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REVIEW ARTICLE

Transition of Care for Young Adult Survivors of Childhood and Adolescent Cancer: Rationale and Approaches

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ABSTRACT

Purpose
Young adult survivors of childhood and adolescent cancer are an ever-growing population of patients, many of whom remain at lifelong risk for potentially serious complications of their cancer therapy. Yet research shows that many of these older survivors have deficient health-related knowledge and are not engaging in recommended health promotion and screening practices that could improve their long-term outcomes. The purpose of this review is to address these disparities by discussing how formal transition of care from pediatric to adult-focused survivorship services may help meet the unique medical, developmental, and psychosocial challenges of these young adults.

Design
Literature review and discussion.

Results
This article summarizes current research documenting the medical needs of young adult survivors, their suboptimal compliance with recommended follow-up, and the rationale, essential functions, current models, and innovative approaches for transition of follow-up care.

Conclusion
Systematic health care transition constitutes the standard of care for young adult survivors of childhood cancer. In developing a transitional care program, it is necessary to consider the scope of services to be provided, available resources, and other local exigencies that help determine the optimal model for use. Additional research is needed to improve health services delivery to this population. Effective advocacy is needed, particularly in the United States, to ensure the availability of uninterrupted health insurance coverage for survivorship services in young adulthood.

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INTRODUCTION

Over the course of the past several decades, the incidence of childhood cancer has increased while its mortality has decreased, and dramatic improvement in survival has been documented in almost every type of malignancy.[1] Combined long-term survival in childhood cancer has increased to approximately 80%, which has resulted in there being more than 270,000 survivors, accounting for approximately 1 in 640 adults up to 40 years of age in the United States today.[1,2] As new patients continue to be diagnosed with childhood cancer and survival continues to improve, these numbers will undoubtedly increase.

It has been recognized for some time that many childhood cancer survivors are affected by persisting and clinically significant complications of their disease and/or treatment. Commonly referred to as late effects, these problems encompass adverse outcomes of both a physical and psychosocial nature. However, only during the past two decades or so, as young survivors have emerged from childhood in substantial numbers and made their way into their 20s and beyond, have the full scope, evolving picture, and pressing impact of their health-related needs become clear. It is now widely acknowledged that being a childhood cancer survivor has both short- and long-range implications that necessitate continuance of medical monitoring and other specific forms of support beyond the pediatric age range across the span of life. When formalized, this process of moving the survivor from child-oriented to adult-focused providers is designated health care transition.

Unfortunately, the implementation of health care transition for older adolescent and young adult survivors of childhood cancer has proven to be as complex and challenging as its case is compelling. Even so, gains are being made as awareness, clinical experience, and some research are increasing in this arena. The rationale, challenges, and emerging models for transition of care in this population are the subject of this review.

LIFELONG FOLLOW-UP: A MIXED PICTURE

Recent studies from the Childhood Cancer Survivor Study (CCSS) indicate that adult survivors of childhood cancer are at increased risk for death, compromised health status, and the development of chronic health conditions. The CCSS is a retrospectively ascertained cohort study of more than 14,000 long-term survivors who were younger than 21 years when diagnosed with cancer between 1970 and 1986 at one of 27 participating centers in the United States and Canada.[3,4] Along with more than 3,000 of their participating siblings, this cohort has been well-characterized and is the subject of a plethora of outcomes studies conducted by the CCSS. In a study of mortality published by Mertens et al,[5] the cumulative all-cause mortality for 5-year survivors was found to be 18.1% at 30 years postdiagnosis, whereas the excess risk of death (overall standardized mortality ratio) compared with the general population in the United States was 8.4. Although recurrence of the original malignancy remained the most common cause of death throughout the study period, after approximately 10 years, death due to late-onset complications (eg, second malignancies and cardiopulmonary disease) emerged as important. By 20 years, the death rate due to second malignancy exceeded that due to all other causes.[5] Health status of young adult survivors was the subject of a recent CCSS report by Hudson et al.[6] In that study, which involved a survey administered to survivors and a randomly selected group of sibling controls, the relative risk among survivors for adverse general health, mental health concerns, functional impairment, and activity limitations was calculated to be 2.5, 1.8, 5.2, and 2.7, respectively. Problems with persisting cancer-related pain and anxiety were reported by 10.2% and 13.2% of survivors, respectively.[6] Finally, the incidence and types of chronic health conditions among adult survivors of childhood cancer were the subject of a recent CCSS study published by Oeffinger et al.[7] Conditions identified in that study included such entities as joint disease, congestive heart failure and coronary artery disease, second malignancies, cognitive dysfunction, stroke, hearing loss, and others. This study found that, for any chronic health condition, the cumulative incidence among survivors at 25 years postcancer diagnosis was 66.8% (33.1% for at least one condition graded by investigators as severe or life-threatening). Importantly, the cumulative incidence for both was noted to increase over time without reaching an apparent plateau.[7] The chronic health conditions identified in that study largely represent what are called late effects of therapy, defined by the Institute of Medicine as any chronic or late-occurring outcome, physical or psychosocial, that persists or develops beyond 5 years from the cancer diagnosis.[2] The late effects of childhood cancer treatment have been the subject of many recent reviews.[8-14]

Because of their risk for late effects, impaired health status, and premature death, the recommendation has been made for childhood cancer survivors to undergo systematic, lifelong medical monitoring and management.[2,15] Unfortunately, the proportion of childhood cancer survivors who participate in appropriate medical follow-up decreases substantially over time after completion of treatment. In another CCSS survey of adult survivors, fewer than half reported having any cancer-related outpatient follow-up during the previous 2 years, whereas fewer than one third reported follow-up at their cancer center.[16] A similar CCSS study found that only 31.5% of adult survivors had received survivor-focused care and 17.8% had received specific advice on risk reduction or screening tests during the previous 2 years.[17] A significant minority of adult survivors at increased risk for breast cancer or cardiac complications were found to have undergone recommended screening tests.[17,18] If survivors are not engaged in appropriate medical follow-up, a missed opportunity exists for early detection, prevention, risk modification, and optimal management of late effects, as well as for longitudinal research in this patient population.

