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# Childhood Cancer Survivors: Transition to Adult-Focused Risk-Based Care

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## KEY WORDS

childhood cancer, survivorship, transition

## ABBREVIATIONS

COG—Children's Oncology Group

LTFU—long-term follow-up

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## abstract

**BACKGROUND:** The issues involved in transition from pediatric cancer care to adult-focused care differ from those in other childhood diseases, because malignant disease itself is no longer a problem. However, the potential for fatal outcome places a greater dependence on the pediatric oncology setting and delays this transition process, often beyond adolescence. Adverse long-term physical and psychological effects accompany survival for many of the cured children, and because these effects may not become manifest until adulthood, programs that support transition for childhood cancer survivors require the expertise of many subspecialists.

**OBJECTIVES:** To describe the issues and barriers to successful transition programs for childhood cancer survivors when they are ready for adult-focused care.

**METHODS:** We reviewed the literature and discuss the barriers to transition at the survivor, provider, and health care system levels for survivors of childhood cancer. We also critically assess the elements of successful transition programs.

**RESULTS:** Education of survivors and providers regarding long-term health risks is necessary for a successful transition. This process should be gradual to address the educational needs of survivors, families, and health care professionals, determine "readiness" for transition, and address financial and insurance concerns. Because little is known regarding adverse long-term health-related sequelae beyond the fourth decade of life, research is needed to quantify and reduce the consequences of these morbidities.

**CONCLUSIONS:** Transition programs for pediatric cancer survivors require experts who are knowledgeable regarding the long-term follow-up needs of childhood cancer survivors and who can provide a bridge between pediatric oncology and primary care that is risk based. *Pediatrics* 2010;126:129–136

Approximately 1 in 350 individuals in the United States develops cancer by the age of 20. Therapeutic advances have enabled ~80% of pediatric patients with cancer to survive for 5 years, and most are cured.<sup>1</sup> Survivors of childhood and adolescent cancer comprise 1 in 570 individuals between 20 and 34 years of age.<sup>2</sup>

Unlike other pediatric conditions for which previous therapy does not impact greatly on adult care, delayed effects of treatment for childhood cancer often accompany survival.<sup>3</sup> Recent studies have revealed significant morbidities in adult childhood cancer survivors: 70% treated between 1970 and 1986 have reported at least 1 chronic condition, and >40% have reported at least 1 severe or life-threatening condition.<sup>4,5</sup> Patients who survive at least 5 years have an excess mortality rate compared with the general population.<sup>6,7</sup> Cancer- and treatment-related effects may become evident months to years after treatment and can persist (see Table 1). They may be clinically obvious, subtle, or subclinical in nature. In addition to physiologic late effects, significant psychological consequences contribute to long-term morbidity.<sup>8</sup>

These potential complications require risk-based follow-up care dedicated to the screening, prevention, and treatment of late effects throughout the life span.<sup>9</sup> The Institute of Medicine published recommendations for follow-up care for all cancer survivors, one of which regarded survivors of childhood cancer and the other regarded adult cancer. In both studies it was recommended that survivorship care plans be developed to assist survivors and their care providers.<sup>2,10</sup> The Children's Oncology Group (COG) guidelines for adverse long-term outcomes ([www-survivorshipguidelines.org](http://www-survivorshipguidelines.org)) are intended to minimize morbidity and mor-

**TABLE 1** Long-term Effects of Childhood Cancer

System	Risk Factor	Potential Effect
Cardiac	Radiation therapy	Valvular disease
	Anthracyclines	Pericarditis Myocardial infarction Congestive heart failure Sudden death
Pulmonary	Radiation therapy	Restrictive lung disease
	Carmustine/Lomustine	Exercise intolerance
	Bleomycin	
Renal/urologic	Radiation therapy	Atrophy or hypertrophy
	Platinums	Renal insufficiency or failure
	Ifosfamide and cyclophosphamide	Hydronephrosis
	Cyclosporine A Nephrectomy	Chronic cystitis
Endocrine	Radiation therapy	Growth failure
	Alkylating agents	Pituitary, thyroid, and adrenal disease Ovarian or testicular failure Delayed secondary sex characteristics Infertility
Central nervous system	Radiation therapy Intrathecal chemotherapy	Learning disabilities
Psychosocial	Childhood cancer	Posttraumatic stress disorder Employment and educational difficulties Insurance discrimination Adaptation and problem-solving difficulties Difficulties with transition to independence
Second malignancies	Radiation therapy	Solid tumors
	Alkylating agents	Leukemia
	Epipodophyllotoxins	Lymphoma
	Type of primary malignancy	Brain tumors

tality by providing anticipatory guidance and surveillance screening.<sup>11</sup>

