oncology survivorship has been described above. This relatively new, but now well-known and appreciated population of cancer survivors has made their voices heard, and national momentum is building on the accomplishments of the last 15 years. AYA cancer survivors have a life-long risk of developing adverse, treatment-related complications.³⁷ As survivors, they have long and fulfilling lives to live. Survivors of AYA cancer face several unique care transitions, but recognition of these by all providers and the subsequent communication that is necessary can ensure that all the transition needs

of the AYA survivor are met in a smooth and comprehensive manner. The responsibilities of this care falls on clinical providers, researchers, the government, and advocacy groups, as well as the survivors and families themselves.³⁷ Specialized AYA-focused training programs must be developed and disseminated to all clinical providers, including medical oncologists, pediatric oncologists, PCPs and nurses, as well as clinical researchers from all disciplines. Such training programs must be implemented in the graduate medical education of physicians, nurses, and any clinical provider in training.³⁸ Additional research studying the feasibility and efficacy of various survivorship models is needed, not only for AYA survivors but for all cancer survivors.

References

1. Armstrong GT, Kawashima T, Leisenring W, et al. Aging and risk of severe, disabling, life-threatening, and fatal events in the childhood cancer survivor study. *J Clin Oncol*. 2014; 32:1218–1227. [PubMed: 24638000]
2. McCabe MS, Partridge AH, Grunfeld E, Hudson MM. Risk-Based health care, the cancer survivor, the oncologist, and the primary care physician. *Semin Oncol*. 2013; 40:804–812. [PubMed: 24331199]
3. Nathan PC, Hayes-Lattin B, Sisler JJ, Hudson MM. Critical issues in transition and survivorship for adolescents and young adults with cancers. *Cancer*. 2011; 117(Suppl 10):2335–2341. [PubMed: 21523755]
4. Nass, SJ., Patlak, M., National Cancer Policy Forum (US), Livestrong Foundation, Institute of Medicine (US). Identifying and addressing the needs of adolescents and young adults with cancer: workshop summary: a Livestrong and Institute of Medicine workshop. Washington, D.C: National Academies Press; 2013. Board on Health Care Services. Available at: http://www.nap.edu/openbook.php?record_id=18547&page=R1 [Accessed November 10, 2014]
5. ASCO University. [Accessed February 10, 2015] Focus under forty. 2014. Available at: <http://university.asco.org/focus-under-forty>
6. Landier W, Bhatia S, Eshelman DA, et al. Development of risk-based guidelines for pediatric cancer survivors: the Children's Oncology Group Long-Term Follow-Up Guidelines from the Children's Oncology Group Late Effects Committee and Nursing Discipline. *J Clin Oncol*. 2004; 22:4979–4990. [PubMed: 15576413]
7. Freyer DR, Kibrick-Lazear R. In sickness and in health: transition of cancer-related care for older adolescents and young adults. *Cancer*. 2006; 107(Suppl 7):1702–1709. [PubMed: 16921480]
8. Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med*. 2006; 355:1572–1582. [PubMed: 17035650]
9. Oeffinger KC, Tonorezos ES. The cancer is over, now what?: Understanding risk, changing outcomes. *Cancer*. 2011; 117(Suppl 10):2250–2257. [PubMed: 21523742]
10. Tonorezos ES, Oeffinger KC. Survivorship after childhood, adolescent, and young adult cancer. *Cancer J*. 2008; 14:388–395. [PubMed: 19060603]
11. Oeffinger KC, Mertens AC, Hudson MM, et al. Health care of young adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Ann Fam Med*. 2004; 2:61–70. [PubMed: 15053285]
12. Nathan PC, Greenberg ML, Ness KK, et al. Medical care in long-term survivors of childhood cancer: a report from the childhood cancer survivor study. *J Clin Oncol*. 2008; 26:4401–4409. [PubMed: 18802152]
13. Suh E, Daugherty CK, Wroblewski K, et al. General internists' preferences and knowledge about the care of adult survivors of childhood cancer: a cross-sectional survey. *Ann Intern Med*. 2014; 160:11–17. [PubMed: 24573662]
14. Nathan PC, Daugherty CK, Wroblewski KE, et al. Family physician preferences and knowledge gaps regarding the care of adolescent and young adult survivors of childhood cancer. *J Cancer Surviv*. 2013; 7:275–282. [PubMed: 23471729]