In seeking to engage survivors in long-term follow-up, several considerations that relate to their maturational status may be relevant. During adolescence, these include the normal shifts toward increasing personal autonomy, capacity for self-awareness, ability to comprehend complex and abstract information, and evolving personal relationships, social roles, identities and responsibilities.[19] A growing body of neuropsychological and functional imaging research suggests that the neurodevelopmental aspects of maturation, once thought to occur decisively in the late teens, may not be completed in many individuals until years later and involves a complex interaction of brain, behavior, and social context.[20-22] From a societal perspective, the emerging adult survivor is typically undergoing changes in educational status, place of residence, employment, marital status, health care provider, and health insurance coverage. Because all of these considerations may have an impact on the survivor's inclination and ability to obtain appropriate follow-up, they imply the need for a transition from child-centered to adult-focused health care services in which they are comprehensively addressed.

What form that transition takes is critically important. The CCSS study cited previously[16] suggests that, historically, transition has amounted to little more than chronologic aging of the survivor and is accompanied by severe attrition in follow-up. This so-called transition by default is unplanned, involves little or no communication among providers, provides suboptimal surveillance and reactive medical care, and results in a high proportion of survivors becoming lost to follow-up. In contrast, transition by design is systematic and offers the possibilities of more effective communication, risk-adapted monitoring, early detection and intervention, preventative strategies, less attrition, and the ability to study long-term outcomes.

HEALTH CARE TRANSITION FOR YOUNG ADULT SURVIVORS OF CHILDHOOD CANCER

General Considerations

A reasonable definition of health care transition, adapted from the classic formulation by Blum et al,[23] is the movement of older adolescents and young adults from a child-centered to an adult-focused health care provider and environment. At this point in history, health care transition is no new concept. Having been the subject of two National Institutes of Health–sponsored conferences in 1984 and 1989[24]; a position paper in 1996 by the American Academy of Pediatrics on children with special health care needs[25]; a joint policy statement in 2002 by the American Academy of Pediatrics, American Academy of Family Physicians, and the American Society of Internal Medicine[26]; and representative articles from pediatric subspecialties,[27-30] health care transition has become the standard of care for patients living with chronic medical conditions originating in childhood. In fact, the goal articulated in the joint academies statement is to have comprehensive, community-based service systems in place for youth with special health care needs in the United States by the year 2010.[26]

Health care transition is also the standard of care for childhood cancer survivors. Childhood cancer survivorship is, by extension, a form of special health care need due to the risk for late effects and the correlative recommendation for lifelong medical surveillance. Representative articles published from the 1990s to the present have articulated the need for transitional care for childhood cancer survivors.[31-34] In 2002, the Children's Oncology Group (COG) established the Survivorship Transition Task Force as a component of its Adolescent/Young Adult (AYA) Committee. In 2006, the International AYA Working Group was convened under the auspices of the International Society of Pediatric Oncology, which published its summary with recommendations for transitional care research and policy priorities in 2008.[35]

Part of the rationale for health care transition is based on the major differences between adult-focused versus child-centered care. Adult care relies more consistently on patient initiative and has the potential to be more collaborative and empowering rather than predominantly nurturing and prescriptive. Medical decision making for young adults is appropriately the domain of the patient rather than the parent/family. Health care professionals for adults have medical and psychosocial expertise in that age group rather than children. Consequently, the fundamental goal of health care transition is to provide care that continues to be both medically and developmentally appropriate for the maturing survivor.

To date, relatively little research has been published concerning required elements of successful health care transition. Using focus-group methodology, Reiss and Gibson[36] found that transitions judged to be successful by parents of grown children with special health care needs had the characteristics of a future orientation that was held by the patient, family, and provider; transition planning that began well ahead of the actual event; personal and medical independence of the child that was encouraged and cultivated over time; a specific transition plan that was mapped out, including identification of the adult provider in advance; and no interruption of reimbursement for services occurred as the patient reached adult age.

Considerations Specific to Childhood Cancer Survivors

Drawn largely from clinical experience and supported by some research, the key transitional care concerns and services that need to be provided for young adult survivors consist of (1) detection and management of late effects, (2) assessment and support of psychosocial functioning, (3) provision of health-related education, and (4) assistance with identifying and meeting financial challenges.[37]

Detection and management of late effects. Given the increased risk of young adult survivors for the development of clinically significant late effects, effective transitional care must continue recommended life-long surveillance for late effects and their management. The specific risk for an individual developing certain late effects is primarily a function of treatment received (eg, alkylator chemotherapy, irradiation) and age at treatment (with younger age generally conferring a greater risk because of the anatomic and physiologic immaturity of the host). Other factors influencing risk for certain outcomes include sex, genetic predisposition, comorbid conditions, and lifestyle. Table 1 provides an overview of some major late effects of childhood cancer treatment, their major causes, and monitoring approaches.