### TRANSITIONS TO RISK-BASED LONG-TERM FOLLOW-UP CARE

To assist in the transition process, long-term follow-up (LTFU) programs have been developed in the past 2 decades in many cancer centers.<sup>12</sup> Institutions differ in how they enable seamless transitions from pediatric oncology to adult medicine, a process that is often difficult to accomplish because specialists in adult medicine lack the necessary knowledge.<sup>13</sup>

Passage from childhood to adolescence and adulthood is marked by physiologic and psychological growth as young adults develop their own identities and separate from their nuclear family. Young adults focus on independent living, intimate relation-

ships, attending college, and pursuing vocational goals. This transition from pediatric to adult care is especially complicated for adolescents who have undergone treatment for a serious illness and must move from a sheltered pediatric environment to an independent adult-medicine environment.<sup>14-16</sup> An optimal transition process is gradual, with a preparatory phase beginning years before the actual transfer occurs. Not all adolescents and young adults are prepared to move into adult-focused care at the same chronological age. Therefore, it is important that the pediatric health care team identify the appropriate "readiness" window for each individual. Adolescents and young adults should be involved early in the process of effecting a transition and should participate in developing a plan for LTFU that is

appropriate. Once a comprehensive medical plan is developed, medical information can be transmitted to a primary care provider or a specialized program for young adult survivors of childhood cancer.

Process guidelines for transition from the pediatric to adult setting have been generated for chronic illnesses such as sickle cell disease, cystic fibrosis, and diabetes mellitus.<sup>17–20</sup> Adolescents and young adults who are long-term survivors of childhood cancer are different; as “survivors” they are no longer troubled by the earlier cancer diagnosis. Oeffinger and Robison<sup>21</sup> described the childhood cancer survivor population as a new medical paradigm, for whom a model different from that for chronic disease would apply. Although the patient is cured of cancer, the sequelae of treatment are often not realized until many years after completion of therapy. In a 2002 Society for Adolescent Medicine position paper, the 5 principles of a successful transition were described.<sup>22</sup> Although developed for children with other illnesses, the following principles can be adapted to the cancer-survivor population:

1. The health care setting must be chronologically and developmentally appropriate.
2. Common concerns of young adulthood must be addressed in addition to specialty care needs.
3. Transition should promote autonomy, personal responsibility, and self-reliance in young adults.
4. Transition programs must be flexible to meet the needs of young adults.
5. A designated professional must take responsibility for the transition process in conjunction with the adult and his or her family.

## OBSTACLES TO TRANSITION TO RISK-BASED LTFU CARE

As with other diseases of childhood, the question of how the transition and transfer of care from the pediatric to the adult health care system should proceed arises. Both the transition process and the event of transfer are often delayed for survivors of childhood cancer, because there is often a disconnect among the treating cancer physicians, the survivors, and primary and specialty care outside of pediatric oncology. Oeffinger<sup>23</sup> adapted a model to describe the factors that contribute to optimal risk-based care for childhood cancer survivors (Fig 1). As depicted in Fig 1, barriers that affect a successful transition originate from those who must facilitate the process: the health care system, survivors, and pediatric and adult health care providers. We consider this model in describing the barriers to transitioning to LTFU care.

