

# Life After Pediatric Cancer: Easing the Transition to the Adult Primary Care Provider

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The increasing survival rate from pediatric cancer has been one of the greatest accomplishments in the medical world in the 20th century. However, as young adult survivors move into adulthood, they must face the long-term side effects of their treatments. For such individuals, the transition to adulthood is complicated by their fragile medical and psychological state. The purpose of this article is to review current transition research and tailor basic principles to meet the needs of pediatric cancer survivors. Advanced practice nurses can take an active role in transitional planning by serving as coordinators and ensuring implementation of these needed services. The goal is to create an environment conducive to a smooth, problem-free transition to adult care.

**H**enry Steele Commager (1962) said, “Change does not necessarily assure progress, but progress implacably requires change” (p. 3). One of the greatest successes made in pediatric care during the late 20th century has been the increasing survival rate from childhood cancers (Hewitt, Weiner, & Simone, 2003), with an overall five-year survival rate reaching 77% (Clegg et al., 2007). Leukemia accounts for 37.6% of cancer in people younger than 20 and has one of the highest survival rates (Clegg et al.).

About 270,000 survivors of pediatric cancer are living in the United States (Hewitt et al., 2003). One of 640 adults aged 20–39 years is a survivor of a pediatric cancer (Hewitt et al.). The successful progress in treatment of childhood cancer has left a subgroup of young adults who have a very unique set of healthcare needs. Survivors of pediatric cancers, although cured from their original diseases, still must face the “late effects” of disease. The late effects will remain with them as they transition through adulthood, and they will need specific medical attention and psychological care.

An estimated 12.8% of children have a special healthcare need that places them at increased risk for chronic physical, developmental, behavioral, and emotional conditions (Betz, 2004). Ninety percent of those children will live to adulthood (Betz, 2004). This includes the 270,000 survivors of pediatric cancer discussed earlier. Successfully navigating through the transition to adulthood is difficult for the average, healthy young adult. Adolescents and young adults who have special healthcare needs face a greater challenge at this juncture in their lives. As adolescents prepare to enter adulthood, they must establish a sense of identity, plan for their careers, and assume responsibility for the financial, physical, and educational realms of their lives. The purpose of this article is to educate providers about

## At a Glance

- ◆ About 270,000 survivors of pediatric cancer are living in the United States.
- ◆ Healthcare transitions are a necessary process in the lives of all adolescents, and they are even more important in the lives of those with special healthcare needs.
- ◆ Healthcare transition is a long-term, continuous process that should include coordinated risk-based follow-up care.

the importance of follow-up care for survivors of pediatric cancer. This article will discuss the history of transition and review the current transition guidelines so that practitioners can integrate the guidelines into their patients' lives as they transition from pediatric to adult primary care providers.

A literature search was conducted in PubMed, Medline®, and Google Scholar™. Key words used in the searches were *pediatrics*, *oncology*, *transition*, and *adult primary care*. The time frame was 2002–2008. Literature that was chosen included published guidelines involving transfer of care from pediatric to adult primary care providers. Special focus was placed on articles that stressed the need for a smooth transition for pediatric cancer survivors.

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## Late Effects

The *New England Journal of Medicine* published the results of a cohort study to determine long-term health status, mortality, and morbidity in adult survivors of pediatric cancers when compared to their sibling cohorts (Oeffinger et al., 2006). Among 10,397 survivors aged 18–48, 62.3% had at least one chronic condition and 27.5% had a severe, life-threatening condition. The study demonstrated that the survivors who received a diagnosis at an older age were more likely to report a serious health condition, and that the risk for developing chronic health conditions increases over time and does not seem to plateau. The findings reinforce the need for continuous follow-up, with special attention to surveillance for second malignancies, cardiac side effects, and endocrinopathies, as well as prevention and management of late effects.

The Children's Oncology Group published a comprehensive set of guidelines to aid primary care providers in understanding health issues related to disease-specific treatment (Landier, 2007). Figure 1 lists common late effects of cancer and its treatment. Providers must be aware of the disease, treatment received, and potential complications so that they can intervene early and efficiently; primary care providers should be a central component in risk-based care (Oeffinger, Nathan, & Kremer, 2008).