Assessment and support of psychosocial functioning. Fortunately, most studies of emotional and behavioral health have shown excellent outcomes and little evidence of maladjustment in the majority of childhood cancer survivors.[38,39] In fact, it is not uncommon for survivors to display a remarkable degree of resilience and post-traumatic growth after their encounter with cancer.[40,41] Approximately 25% of survivors demonstrate difficulties, including neurocognitive deficits (especially in subjects treated with cranial irradiation and/or intrathecal chemotherapy), academic problems, interpersonal difficulties, low self-esteem, anxiety, and features of depression or post-traumatic stress.[39] Post-transition survivors need access to mental health specialists capable of addressing these issues.

Provision of health-related education. Important knowledge deficits exist among adult survivors of childhood cancer concerning their disease, past therapy, and risk for late effects. One study from the CCSS found that 72% of participating young adult survivors accurately recalled their cancer diagnosis; 30% of doxorubicin recipients recalled receiving the drug; and only 35% reported any awareness of their health risks.[42] Health behaviors also are less than optimal among this group. Studies by the CCSS have documented suboptimal use of cancer screening practices among survivors[17,18,43] and continued use of tobacco products at a rate comparable to that of their siblings.[44]

Assistance with identifying and meeting financial challenges. Challenges related to health insurance and employment among young adult survivors are characteristic of both their age group and their medical condition. Data from the US General Accounting Office indicate that young adults age 18 to 34 years are the most uninsured segment of the American population.[45] According to the Commonwealth Fund, young adults account for 13 million (27.7%) of the 47 million Americans who are currently without health insurance.[46] A CCSS study found a persisting, significantly lower proportion of young adult survivors having health insurance compared with their siblings, with approximately one third reporting problems obtaining insurance beginning at approximately 18 years of age.[47] In the United States, this insurance deficit stems from the phenomenon of young adults "aging out" of the coverage they received as child dependents on a parental policy, through Medicaid, or via the State Children's Health Insurance Program (S-CHIP), all of which generally terminate at 21 years of age (or at 26 years of age for most full-time college students covered by a parental policy).[45,48] Beyond that age, obtaining and maintaining health insurance requires employment with an insurance benefit, purchasing expensive insurance directly through a high-risk pool, or qualifying for public assistance by having a significant disability or low income. Consequently, few options or incentives exist for the many relatively healthy survivors who want to work but are not employed with benefits. To help them understand and navigate their way through this complex maze, young adult survivors need the expertise of knowledgeable social workers. Without insurance, survivors are generally unable to gain access to the survivorship care they need. Part of preparing adolescents for health care transition includes teaching them about the interplay of formal education, career/vocational planning, employment, health insurance, and obtaining health care as an adult survivor. In the United States, where health insurance is

Table 1. Overview of Selected Late Effects Observed in Young Adult Survivors of Childhood Cancer

Organ System	Late Effect	Major Treatment-Related Factor(s)	Periodic Evaluation/Screening
Eyes	Cataracts	Corticosteroids, RT	Regular eye examination
Ears	Hearing loss, tinnitus	Cisplatin, RT	Audiologic evaluation
Oral	Dental caries, dysgenesis	RT, alkylators (at young age)	Regular dental examination
	Dry mouth	RT	
Cardiovascular	Cardiomyopathy	Anthracyclines, RT	Serial echocardiography
	Coronary artery disease	RT	Clinical history
	Carotid artery narrowing	RT	Carotid artery ultrasound
Lungs	Pulmonary fibrosis, restrictive or obstructive lung disease	Bleomycin, busulfan, lomustine, carmustine, RT	Chest x-ray, pulmonary function testing
Urinary tract	Reduced GFR	Cisplatin, RT	Serum creatinine
	Tubular dysfunction	Cisplatin, ifosfamide	Serum electrolytes, Mg, Phos
	Hemorrhagic cystitis, bladder fibrosis	Cyclophosphamide, ifosfamide, RT	Urinalysis
Musculoskeletal	Osteopenia/osteoporosis	Corticosteroids, methotrexate	Bone density measurement
	Osteonecrosis (AVN)	Corticosteroids	Clinical examination, MRI
	Altered bone growth	RT	Clinical examination
Neurologic	Neurocognitive delay	Methotrexate, cytarabine, RT	Neuropsychological testing
	Leukoencephalopathy	Methotrexate, cytarabine, RT	Neurologic examination, MRI
	Peripheral neuropathy	Vincristine, vinblastine	Neurologic examination
Endocrine	Hypothyroidism	RT	TSH, free T4
	Growth hormone deficiency	RT	Serial height
	Gonadal failure	RT, alkylators	Testosterone, estradiol, FSH, LH
Reproductive	Infertility	Alkylators, RT	Clinical history, specialty assessment
Secondary neoplasm	Melanoma, breast carcinoma, thyroid carcinoma, sarcoma, bowel cancer, brain tumor	RT	Site-specific surveillance (eg, clinical examination, mammography or MRI, or colonoscopy)
	Acute myeloid leukemia/myelodysplastic syndrome	Etoposide, anthracyclines, RT	CBC
Psychosocial	Post-traumatic stress syndrome, interpersonal difficulties, special educational needs, career and vocational challenges, insurance deficits	The cancer experience; functional disabilities arising from specific late effects	Clinical history, psychological evaluation, social work assessment