### Survivor Factors

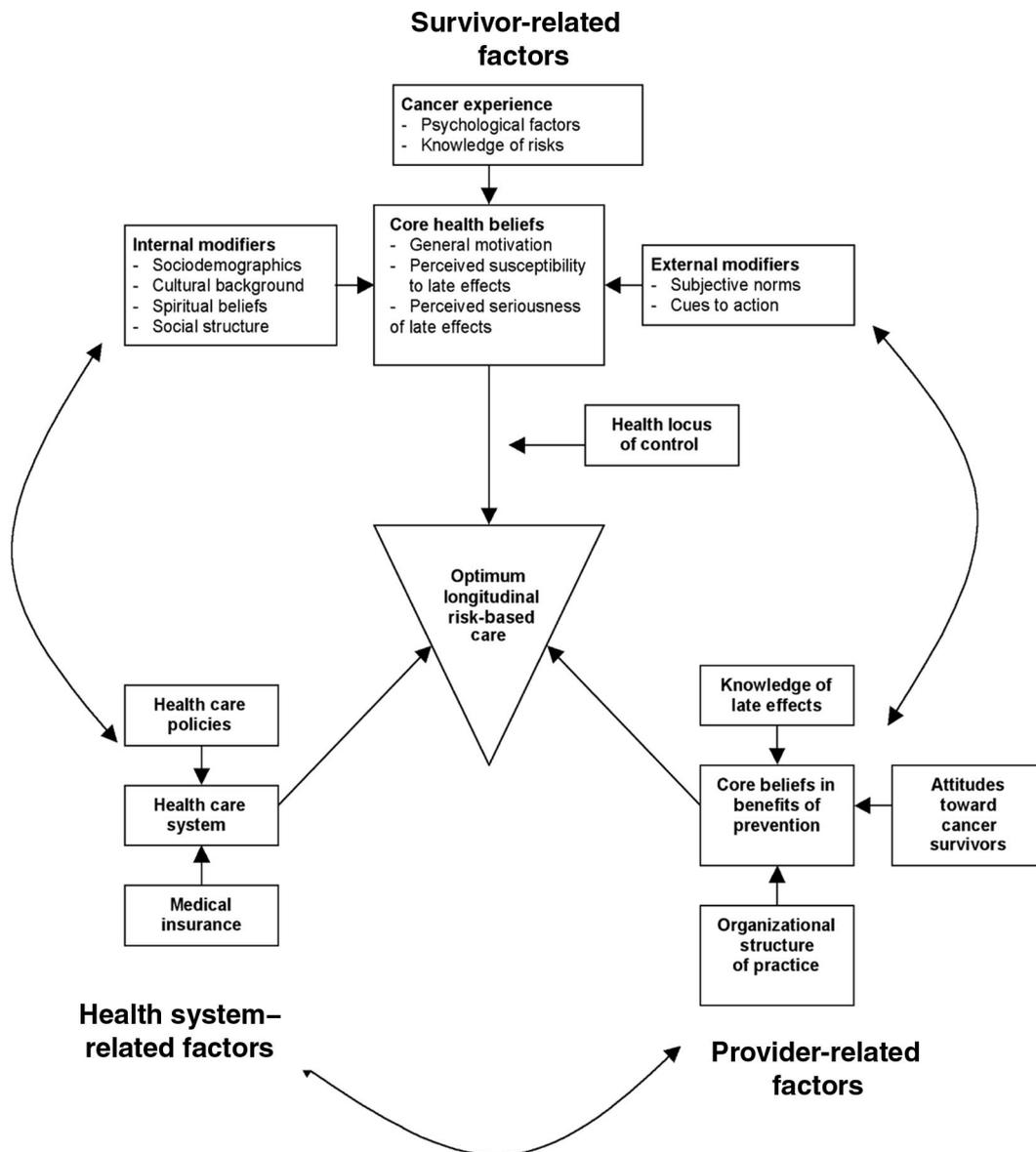
In many countries, including the United States, Canada, and the United Kingdom, the majority of adult survivors are no longer followed at their treating institutions.<sup>24,25</sup> Fewer than 20% of adult survivors have reported receiving follow-up care at a cancer center, and a significant proportion of them are not receiving appropriate risk-based screening.<sup>25,26</sup> Most adult childhood cancer survivors are not well informed regarding their previous therapy or potential risks for sequelae. In another Childhood Cancer Survivor Study,<sup>27</sup> only 35% of the survivors recognized that there are serious health problems associated with cancer treatment.