In addition to the physical late effects of pediatric cancer, survivors face many psychosocial adverse effects as well (Rourke, Hobbie, Schwartz, & Kazak, 2007). Survivors entering into early adulthood may be more vulnerable to post-traumatic stress symptoms, which may lead to difficulties with the typical challenges

of adulthood most face, including forming intimate relationships and making independent financial and healthcare decisions. Survivors may exhibit persistent re-experiencing of the trauma, avoidance of reminders, emotional numbing, and a high level of anxiety (Langeveld, Grootenhuys, Voûte, & de Haan, 2004).

## Transition Concepts

In 2004, Cecily Betz conducted a comprehensive review and analysis of 43 transition studies that were published from 1982–2003. The review demonstrated that transition research was still in its early stages and identified the need for further research studies. Betz believed that future transition research would benefit from the use of reliable instruments and tools designed to measure concepts of interest to transition planning. The concept of transition has been established as a major quality-of-care issue for pediatric and adult healthcare providers.

In 2001, the American Academy of Pediatrics, American Academy of Family Physicians, and American Society of Internal Medicine made successful transitions a goal for Healthy People 2010 (Centers for Disease Control and Prevention, National Institute on Disability and Rehabilitation Research, & U.S. Department of Health and Human Services, 2002). Transitional research has been brought to the forefront, and a variety of studies have emerged since 2002 aimed at discovering the most efficient, cost-effective, and comprehensive transition models of care. Table 1 provides a summary of more recent studies (from 2002–2008). Unfortunately, as demonstrated in the table, most studies continue to stress the need for further research to establish evidence-based practice guidelines.

## Principles of Successful Transitions

Healthcare transitions are a necessary process in the lives of all adolescents and young adults; they are even more important in the lives of those with special healthcare needs. However, healthcare transitions remain an unfulfilled promise for many such people (Reiss, Gibson, & Walker, 2005). Many of the existing transition models are in place for adolescents with developmental disabilities. The concepts can be modified to fit survivors of pediatric cancer.

A variety of attempts have been made to define transition. In one article, transition was defined as an active, multifaceted process that eases the patient, without a break in health care, into all aspects of his or her adult life (Blum et al., 1993).

When discussing transitional planning for survivors of pediatric cancer, healthcare providers should remember the major difference between children with developmental disabilities and survivors of pediatric cancer. Survivors of pediatric cancer do not display active disease and have limited access to information pertaining to their disease and treatment at the time they occurred (Kadan-Lottick et al., 2002). Ginsberg, Hobbie, Carlson, and Meadows (2006) looked at the challenges presented to adolescent survivors of pediatric cancer when transitioning to adult primary care providers. Survivors often lacked knowledge regarding their diagnoses, treatments, side effects experienced, and potential late effects that could develop over time. The young adults need to transition from a sheltered and predictable medical environment to an independent adult environment. As

<b>Cardiac</b> Cardiomyopathy Arrhythmias Myocardial infarction Atherosclerotic disease Pericardial infarction	<b>Neurologic (continued)</b> Cataracts Peripheral neuropathy Neurocognitive dysfunction
<b>Endocrine</b> Growth hormone deficiency Precocious puberty Obesity Hypothyroidism	<b>Psychosocial</b> Post-traumatic stress disorder Chronic pain and fatigue
<b>Gastrointestinal</b> Chronic enterocolitis Strictures Bowel obstruction	<b>Pulmonary</b> Pulmonary fibrosis Interstitial pneumonitis Restrictive lung disease Obstructive lung disease
<b>Hepatic</b> Hepatic fibrosis Cirrhosis	<b>Renal</b> Renal insufficiency Hypertension Glomerular injury Tubular injury
<b>Neurologic</b> Functional deficits Behavioral changes Hearing loss	<b>Reproductive</b> Gonadal dysfunction Infertility Premature menopause

### Figure 1. Late Effects of Childhood Cancer or Its Treatment

*Note.* From "Primary Care Management of the Childhood Cancer Survivor," by B.A. Kurt, G.T. Armstrong, D.K. Cash, M.J. Krasin, E.B. Morris, S.L. Spunt, et al., 2008, *Journal of Pediatrics*, 152(4), p. 460. Copyright 2008 by Elsevier. Adapted with permission.