NOTE. This represents a general summary of selected late effects, major treatment-related determinants, and monitoring approaches. Comprehensive information about this subject can be obtained in several sources[8-14] and in the Children's Oncology Group Long-Term Follow-up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers.[55]

Abbreviation: RT, radiation therapy; GFR, glomerular filtration rate; Mg, magnesium; Phos, phosphorous; AVN, avascular necrosis; MRI magnetic resonance imaging; TSH, thyroid stimulating hormone; FSH, follicle-stimulating hormone; LH, leuteinizing hormone.

predominantly employer-based, unemployment exacerbates the insurance problem. A recent CCSS study found that there was a persisting, significantly higher rate of unemployment among young adult survivors than their siblings, the risk for which was highest among survivors of brain tumors or cranial irradiation.[49]

Current Practices in Transitional Care

Surveys of pediatric oncologists provide insight into current transitional care practices. In the United States, Oeffinger et al[50] queried 219 member institutions of the Pediatric Oncology Group and Children's Cancer Group and reported in 1998 that 44% claimed some mechanism for following up with young adult survivors. Of those, 93% exclusively involved a pediatric oncologist, 13% included a medical oncologist, and 8% included an adult-oriented primary care provider. In the United Kingdom, Taylor et al[51] surveyed 22 institutions and found that 52% of pediatric oncologists reported following up with their patients for life, whereas 45% discharge at least some for continued follow-up, usually with a general practitioner. In France, Tabone et al[52] conducted a survey of 40 pediatric oncologists in 28 centers. Most reported following up with their patients until 20 to 25 years of age and that subsequent follow-up is performed by general practitioners, medical oncologists, or other medical specialists in roughly equal proportions. In a Canadian study,[53] 71% of adult survivors of childhood cancer and 73% of controls had at least one encounter with a general practitioner in the previous year. Use of specialists was higher among survivors, though usually this was not an oncologist. Finally, a survey recently conducted within the COG by its Nursing Discipline and AYA and Late Effects Committees will provide an updated and more detailed description of young adult survivor services and transitional care practices among its member institutions.

Models of Transitional Care

The pediatric oncology literature contains numerous descriptions of follow-up programs encompassing young adult survivors. In general, these may be categorized under the headings of the cancer center–based model, community-based model, or hybrid model.[37] The cancer center–based model is generally located at the pediatric treatment center or within its larger governing institution (eg, university or health system). In this model, transitional care is delivered within the same system as treatment was given and involves direct, on-site collaboration of the pediatric oncology team and adult care providers. The community-based model is located in the office or clinic of the care provider, typically a primary care clinician. This model requires a coordinated transition of care that includes transfer of all pertinent clinical information and follow-up responsibility from the treatment center to the adult provider. With the hybrid model, care is also transferred to the office or clinic of the primary care provider but relies on an ongoing interaction with the cancer treatment center that includes bidirectional updates on patient status, assistance with clinical management, and provision of current survivorship care guidelines. All three of these models offer potential advantages and disadvantages, which are outlined in Table 2.

The Process of Health Care Transition

Personnel involved in health care transition vary slightly according to the model used (Table 2). For all three models, the pretransition phase relies on the pediatric long-term follow-up team (typically a pediatric oncologist, an advanced practice nurse, and a medical social worker). In the post-transition phase, the cancer center-based model involves an on-site clinical interaction between one or more representatives of the pediatric team and the managing adult-focused team led by a physician from family medicine, internal medicine, medicine–pediatrics, or perhaps medical oncology. In both the community-based and hybrid models, post-transitional care is provided exclusively by the adult-focused primary care provider, but in the hybrid model, that provider is part of a dynamic, supportive relationship with the pediatric long-term follow-up center.

In all three models, the actual transition of care ordinarily takes place when the survivor reaches approximately 18 to 25 years of age and demonstrates transition readiness (ie, a satisfactory level of health-related knowledge and skills to enable successful follow-up in the adult setting). A formal transitional visit occurs, representing the final interaction solely with the pediatric team. After that visit, a detailed clinical summary is prepared outlining the cancer diagnosis and treatment history, current physical findings and results of diagnostic studies, a complete list of current health issues and potential late effects, and a risk-adapted monitoring and management plan. That clinical summary is provided to the survivor and the receiving post-transitional care provider to use at the first visit the following year. Resources useful for planning and executing post-transitional care include the Long-Term Follow-up Guidelines and the Long-Term Follow-up Program Resource Guide, both developed by the COG.[54,55] Similar guidelines are available from the United Kingdom Children's Cancer and Leukemia Group and the Scottish Intercollegiate Guidelines Network[56,57]

Largely on the basis of shared clinical experience, the following principles may help achieve successful health care transitions: (1) the transition more resembles a process than a discrete event; (2) the transition process needs to be initiated early—it is not too early to begin mentioning transition when the child is initially diagnosed with cancer—beginning at 18 years of age is almost certainly too late; (3) a future-directed orientation, which looks to life beyond cancer treatment, should be maintained throughout active therapy; (4) "medical independence" of the child should be cultivated through developmentally appropriate but guided, progressively greater participation in medical decision making—in very young children, this might be limited to simple choices about medication flavor, but in older, more experienced adolescents, this should include more substantive involvement in decisions concerning cancer treatment; (5) a specific transition plan should be developed for each survivor beginning at least 12 to 18 months before the planned event, including identifying and initiating communication with the patient's post-transitional medical provider; and (6) as part of that transition plan, viable options for continuance of health insurance coverage should be explored.