The issues of transition to adult health care in the United States differ from those in Canada and the United Kingdom, where universal health care exists. In the United States, many adult

survivors are not engaged in their follow-up because of their lack of insurance as they age out of parental/public insurance and they lack full-time employment.<sup>28,29</sup>

Psychological barriers also negatively affect the transition. Survivors may have overdependency on their families, anxiety, or lack of trust in caregivers. Family members may display control, emotional dependency, overprotectiveness, heightened awareness of health issues, and a lack of trust in caregivers.<sup>30</sup> Although the results of several studies have demonstrated that survivors are living and coping well, there are survivors who struggle to cope with life after cancer.<sup>31–33</sup> Some survivors suffer from posttraumatic stress disorder, with symptoms including reexperiencing, arousal, and avoidance behaviors.<sup>8,34,35</sup> Avoidance can interfere with subsequent care and obtaining health information, especially if they need to return to the treating institution. Some survivors exhibit cognitive and developmental delays that increase their dependency on their families and pediatric providers and prevent them from independently transitioning from a pediatric to an adult health care setting.<sup>36–38</sup> In a Dutch study, developmental milestones in chronically ill children, including 348 childhood cancer survivors, were assessed.<sup>39</sup> In this study, childhood cancer survivors reported fewer milestones with respect to autonomy and psychosexual and social development than those in the reference group, which highlights the fact that attention should be directed toward survivors' social and independent functioning when considering transitions to adult-based care.

Patients with cancer develop relationships with their pediatric oncology providers on the basis of a significant sense of trust, especially because of the life-threatening nature of their dis-



**FIGURE 1** Optimal risk-based care model. (Adapted with permission from Oeffinger KC. *Curr Probl Cancer*. 2003;27[3]:143–167.)

ease. This attachment has been described for doctor-patient relationships in other chronic illnesses and may create an additional barrier to the transition process. Recently, Cheung et al<sup>40</sup> examined adult cancer survivors' expectations of their health care and compared those expectations with medical oncologists and primary care physicians. Survivors expected more of their survivorship care than did their oncologists, who believed that care should shift

to a primary care physician. This expectation reflects the attachment of patients with cancer to their oncologists.

### Physician Factors

Physician knowledge of the health care issues and follow-up for cancer survivors is a recognized barrier to transition. In a recent survey of pediatric oncologists, many reported being uncomfortable caring for survivors over the age of 21 but preferred

to care for them as long as possible. In addition, many pediatric oncologists reported being unfamiliar with LTFU guidelines for childhood cancer survivors. When queried about surveillance for a 29-year-old woman who received mantle radiation for Hodgkin lymphoma when she was 16 years old, only one-third recognized the need for breast, cardiac, and thyroid surveillance, as recommended by the COG LTFU guidelines ([www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)).<sup>41</sup>

Pediatric oncologists who have an intense bond with survivors create ambivalence to transition. If survivors have clinically silent health issues, the transition to adult care becomes more difficult.

Many health care providers outside of oncology are not aware of these patients' long-term health risks and need for risk-based screening, because there are relatively few adult childhood cancer survivors.<sup>42,43</sup> A Delphi panel of health care experts identified a key barrier to adult risk-based care in childhood cancer survivors: limited awareness of health care needs of this population by primary care physicians.<sup>42</sup> One study revealed that internists and adult specialists clearly expressed a need for better training in childhood-onset conditions.<sup>13</sup> When adult practitioners undertake follow-up, they may provide inadequate surveillance or subject patients to inappropriately excessive monitoring. In a recent study of mammography practices in 551 childhood cancer survivors exposed to chest radiation for childhood cancer, 63.5% of women aged 25 through 39 and 23.5% of women aged 40 through 50 years had not had mammography in the previous 2 years.<sup>44</sup> Screening rates were highest among those survivors who reported a physician recommendation, which highlights that practices likely depend on physician awareness of second cancer risks and surveillance recommendations.