**Table 1. Review of Literature From 2002–2008**

STUDY	SAMPLE AND SETTING	RESEARCH DESIGN	PURPOSE	FINDINGS
Bryant & Walsh, 2008	Chronically ill youth with hemoglobinopathy	Comprehensive empirical review	To synthesize literature and clinical recommendations	Further research is needed, especially in this population.
Burke et al., 2008	Primary care providers in Rhode Island (N = 169 with a 60.9% response rate)	13-question descriptive survey instrument	To gain descriptive information about the existing state of transfer of care from pediatrics	Few practices had transition policies. Few communicated with adult providers. Many pediatric practices had patients after age 22. A need exists for further study and additional training of providers.
Duffey-Lind et al., 2006	4 adolescent pediatric cancer survivors, 7 parents, 14 young adult survivors, and 3 pediatricians	Four focus group interviews and physician phone interviews	To describe the experiences of survivors of pediatric cancer and those of their parents and providers in the transition to survivorship	Transitioning for survivors of pediatric cancer still requires further investigation; survivors stated that transition programs would be beneficial.
Ford et al., 2008	Greater London Child and Adolescent Mental Health Services (N = 65 with a 65% response rate)	Questionnaire survey	To identify transition protocols and collect data about team size, structure, population served, and referral rates to adult services	13 transition programs were in operation in London in 2005. Not all protocols met all requirements. Variations in programs existed. Some patients get lost in transition.
Freyer & Brugieres, 2008	Review article	—	To summarize concepts in transitional care issues for survivors of pediatric cancer	Pediatric oncology research and advocacy organizations should develop a joint statement for transition of oncology survivors.
Geenen et al., 2003	753 parents of adolescents with special healthcare needs	Questionnaire	To assess parental perception of their providers' involvement in transition and the degree to which it is the providers' responsibility to participate in such activities	A need exists for parents and providers to have open discussions about goals and expectations regarding transition.
Kennedy et al., 2007	Transition program in Royal Children's Hospital, Melbourne, Australia	Descriptive review	To learn from the experiences in an existing transition program for future development and improvement	Successful continuity of health care is dependent upon collaboration among adult care providers, pediatric care providers, and patients. Hospital-based transition programs allow for continuous collaboration to improve the system and overcome barriers.
Kennedy & Sawyer, 2008	Review article	—	To examine recent studies and position statements to determine existing issues relating to transitions	Successful transition needs continuous collaboration between pediatric care providers and patients with cancer. Stronger, evidence-based research is needed for advocacy and government policy-makers.
Lotstein et al., 2005	2001 National Survey of Children With Special Health Care Needs	Analyzed responses to transition questions on the survey of parents or guardians of youth with special healthcare needs aged 13–17	To describe the proportion of children with special healthcare needs who receive transition services and evaluate socio-demographic-related factors	Overall, 50% had discussed transition-related concepts. Lower rates existed for ethnic minorities. Transition services were most likely to occur within the "medical home." Significant efforts are needed to ensure evenly distributed services.
McDonagh, 2005	Transition in pediatric transplantation; review article	—	To present an evidence-based approach to transitional care	A need exists for continued research from the adult site of transplantation so that the desired outcome can be carried out. Close collaboration among all providers will help create evidence-based guidelines.
Okumura et al., 2008	1,288 of 2,434 internists and pediatricians who treated patients with sickle cell disease and cystic fibrosis	Mail-in survey	To assess the comfort of internists and pediatricians in treating young adults with childhood illnesses	Primary care providers, for adult and pediatric patients alike, were not comfortable providing care to individuals with chronic childhood illnesses.