Barriers to Health Care Transition

Derived largely from collective experience in clinical survivorship practice, numerous barriers can interfere with transition of follow-up care for young adult survivors and are summarized in Table 3. A recent prospective, single-site study of more than 900 childhood cancer survivors (median age, 18.2 years; range, 7.3 to 39.5 years) sought to identify barriers to long-term follow-up care.[58] Approximately 15% of the sample did not attend their scheduled follow-up visit to the late effects center. After multivariate analysis, predictors that continued to be significantly associated with nonattendance at that visit were being nonwhite, lacking private insurance, and mode of travel. Although that study was not designed to address barriers to health care transition per se, inasmuch as many survivors were in the AYA age range, it does offer some insight into an area where more research is clearly needed.

Innovative Approaches to Post-Transitional Care

Several groups have developed systematic approaches to address the follow-up needs of young adult survivors. In the United Kingdom, a system described by Wallace et al[59] incorporates a tiered approach, with differing levels of follow-up dictated by the current medical issues and level of risk stemming from prior treatment. Survivors in level 1 (treated with surgery alone and/or low-risk chemotherapy) are followed up by the late-effects center via mail and telephone contact; level 2 (chemotherapy and cranial irradiation < 24 Gy) are followed up by the primary care provider; and level 3 (all other radiation therapy and/or high-dose chemotherapy with hematopoietic stem-cell rescue) are followed up in the late-effects clinic. In a successor study of 198 survivors classified according to this system by six independent investigators, discordance was noted in only seven cases, and the subjects' self-reported symptoms/late effects were found to be significantly related to their assigned risk level.[60] Investigators in the Netherlands recently reported encouraging pilot experience using a system of shared care of survivors by family physicians and pediatric oncologists.[61] In that study, 123 randomly selected adult survivors were evaluated by 115 local family doctors using a monitoring plan devised at the patients' late-effects visit 1 year earlier. Complete diagnostic data from the follow-up visit were submitted to the late-effects center by 85% of family doctors. High levels of satisfaction were reported by both survivors (88%) and family physicians (97% positive or neutral views).[61] In Canada, the Pediatric Oncology Group of Ontario has developed a comprehensive, regional network of pediatric and adult cancer centers and satellite programs, called the Aftercare Program, to provide seamless follow-up of survivors into adulthood.[62] In the United States, investigators at Baylor College of Medicine and Texas Children's Cancer Center, working in collaboration with the COG and CCSS, have developed an interactive online program called Passport for Care, which provides survivors and clinicians with the means to query its virtual resource center with patient-specific history and to receive individualized monitoring recommendations. Key details of the survivor's cancer treatment history are uploaded onto the system

Table 2. Major Post-Transitional Care Models and Their Potential Advantages and Disadvantages

Type	Description	Personnel	Advantage	Disadvantage
Cancer center-based model	Occurs at pediatric oncology center or within larger organizational structure (eg, university cancer center, health system, or medical–surgical hospital), ideally in location separate from acute oncology clinic. Patient is expected to have a separate primary care provider	Adult-focused team led by primary care physician and involving clinician from pediatric survivorship team to provide expertise in previous disease, treatment, and late effects	Continuity of care	Resource-intensity unnecessary for many survivors
			Survivorship expertise and familiarity with risk-adapted care	Specialty-based and potentially excessively disease-oriented
			Patient familiarity with system and care providers	May foster mentality of medical dependence
			Ready access to medical specialists	Geographically fixed and possibly inconveniently located
			Resources suited for providing comprehensive services	Care not portable
			Potential for resource-sharing with adult survivorship program	Potentially difficult to integrate into life as a survivor
			Existing infrastructure conducive to research	
			Context facilitates professional training in survivorship	
Community-based model	Occurs at office or clinic of community-based primary care provider, with transfer of all pertinent clinical information and primary management responsibility	Primary care physician	Level of available resources suitable for majority of survivors	Greater potential for discontinuity of care
			Primary care-based and wellness-oriented	Patient anxiety due to separation from oncology team
			Congruent with sense of empowerment and medical independence	Appropriate survivorship care dependent upon patient and provider initiative
			Geographically convenient	Difficult to provide breadth of survivorship expertise and resources
			Care portable	Infrastructure lacking for research studies
			Likely cost-effective	
Hybrid model	Same as community-based model, but primary care physician is provided with information resources and expertise of pediatric survivorship team through a formal, ongoing, collaborative relationship	Primary care physician supported by virtual presence of pediatric survivorship team	Advantages of community-based model	Relative lack of experience with model currently
			Provider and patient access to survivorship expertise and resources readily available	Requires establishment of systems to support interactions between center and provider
			More amenable to conducting longitudinal survivorship research	

Table 3. Potential Barriers to Health Care Transition for Young Adult Survivors of Childhood Cancer[35]