15. Henderson TO, Hlubocky FJ, Wroblewski KE, Diller L, Daugherty CK. Physician preferences and knowledge gaps regarding the care of childhood cancer survivors: a mailed survey of pediatric oncologists. *J Clin Oncol*. 2010; 28:878–883. [PubMed: 20038717]
16. Eshelman-Kent D, Kinahan KE, Hobbie W, et al. Cancer survivorship practices, services, and delivery: a report from the Children's Oncology Group (COG) nursing discipline, adolescent/young adult, and late effects committees. *J Cancer Surviv*. 2011; 5:345–357. [PubMed: 21894490]
17. de Boer AG, Verbeek JH, van Dijk FJ. Adult survivors of childhood cancer and unemployment: a metaanalysis. *Cancer*. 2006; 107:1–11. [PubMed: 16718655]
18. Kirchhoff AC, Krull KR, Ness KK, et al. Occupational outcomes of adult childhood cancer survivors: a report from the childhood cancer survivor study. *Cancer*. 2011; 117:3033–3044. [PubMed: 21246530]
19. Michel G, Greenfield DM, Absolom K, et al. Follow-up care after childhood cancer: survivors' expectations and preferences for care. *Eur J Cancer*. 2009; 45:1616–1623. [PubMed: 19328676]
20. Sadak KT, Dinofia A, Reaman G. Patient-perceived facilitators in the transition of care for young adult survivors of childhood cancer. *Pediatr Blood Cancer*. 2013; 60:1365–1368. [PubMed: 23441065]
21. Zebrack BJ, Eshelman DA, Hudson MM, et al. Health care for childhood cancer survivors: insights and perspectives from a Delphi panel of young adult survivors of childhood cancer. *Cancer*. 2004; 100:843–850. [PubMed: 14770443]
22. Kinahan KE, Sharp LK, Arntson P, Galvin K, Grill L, Didwania A. Adult survivors of childhood cancer and their parents: experiences with survivorship and long-term follow-up. *J Pediatr Hematol Oncol*. 2008; 30:651–658. [PubMed: 18776756]
23. Casillas J, Kahn KL, Doose M, et al. Transitioning childhood cancer survivors to adult-centered healthcare: insights from parents, adolescent, and young adult survivors. *Psychooncology*. 2010; 19:982–990. [PubMed: 20017115]
24. Metayer C, Lynch CF, Clarke EA, et al. Second cancers among long-term survivors of Hodgkin's disease diagnosed in childhood and adolescence. *J Clin Oncol*. 2000; 18:2435–2443. [PubMed: 10856104]
25. Hudson MM, Ness KK, Gurney JG, et al. Clinical ascertainment of health outcomes among adults treated for childhood cancer. *JAMA*. 2013; 309:2371–2381. [PubMed: 23757085]
26. Robison LL. The Childhood Cancer Survivor Study: a resource for research of long-term outcomes among adult survivors of childhood cancer. *Minn Med*. 2005; 88:45–49.
27. American College of Surgeons Commission on Cancer. [Accessed November 10, 2014] Cancer program standards 2012. V 1.2.1: Ensuring patientcenteredcare. 2012. Available at: <http://www.facs.org/cancer/coc/cocprogramstandards2012.pdf>
28. American Society of Clinical Oncology. [Accessed November 10, 2014] ASCO cancer survivorship compendium. 2014. Available at: <http://www.asco.org/practice-research/asco-cancer-survivorship-compendium>
29. Coccia PF, Pappo AS, Altman J, et al. Adolescent and young adult oncology. Version 2.2014. *J Natl Comp Cancer Netw*. 2014; 12:21–32. quiz 32.
30. Oeffinger KC, McCabe MS. Models for delivering survivorship care. *J Clin Oncol*. 2006; 24:5117–5124. [PubMed: 17093273]
31. Friedman DL, Freyer DR, Levitt GA. Models of care for survivors of childhood cancer. *Pediatr Blood Cancer*. 2006; 46:159–168. [PubMed: 16369920]
32. Shapiro CL, McCabe MS, Syrjala KL, et al. The LIVESTRONG Survivorship Center of Excellence Network. *J Cancer surviv*. 2009; 3:4–11. [PubMed: 19169829]
33. American Society of Clinical Oncology. [Accessed November 1, 2013] ASCO releases original research in the areas of oncology workforce, geographic treatment patterns. 2013. Available at: <http://am.asco.org/asco-releases-original-research-areas-oncology-workforce-geographic-treatment-patterns>
34. Hewitt, ME., Greenfield, S., Stovall, E., National Cancer Policy Board (US). From cancer patient to cancer survivor: lost in transition. Washington, D.C: The National Academies Press; 2006. Committee on Cancer Survivorship: improving care and quality of life. http://www.nap.edu/openbook.php?record_id=11468 [Accessed November 10, 2014]

35. Blaauwbroek R, Tuinier W, Meyboom-de Jong B, Kamps WA, Postma A. Shared care by paediatric oncologists and family doctors for long-term follow-up of adult childhood cancer survivors: a pilot study. *Lancet Oncol.* 2008; 9:232–238. [PubMed: 18282804]
36. Potosky AL, Han PK, Rowland J, et al. Differences between primary care physicians' and oncologists' knowledge, attitudes and practices regarding the care of cancer survivors. *J Gen Intern Med.* 2011; 26:1403–1410. [PubMed: 21785923]
37. Robison LL, Hudson MM. Survivors of childhood and adolescent cancer: life-long risks and responsibilities. *Nat Rev Cancer.* 2014; 14:61–70. [PubMed: 24304873]
38. Hayes-Lattin B, Mathews-Bradshaw B, Siegel S. Adolescent and young adult oncology training for health professionals: a position statement. *J Clin Oncol.* 2010; 28:4858–4861. [PubMed: 20823410]

Figure 1. A risk-stratified shared care model for cancer survivors assigns follow-up services based on the risk of long-term and late effects, cancer recurrence, and second primaries. Roles and responsibilities of the oncologist and PCP are defined across the survivorship spectrum, from diagnosis to long-term follow-up. Such an approach optimizes the provision of health care resources by identifying services and specialty provider by need. (From McCabe, MD, Partridge, AH, Grunfeld, E. et al. Risk-based health care, the cancer survivor, the oncologist, and the primary care physician. Reprinted from Semin Oncol 2013; 40:804-812, with permission from Elsevier.²⁾)

Table 1
Models for AYA Survivorship Care

Model Type	Features	Advantages	Disadvantages
Cancer center care	Oncology team or a specialized survivorship clinic within an oncology setting leads care	Multidisciplinary specialists can meet needs of high-risk AYA survivors	May discourage AYA survivor from developing relationship with PCP
Primary care provider (PCP)	General and cancer survivor-focused care provided by internist, family practice, or nurse practitioner	Convenience for AYA survivor, most appropriate for patients at low risk for late effects from therapy	PCPs lack knowledge and expertise of cancer treatment effects and risk of late effects from therapy
Shared-care	Care led by a team of providers, including PCP, oncologist, and oncology nurse practitioner	Access to general medical care and cancer survivor-focused risk-based follow-up care; potential for communication between providers	Potential cost and extensive resources