*(Continued on next page)*

**Table 1. Review of Literature From 2002–2008 (Continued)**

STUDY	SAMPLE AND SETTING	RESEARCH DESIGN	PURPOSE	FINDINGS
Reiss et al., 2005	Qualitative approach using focus groups of 143 young adults with disabilities and special healthcare needs	34 focus groups and interviews were given to the young adults, family members, and healthcare providers.	To determine what transition experiences youth with special healthcare needs have and what practices facilitate a successful transition	A trusting reciprocal relationship with the provider is crucial.
Scal, 2002	13 primary care givers (pediatricians, nurse practitioners, family physicians, and internists) chosen by nomination	Nominees completed an in-depth survey.	To assess the role of the primary care provider in facilitating transition and how transition occurs in a primary care setting	More training of primary care providers is needed.
Scal & Ireland, 2005	4,332 adolescents aged 14–17 from the 2001–2002 National Survey of Children With Special Health Care Needs	Adequacy of transition services was assessed with parent self-report.	To assess factors associated with successful transitions in youth with special healthcare needs	The older and more complicated the patient, the more likely transition issues were discussed. A high-quality parent-provider relationship is necessary.

will be discussed, many models exist to provide appropriate long-term follow-up care, and the models can and should be expanded to include transitional care within them.

A study by Scal and Ireland (2005) aimed to determine the factors associated with addressing the transition to adult health care in individuals with special healthcare needs. Data were collected from 2000–2001 in 4,332 adolescents aged 14–17 years old who were registered with the National Survey of Children With Special Health Care Needs. The sample was not specifically survivors of pediatric cancer. The adequacy of transition services was determined by parental self-report. Fifty percent of parents reported that they had discussed transition issues with their providers; however, only 16.4% had reported that they had developed an actual transitional care plan. Statistical analysis revealed that transitional issues were addressed more frequently in older, more medically complicated patients. A strong association was found between high-quality parent-provider relationships and discussion of transitional services. The study did not assess the overall impact of healthcare services but did demonstrate that high-quality parent-physician interaction may lead to improvement in the delivery of successful healthcare transitions.

Reiss et al. (2005) conducted a study to answer two questions regarding the transition process: What are the experiences that youth and young adults with special healthcare needs have had? What are practices that facilitate successful transitions? The study was designed with three focus groups (youth with special healthcare needs, family members, and healthcare providers). A total of 143 individuals participated and were almost equally divided among the focus groups. Participants were drawn from more than 20 different states. The themes from the interview were organized into three broad domains: stages of transition, healthcare systems, and transition narratives. Two factors were identified as having an effect on transition: the cognitive ability of the young adult and the extent of disability.

In all three groups, participants viewed transition as an ongoing process that included “envisioning a future,” “age of responsibility,” and “age of transition.” The first two stages are necessary foundations for the final stage. Parents and healthcare providers alike believed that starting early was most beneficial. “Envisioning a future” can be as simple as asking parents where they would like to see the child 10 years from now. “Age of responsibility” is the time period when the adolescents can begin to take active participation in their care. It may start with the simple task of reminding themselves to take their morning medications and eventually scheduling their own doctor appointments. “Age of transition” is centered on the legal age, 18, when young adults are emancipated from their parents (Reiss et al., 2005).

Ledlie (2007) stated that a successful healthcare transition begins with the assessment process. The assessment process allows providers to initiate discussion with the patient and his or her parents to identify their needs and goals and develop an individualized plan. Youth with special healthcare needs, including survivors of pediatric cancer, need to meet transition readiness criteria before beginning the transition process. These include developmental level, cognitive ability, medical condition, self-care skills, family functioning, social support system, and self-advocacy. Areas of assessment and a sample of applicable questions to ask a patient are listed in Figure 2. Assessment tools in the form of questionnaires, checklists, and surveys can help determine a patient’s ability and readiness for the transition process and assist the provider in tailoring a healthcare plan to the specific needs of the patient. Also helpful is providing youths with life maps (identify end goals of the transition plan), transition timelines, and healthcare skills checklists, so that they can be informed, active participants in their plans. Web sites to aid in transitioning are included in Figure 3. Many of these transition resources are available through specific hospital- and state-based Web sites.