Category	Barriers
Survivor-related	Complex cancer treatment history and multiple long-term health risks Occasionally complex medical conditions Failure or inability to assume personal responsibility for health Lack of personal support systems Lack of trust in new health care provider
Survivor/family-related	Over-protectiveness toward child survivor Fear of loss of control Emotional dependency on child survivor Lack of trust in new health care provider
Adult-focused provider-related	Lack of knowledge or experience in post-transitional care and survivor's underlying medical condition and health risks No preexisting emotional bond with survivor/family Burden of assuming care for unfamiliar, occasionally complex survivors with uncertain future
Health system–related	Lack of seamless referral networks linking pediatric and adult-oriented providers Lack of systematic training of health care professionals in post-transitional health care Loss of health insurance needed for continuation of survivorship care in young adulthood and beyond

by the late effects center using a Web-based application developed for the Passport for Care project. Content available confidentially to the survivor and care providers through secure systems include an end-of-treatment care summary, individualized monitoring recommendations and survivor education resources dynamically assembled by the web application, and an online survivor forum and news stories. Funding to date has come principally from several charities and foundations and private donors. This program is now entering the beta-testing phase at several sites and is ultimately intended to be widely accessible.[63,64]

THE IMPACT AND "TAXONOMY" OF CHILDHOOD CANCER SURVIVORSHIP IN YOUNG ADULTHOOD

In light of all the above, it is appropriate to contemplate childhood cancer survivorship briefly in terms of both its impact on health care resources and its relationship to the emerging field of AYA oncology. As mentioned previously, there are currently almost 300,000 survivors of childhood cancer in the United States. Although numerically substantial and noteworthy as a marker of success for pediatric cancer research, this number constitutes but a small fraction of the more than 9.8 million cancer survivors of all ages in the United States.[65] As noted, providing medically and developmentally appropriate survivorship care to childhood cancer survivors across the span of life requires substantial commitment of resources on the part of institutions and health care systems. Yet it is likely that the return on investment is disproportionately high, given the large number of patient-years saved in this population that is just entering the work force and the most productive phases of their lives. Further study is needed to understand fully the costs and benefits associated with extended childhood cancer survivorship care generally, as well as within the contrasting government-sponsored systems that provide universal coverage versus the alternative exemplified by the United States.

Similarly, the relationship of childhood cancer survivorship to AYA oncology is only now becoming amenable to definition. AYA oncology is chiefly concerned with addressing the disparity in survival gains observed over the past few decades for patients in this age group compared with those in younger or older age groups.[66] In contrast, care of young adult survivors of childhood cancer is chiefly focused on continuing systematic late-effects detection, management, and risk reduction initiated during childhood, all of which are optimized by formal transition of care from pediatric to adult-focused services. Whereas AYA oncology requires the combined expertise of pediatric and medical oncologists and other subspecialties for cancer-directed care, childhood cancer survivorship for young adults requires an alliance of pediatric cancer survivorship experts and adult-oriented primary care providers and specialists more likely to be located in the community. Common to both is the need for psychosocial services that support these emerging adults in areas that include medical decision making, interpersonal relationships, family and societal roles, health behaviors, and obtaining and maintaining employment and health insurance. From the perspective of providing survivorship services, it is clear that the universe of AYA cancer survivors includes both those whose cancer was diagnosed as children and those diagnosed as young adults. These two survivor streams converge in the AYA age range and arguably could be managed effectively in yet another survivorship care model that involves a substantial degree of resource sharing to address their overlapping needs. It is conceivable that the accelerating development of AYA oncology programs may facilitate experimentation with novel approaches to survivorship care designed along these lines.

FUTURE DIRECTIONS

Formal transition of follow-up care represents the standard of practice for older adolescent and young adult survivors of childhood cancer. Although the systems necessary to support this practice (institutional, educational, and financial) are in development and will require time and persistent effort to complete, it can no longer be considered optimal for adult survivors to be observed indefinitely solely by pediatric providers in a child-oriented setting or be considered acceptable for the current attrition of vast numbers of adult survivors to continue unchecked. In developing a transitional care program, two principles can be applied. First, as in architecture, form follows function. The key clinical needs of young adult survivors drive the services that should be provided (management and detection of late effects; support of psychosocial functioning; provision of health education; and assistance with financial issues). Second, as in advocacy, think globally but act locally. Although three general models of transitional care have been presented, it must be acknowledged there is no single model that is ideal for every locale and that additional variations on these models can certainly be devised. The "best" program design is the one that suits local considerations of institutional resources, regional medical resources, survivor demographics, and geography.

Many opportunities exist for formal research, experimentation, and advocacy in transitional care for this group of survivors. In the area of health services, published pilot experience is needed, with additional models of care that can be compared with existing designs and adapted to other settings. Research is needed to define the functional criteria for transition readiness of survivors and to develop effective approaches to transition skills training. In the area of professional education, lectures in childhood cancer survivorship need to be introduced into the curriculum of medical students. Clinical rotations and fellowships in cancer survivorship need to be developed not only for pediatric oncology trainees, but perhaps even more urgently for residents in the primary care fields of family medicine, internal medicine, and medicine–pediatrics. Finally, in the area of health care finance, a multilateral solution must be developed to ensure that adolescent survivors are able to maintain uninterrupted health insurance as they enter adulthood.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

REFERENCES

1. Reis LAG, Eisner MP, Kosary CL, et al (eds): SEER Cancer Statistics Review, 1975-2004: Based on November 2006 SEER data submission (posted to SEER web site). Bethesda, MD, National Cancer Institute, 2007. http://seer.cancer.gov/csr/1975_2004/