A recent study examined primary care physicians' attitudes toward caring for survivors of adult cancer.<sup>45</sup> Physicians reported feeling comfortable caring for survivors; those who were already providing survivorship care were willing to provide exclusive care sooner. Primary care physicians reported that oncologists would assist them in assuming exclusive responsibility for follow-up cancer care with (1) a

patient-specific referral letter, (2) printed recommendations, (3) expedited routes of referral, and (4) expedited access to investigations for suspected cancer recurrence.

### Health Care Factors

A barrier for many young adults in the United States is insurability; health benefits are largely provided by employers, and survivors age out of parent or public insurance.<sup>29</sup> Park et al<sup>28</sup> examined the employment status of childhood cancer survivors older than 18 years; rates of unemployment were 3.7-fold higher than those of sibling controls. For those survivors with coverage, many of the suggested tests for necessary surveillance may not be covered by their policies. For example, the American Cancer Society recommends that women who received thoracic radiotherapy for a pediatric cancer start breast cancer surveillance with breast MRI and mammogram by 30 years of age.<sup>46</sup> Some policies may not provide reimbursement for such specialized recommendations. Also, insurance policies often have limited rosters of covered physicians, and finding someone with the willingness and expertise to follow childhood cancer survivors may be difficult. Specialized LTFU programs developed for young adult and adult childhood cancer survivors also might not be covered.

### CRITICAL ASSESSMENTS AND PLAN FOR SUCCESSFUL TRANSITIONS

The process of transition begins when recurrence risk is negligible. Transfer of care to adult practitioners may occur between 18 and 21 years of age. Transition in pediatric oncology refers to this adult "transfer" of care. Pediatric oncologists are unable to assume adult-focused care for young adults who are no longer at risk for cancer recurrence. For successful transition, the barriers that are implicit for survivors, the health care providers, and

the current US system must be considered. Several models of transition have been proposed for children with serious or chronic illnesses, each of which approaches those barriers from a different perspective.<sup>14,47,48</sup> The disease-specific model uses a transition team of subspecialists in pediatric and adult medicine as a bridge between the pediatric and general adult medicine teams. Generic models fit more with the traditional medical training models of pediatric, then adolescent, then adult health care providers. In primary care models a family physician is viewed as the care coordinator, and subspecialty consultants are used as needed. Single-site models are similar to generic models; the site of care remains constant as transition occurs from pediatric to adolescent to adult health care.

Health care throughout this transition process would include developmentally appropriate education of survivors regarding their previous therapies and the potential health risks, a discussion of lifestyle issues and risk-taking behaviors, surveillance for late effects and second malignant neoplasms, identifying psychological and cognitive issues, as well as clinical studies aimed at identifying, quantifying, preventing, and treating late effects. This process would be an organized and gradual one to address the educational needs of survivors, families, and health care professionals, "readiness" of survivors, families, and pediatric oncologists, as well as the financial and insurance concerns as survivors become adults.

On the basis of the issues that face survivors engaged in long-term care, a disease-specific transition clinic model seems to best fit the LTFU needs of childhood cancer survivors.<sup>44,49</sup> Adolescents or young adults move from a pediatric specialty team to a transition team with both pediatric and adult

**TABLE 2** Elements of an Ideal Transition and Transfer Plan

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Before the visit
Initial data collection: chart review and entry into computerized database
Core team meeting: case presentations and development of initial patient care plan
Clinic visit
Introduction of transition-program concepts
History and physical examination
Participation by and education of health care trainees
Patient education
Modification of patient care plan to include additional diagnostic studies
Appropriate therapeutic intervention
Referral to additional members of core team, specialists, and primary care providers
After the clinic visit
Review of previously collected data, additional diagnostic studies, and reports from referrals
Finalization of patient care plan and formulation/modification of long-term care plan
Communication with other involved health care providers
Communication with patient and family members
Ongoing
Web-based educational system for cancer survivors
Clinical research studies
Education of health care professionals
Development and maintenance of support groups for childhood cancer survivors and their families
Development of protocols for the LTFU of childhood cancer survivors