### Health-Related Care

- What does the youth know about his disease, medications, side effects, and long-term complications?
- Can he or she arrange and keep appointments?
- Is the youth's medical condition stable?

### Living Arrangements

- Where does the youth live?
- Does he or she wish to move?
- With whom does the youth live?
- Do any environmental concerns exist?

### Education

- Did the youth finish high school?
- Does he or she plan to attend college? Nearby?
- What kind of medical care can he or she receive there?

### Employment and Finances

- Does the youth have a job?
- Is he or she interested in employment?
- What are his or her sources of money? Insurance?

### Socialization and Lifestyle

- Does the youth have friends? Girlfriends or boyfriends?
- Is he or she sexually active?
- Does he or she smoke or drink alcohol?

## Figure 2. Areas of Transition Assessment and Planning

*Note.* From "Methods of Assessing Transition Health Care Needs" (pp. 119–136), by S.W. Ledlie in C.L. Betz and W.M. Nehring (Eds.), *Promoting Health Care Transitions for Adolescents With Special Health Care Needs and Disabilities*, 2007, Baltimore, MD: Paul H. Brookes Publishing Co. Copyright 2007 Paul H. Brookes Publishing Co. Adapted with permission.

Rosen (2003) identified five principles to successful transitions: (a) Healthcare delivered must be developmentally and chronologically age appropriate, (b) programs should address the common problems of young people in addition to disease-specific problems, (c) transition should promote the individual's independence, (d) transition programs should meet the needs of a wide range of patients and then be tailored for each individual, and (e) a designated professional should be appointed as the coordinator for the entire transition process. The ideal transition process would occur when the adolescent has met readiness criteria and the five principles have been met.

### Readiness Criteria

Kennedy, Sloman, Douglass, and Sawyer (2007) and Ledlie (2007) mentioned various tasks and milestones that children should reach that signify that they are ready to move on to the next step of transition. These include having the ability to explain their disease processes, understand the purpose and side effects of medications, schedule their own appointments, recognize a problem, and know where to go for help. The basic developmental tasks of adolescents apply to survivors of pediatric cancers. However, they may accomplish the tasks on an individual timeline that differs from average adolescents. Maturity levels among survivors of pediatric cancers can vary. Some children can be mature way ahead of their years, whereas

others may regress. Parents and providers should begin to give adolescents autonomy in a gradual process. This can begin by allowing adolescents some independent time with providers, without parents being present. The one-on-one time with providers also can provide an opportunity to inform adolescents on issues of confidentiality (McDonagh, 2005).

### Age of Responsibility

Healthcare transition plans should be written as early as possible, depending on age of diagnosis and stage of treatment. A definitive age to start the process is difficult to establish in patients with cancer, as they are diagnosed at all different ages and different developmental stages. Transition plans should be written by age 14 in children with special healthcare needs (Scal & Ireland, 2005). Transition planning should begin well in advance of the actual transition to allow all active participants to fully understand and become comfortable with their new roles. All participants must maintain a level of flexibility in the timing of transition activities, because many contributing factors exist. Patients and providers may be pressured to enter into early transition by institutional barriers that will be discussed later in this article.

### The Medical Summary

The primary oncologist should provide patients and their parents with a complete medical summary. The summary should include cancer diagnosis, treatments received, potential long-term complications from treatment, and other clinically significant events that may have occurred during treatment. The summary should include diagnosis and comorbidities that are not associated with the cancer diagnosis. It also should provide an assessment of current health status and psychosocial assessment. The assessment should outline a problem-oriented plan for management of active problems and include recommended screening for long-term effects as detailed by current risk-based guidelines (Freyer & Brugieres, 2008). Examples of medical summaries can be found at [www.medicalhomeinfo.org/tools/assess.html](http://www.medicalhomeinfo.org/tools/assess.html).

### Transition Models of Care

Transition of care is not a new topic. The U.S. Surgeon General addressed it in 1984. In the 1990s, multiple position papers were published by diverse organizations. In 2001, successful health transitions became a goal for Healthy People 2010. Unfortunately, in 2009, more than 20 years later, only minimal progress has been made (Freyer & Kibrick-Lazear, 2006).