2. Weiner SL, Simone JV, Hewitt M (eds): Childhood Cancer Survivorship: Improving Care and Quality of Life—National Cancer Policy Board, Institute of Medicine, and National Research Council. Washington, DC, National Academies Press, 2003, p 1

3. Robison LL, Mertens AC, Boice JD, et al: Study design and cohort characteristics of the Childhood Cancer Survivor Study: A multi-institutional collaborative project. Med Pediatr Oncol 38:229-239, 2002

4. St Jude Children's Research Hospital: Childhood Cancer Survivor Study. http://www.stjude.org/ccss

5. Mertens AC, Liu Q, Neglia JP, et al: Cause-specific late mortality among 5-year survivors of childhood cancer: The Childhood Cancer Survivor Study. J Natl Cancer Inst 100:1368-1379, 2008

6. Hudson MM, Mertens AC, Yasui Y, et al: Health status of adult long-term survivors of childhood cancer: A report from the Childhood Cancer survivor study. JAMA 290:1583-1592, 2003

7. Oeffinger KC, Mertens AC, Sklar CA, et al: Chronic health conditions in adult survivors of childhood cancer. N Engl J Med 355:1572-1582, 2006

8. American Academy of Pediatrics section on Hematology/Oncology Children's Oncology Group: Long-term follow-up care for pediatric cancer survivors. Pediatrics 123:906-915, 2009

9. Hudson MM: Survivors of childhood cancer: Coming of age. Hematol Oncol Clin North Am 22:211-231, 2008

10. Schwartz CL, Hobbie WL, Constine LS, et al (eds): Survivors of Childhood and Adolescent Cancer (ed 2). Berlin, Germany, Springer-Verlag, 2008

11. Dickerman JD: The late effects of childhood cancer therapy. Pediatrics 119:554-568, 2007

12. Goldsby RE, Taggart DR, Ablin AR: Surviving childhood cancer: The impact on life. Paediatr Drugs 8:71-84, 2006

13. Bhatia S, Landier W: Evaluating survivors of pediatric cancer. Cancer J 11:340-354, 2005

14. Friedman DL, Meadows AT: Late effects of childhood cancer therapy. Pediatr Clin North Am 49:1083-1106, 2002

15. Centers for Disease Control and Prevention–Lance Armstrong Foundation: A national action plan for cancer survivorship: Advancing public health strategies, 2004. http://www.cdc.gov/cancer/survivorship

16. 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 2:61-70, 2004

17. 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 26:4401-4409, 2008

18. Oeffinger KC, Ford JS, Moskowitz CS, et al: Breast cancer surveillance practices among women previously treated with chest radiation for a childhood cancer. JAMA 301:404-414, 2009

19. Sigel E: Adolescent growth and development, in Greydanus DE, Patel DR, Pratt HD (eds): Essential Adolescent Medicine. New York, NY, McGraw-Hill, 2006, pp 3-16

20. Dahl RE: Adolescent brain development: A period of vulnerabilities and opportunities. Ann NY Acad Sci 1021:1-22, 2004

21. Steinberg L: Cognitive and affective development in adolescence. Trends Cogn Sci 9:69-74, 2005

22. Paus T: Mapping brain maturation and cognitive development during adolescence. Trends Cogn Sci 9:60-68, 2005

23. Blum RW, Garell D, Hodgman C, et al: Transitions from child-centered to adult health care systems for adolescents with chronic conditions: A position paper of the Society of Adolescent Health. J Adolesc Health 14:570-576, 1993

24. Blum RW: Introduction. Pediatrics 110:1301-1303, 2002

25. American Academy of Pediatrics, Committee on Children with Disabilities, and Committee on Adolescence: Transition of care provided for adolescents with special health care needs. Pediatrics 98:1203-1206, 1996

26. American Academy of Pediatrics, American Academy of Family Physicians, American Society of Internal Medicine: A consensus statement on health care transitions for young adults with special health care needs. Pediatrics 110:1304-1306, 2002

27. Nasr SZ: Cystic fibrosis in adolescents and young adults. Adolesc Med 11:589-603, 2000

28. Cameron JS: The continued care of children with renal disease into adult life. Pediatr Nephrol 16:680-685, 2001

29. Knauth A, Verstappen A, Reiss J, et al: Transition and transfer from pediatric to adult care of the young adult with complex congenital heart disease. Cardiol Clin 24:619-629, 2006

30. McDonagh JE: Transition of care from paediatric to adult rheumatology. Arch Dis Child 92:802-807, 2007

31. Konsler GK, Jones GR: Transition issues for survivors of childhood cancer and their healthcare providers. Cancer Pract 1:319-324, 1993

32. Harvey J, Hobbie WL, Shaw S, et al: Providing quality care in childhood cancer survivorship: Learning from the past, looking to the future. J Pediatr Oncol Nurs 16:117-125, 1999

33. Oeffinger KC: Longitudinal risk-based health care for adult survivors of childhood cancer. Curr Probl Cancer 27:143-167, 2003

34. Ginsberg JP, Hobbie WL, Carlson CA, et al: Delivering long-term follow-up care to childhood cancer survivors: Transitional care issues. Pediatr Blood Cancer 46:169-173, 2006