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health care providers and, finally, to an adult provider system (described in Table 2). This process begins for childhood cancer survivors when recurrence is no longer an issue; thus, in many instances, the survivor may be between 18 and 21 years of age. Certain health professionals such as social workers, psychologists, and nurses assist in maintaining continuity across each setting and identify any special psychosocial, educational, or vocational needs of the survivors. Thus, coordination involves both primary and subspecialty pediatric and adult health care providers within the health care, educational, vocational, and social service systems. In other chronic childhood conditions, acquiring appropriate beliefs about adult care before the transfer is associated with a successful transition to adult care.<sup>50,51</sup>

Research needs to be inherent to the transitioning of childhood cancer survivors. Little is known regarding the many survivors who need LTFU care but fail to or are unable to seek it.<sup>52</sup> Health care providers and researchers must consider formal studies that evaluate the optimal care of survivors

in different communities and health care institutions. A core principle of transition studies in many childhood illnesses is specialized focus on the adolescent.<sup>16</sup> However, approximately half of the pediatric cancer population is older than 10 years at diagnosis, and because there is a risk of recurrence for many years, the adolescent survivor often remains tied to the pediatric team. Thus, there exists a gap for understanding the most effective means to transition the young adult childhood cancer population. Furthermore, outcomes-based research must be incorporated into long-term care to examine the changing issues that face survivors as modern cancer therapies evolve. Studies of the impact and cost/benefit of the current surveillance recommendations for late effects and second malignant neoplasms on morbidities and mortality must be designed and implemented. Also, intervention studies focused on improving the participation in risk-based care, as well as improving survivor health behaviors, are essential for improving the health of this population.<sup>53</sup>

An important first step in transitioning survivors is to address the knowledge

deficits about long-term risks among both physicians and survivors. A well-described tool for improving this knowledge is to provide survivors, their families, and adult health care providers with a comprehensive medical summary.<sup>14</sup> This summary, together with an appropriate care plan, provides the knowledge necessary for self-advocacy. It initiates discussion regarding the need for lifelong health maintenance despite periods of clinical silence. Many primary care providers for adults (internal medicine, family practice, obstetrics and gynecology) are unaware of the various sequelae of childhood cancer and the available LTFU guidelines, although primary care physicians may be more comfortable with survivors' long-term care. Such a summary may cue the physicians responsible for long-term adult care to the LTFU guidelines for childhood cancer survivors developed by the COG. An additional approach to increasing the knowledge of practitioners is to incorporate survivorship care into the training of internists, family practitioners, obstetricians, and gynecologists. In large institutions, formal arrangements with residency programs could encourage trainees to participate in rotations that focus on cancer survivors.

Web-based educational networks need to be developed to further improve the knowledge base of survivors and health care providers. A program that incorporates individuals' previous treatment and recommendations according to the current COG LTFU guidelines is currently being developed at Texas Children's Hospital and piloted at several cancer centers across the United States (T.O.H. and Marc Horowitz, MD, written communication, 2009). In addition to the medical needs of survivors, appropriate psychological services also need to be available to enable young adults to better adapt to

maintaining care independently. Adolescent and young adult survivors should be informed of the availability of support groups that can assist in their transition to adulthood.

Barriers intrinsic to our health care system need to be addressed. Nationally, we need to continue to strive to provide comprehensive, accessible, and affordable care to all citizens, especially to vulnerable populations such as childhood cancer survivors. Health care coverage is often discontinued when young adults are no longer in school, but special efforts should be made to maintain coverage

for the life of cancer survivors. Policy makers should be educated on the growing, at-risk nature of the cancer-survivor population.

## CONCLUSIONS

As more patients with childhood cancer are cured, the number of young adults who require LTFU will increase. Future young adult childhood cancer survivors will have benefited from changes in therapy that reduced or eliminated some of the treatments responsible for many of the medical problems experienced by patients who were treated during the 1970s and 1980s.<sup>4,5</sup> There are, nevertheless, long-

term effects of childhood cancer therapy that become more evident as survivors age. Providing a smooth transition for these patients to age-appropriate risk-based health care is a priority and can only occur by actively addressing the barriers in survivors, providers, and the health care system. We hope that once these barriers are overcome childhood cancer survivors will live healthier, longer lives.

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