When considering the different transition models, healthcare professionals should understand the fundamental differences between pediatric care and adult-oriented care. Freyer and Kibrick-Lazear (2006) stated that the difference rests in the style of care, which is described as nurturing and directive in children versus collaborating and empowering in adults.

Healthcare transition for survivors of pediatric cancer should not be limited to long-term follow-up but should include diagnosis, end of therapy, disease relapse, secondary treatment, and, in some cases, terminal care. The aim of long-term follow-up

### [American Academy of Pediatrics](#)

[www.medicalhomeinfo.org/tools/trans.html#assess](http://www.medicalhomeinfo.org/tools/trans.html#assess)

Tools, checklists, and worksheets

### [Healthy and Ready to Work State Program](#)

[www.hrtw.org/tools/check\\_transition.html](http://www.hrtw.org/tools/check_transition.html)

Tools, checklists, and worksheets for patients and providers

### [National Center of Medical Home](#)

[www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)

Excellent resource for clinicians to implement the medical home

### [Transition Coalition](#)

<http://transitioncoalition.org/transition/index.php>

Provides online support and professional development transition topics

### [University of Florida](#)

<http://hctransitions.ichp.ufl.edu/resources.html>

Resources on transition

### [University of Illinois](#)

<http://internet.dsccl.uic.edu/dscclroot/parents/transition.asp>

Transition resources, including checklists and timelines

### [Youth in Transition Project at the University of Washington](#)

Division of Adolescent Medicine

<http://depts.washington.edu/healthtr/Checklists/intro.htm>

Transition checklist

### [Youth Workbook](#)

<http://chfs.ky.gov/ccshcn/ccshcntransition.htm>

Life map

## Figure 3. Web Site Transition Resources

and care for survivors of childhood cancer is to optimize their physical and psychological health, enabling them to enjoy the same quality of life as their peers. Who, where, and how patients transition to follow-up care varies greatly among providers and cancer centers.

Skinner, Wallace, and Levitt (2006) reviewed the present variations in follow-up care and enabled the development of future models. The most common transition of care occurs with the individual completing treatment and becoming a long-term survivor (most commonly defined as disease-free for at least five years). To date, the pediatric oncologists responsible for a patient's initial treatment are providing most of the long-term follow-up. In some large centers, patients are transferred to specific long-term follow-up clinics once they have reached a specific time point after diagnosis. Such centers usually are based out of existing pediatric units, despite recognition that a pediatric environment is not ideal for young adults.

## The Medical Home Model

Transitional care should be provided for and included under the umbrella of the "medical home" model. In a position statement, the American Academy of Pediatrics (2002) described that the medical home model represents a concept that health care should be accessible, continuous, comprehensive, compassionate, and coordinated among all providers participating in a patient's care. Primary providers should be well trained and able to manage and coordinate all aspects of care. One of the services delineated in the statement includes "provision of care over

an extended period of time to ensure continuity. Transitions, including those to other pediatric providers or into the adult health care system, should be planned and organized with the child and family" (American Academy of Pediatrics, p. 1545).

Currently, the pediatric oncologist most commonly initiates follow-up care and the patient eventually transitions to an adult-oriented provider (a primary care provider). Those individuals would follow what Freyer and Kibrick-Lazear (2006) named the "health-oriented transition" and can be either institution based or community based. Freyer and Kibrick-Lazear included all of the previously discussed principles necessary for successful transition in their model. Like Skinner et al. (2006), Freyer and Kibrick-Lazear believed that the guidelines for follow-up care provided by United Kingdom Children's Cancer Study Group ([www.cclg.org.uk/index.php](http://www.cclg.org.uk/index.php)), Children's Oncology Group ([www.childrensoncologygroup.org](http://www.childrensoncologygroup.org)), and Scottish Intercollegiate Guidelines Network ([www.sign.ac.uk](http://www.sign.ac.uk)) are useful to adult and primary care providers.