35. Freyer DR, Brugieres L: Adolescent and adult oncology: Transition of care. Pediatr Blood Cancer 50:1116-1119, 2008

36. Reiss J, Gibson R: Health care transitions: Destinations unknown. Pediatrics 110:1307-1314, 2002

37. Friedman DL, Freyer DR, Levitt GA: Models of care for survivors of childhood cancer. Pediatr Blood Cancer 46:159-168, 2006

38. Zeltzer LK, Lu Q, Leisenring W, et al: Psychosocial outcomes and health-related quality of life in adult childhood cancer survivors: A report from the Childhood Cancer Survivor Study. Cancer Epidemiol Biomarkers Prev 17:435-446, 2008

39. Patenaude AF, Kupst MJ: Psychosocial functioning in pediatric cancer. J Pediatr Psychol 30:9-27, 2005

40. Phipps S: Adaptive style in children with cancer: Implications for a positive psychology approach. J Pediatr Psychol 32:1055-1066, 2007

41. Jim HS, Jacobsen PB: Post-traumatic stress and post-traumatic growth in cancer survivorship: A review. Cancer J 14:414-419, 2008

42. Kadan-Lottick NS, Robison LL, Gurney JG, et al: Childhood cancer survivors' knowledge about their past diagnosis and treatment: Childhood Cancer Survivor Study. JAMA 287:1832-1839, 2002

43. Yeazel MW, Oeffinger KC, Gurney JG, et al: The cancer screening practices of adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. Cancer 100:631-640, 2004

44. Emmons K, Li FP, Whitton J, et al: Predictors of smoking initiation and cessation among childhood cancer survivors: A report from the Childhood Cancer Survivor Study. J Clin Oncol 20:1608-1616, 2002

45. White PH: Access to health care: Health insurance considerations for young adults with special health care needs/disabilities. Pediatrics 110:1328-1335, 2002

46. The Commonwealth Fund: Annual report 2007. http://www.commonwealthfund.org/usr_doc/site_docs/annualreports/2007/index.htm

47. Park ER, Li FP, Liu Y, et al: Health insurance coverage in survivors of childhood cancer: The Childhood Cancer Survivor Study. J Clin Oncol 23:9187-9197, 2005

48. Fishman E: Aging out of coverage: Young adults with special health needs. Health Aff (Millwood) 20:254-266, 2001

49. Pang JW, Friedman DL, Whitton JA, et al: Employment status among adult survivors in the Childhood Cancer Survivor Study. Pediatr Blood Cancer 50:104-110, 2008

50. Oeffinger KC, Eshelman DA, Tomlinson GE, et al: Programs for adult survivors of childhood cancer. J Clin Oncol 16:2864-2867, 1998

51. Taylor A, Hawkins M, Griffiths, et al: Long-term follow-up of survivors of childhood cancer in the UK. Pediatr Blood Cancer 42:161-168, 2004

52. Tabone MD, Sommelet D: Childhood cancer surviving. Arch Pediatr 13:607-609, 2006

53. Shaw AK, Pogany L, Speechley KN, et al: Use of health care services by survivors of childhood and adolescent cancer in Canada. Cancer 106:1829-1837, 2006

54. 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 22:4979-4990, 2004

55. Children's Oncology Group: Long-Term Follow-Up Program Resource Guide. http://www.survivorshipguidelines.org

56. Children's Cancer and Leukaemia Group: Therapy-based long-term follow-up (ed 2), 2005 (updated 2006). http://www.cclg.org.uk/researchandtreatment/

57. Scottish Intercollegiate Guidelines Network: Long term follow up care of survivors of childhood cancer, 2004. http://www.sign.ac.uk/guidelines/fulltext/76/index.html

58. Klosky JL, Cash DK, Buscemi J, et al: Factors influencing long-term follow-up clinic attendance among survivors of childhood cancer. J Cancer Surviv 2:225-232, 2008

59. Wallace WH, Blacklay A, Eiser C, et al: Developing strategies for the long term follow up of survivors of childhood cancer. BMJ 323:271-274, 2001

60. Eiser C, Absolom K, Greenfield D, et al: Follow-up after childhood cancer: Evaluation of a three-level model. Eur J Cancer 42:3186-3190, 2006

61. Blaauwbroek R, Tuinier W, Meyboom-de Jong B, et al: Shared care by paediatric oncologists and family doctors for long-term follow-up of adult childhood cancer survivors: A pilot study. Lancet Oncol 9:232-238, 2008

62. Pediatric Oncology Group of Ontario: Provincial pediatric oncology aftercare program, 2006. http://www.pogo.ca/care/aftercareclinics/

63. National Cancer Institute: Passport for care: An internet-based survivorship care plan. Bethesda, MD, National Cancer Institute, NIH publication 05-5498, 2006

64. Texas Children's Cancer Center: Passport for care, 2009. http://www.txccc.org

65. Centers for Disease Control and Prevention: Cancer survivorship: United States, 1971-2001. MMWR Morb Mortal Wkly Rep 53:525-529, 2004

66. Bleyer WA, O'Leary M, Barr R, et al (eds): Cancer Epidemiology in Older Adolescents and Young Adults 15-29 Years of Age, Including SEER Incidence and Survival, 1975-2000. Bethesda, MD, National Cancer Institute, NIH publication 06-5767, 2006 http://seer.cancer.gov/publications/aya/

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