The institution-based model and community-based model are similar to the models suggested by Betz and Telfair (2007). The former is based on a pediatric oncology program that is provided in an institution where pediatric and adult healthcare services are offered. The pediatric providers observe the survivors, and adult general medicine specialists (not oncologists) provide follow-up care. This model involves transition but not transfer of care. The community-based model involves an adult primary care provider who is willing to assume responsibility for the management of follow-up care and receives support from the survivor's pediatric team. Advantages and disadvantages of the two approaches are outlined in Figure 4 (Freyer & Kibrick-Lazear, 2006). If the survivor of pediatric cancer receives the appropriate information (e.g., treatment summary, possible long-term complications) and has met transition readiness criteria, then the community-based model should provide a smooth transition.

Freyer and Kibrick-Lazear (2006) concluded that no single model is best in every setting. Selecting an individual transition model is dependant on resources, geographic availability, and health services. Evidence is lacking as to which model is most preferable in terms of patient and provider preference, cost effectiveness, and outcomes. Most important is developing a transitional care model that incorporates survivors' individual needs and is deliberate, thoughtful, and effective in design (McDonagh, 2005).

## Barriers to Transition

Despite the recognized importance of a smooth transition, little evidence is available to guide healthcare providers, parents, and cancer survivors through the transition off therapy and back to a primary care provider. Barriers to healthcare transitions occur each step of the way. Adult primary care providers may be unaware of long-term side effects and complications of a child's specific treatment because of the minimum amount of cancer survivors in their practices. Anxiety and stress are common among adolescents and their families as transition time approaches (Duffey-Lind et al., 2006). Many articles identified common barriers that were encountered by patients, families, and medical caregivers (see Figure 5).

### **Institution-Based Model of Care\***

#### **Potential advantages**

- Continuity maintained with cancer treatment team
- Adherence to follow-up standards verifiable
- Research data accessible
- Relatively easy to develop at a single site

#### **Potential disadvantages**

- Geographically inconvenient for some patients
- Care not "portable" if patient moves
- Greater level of follow-up intensity may be disproportionate to medical issues for healthy survivors
- Potentially great attrition rate because of above factors

### **Community-Based Model of Care\*\***

#### **Potential advantages**

- Continuity maintained with primary care provider
- Geographically convenient and portable
- Wellness-oriented setting
- Lower level of follow-up intensity probably proportionate to medical issues for most survivors

#### **Potential disadvantages**

- Adherence to follow-up standards difficult to verify
- Easier for patients to become lost to follow-up
- May be more challenging to maintain research database
- Treatment center must actively maintain liaison with primary care practitioner

\* This model may involve follow-up at primary cancer treatment center by a multidisciplinary team that includes an adult-oriented physician (e.g., internist, medicine-pediatrics specialist, family practitioner) or the primary pediatric oncologist at some centers. Transition of care within center from the pediatric to the adult-oriented team is assumed.

\*\* This model assumes formal transition of care from pediatric cancer treatment or long-term follow-up team to adult-oriented primary care provider.

## **Figure 4. Comparison of Institution-Based Versus Community-Based Models of Care**

*Note.* From "In Sickness and in Health: Transition of Cancer-Related Care for Older Adolescents and Young Adults," by D.R. Freyer & R. Kibrick-Lazear, 2006, *Cancer*, 107(S7), p. 1706. Copyright 2006 by John Wiley & Sons, Inc. Reprinted with permission.

Reiss et al. (2005) noted that the difference between pediatric and adult healthcare systems creates an environment more likely to have barriers. The four system barriers are aging out of treatment, insurance and funding, availability of care, and practice differences. Most hospitals use the age of 18 or 21 as the cutoff to suspend pediatric services. In addition, licensing guidelines vary according to state regulations, and some states do not allow pediatric nurse practitioners to treat individuals aged 18–25 (Reiss et al.).

Continuation of health insurance is a major barrier for survivors of pediatric cancer entering the adult world. Private health insurance until the age of 23 usually is dependant on the survivor continuing formal education. This is a problem if the medical or psychological condition of the survivor is not optimal for that setting. Medicaid eligibility also becomes more stringent after the age of 18 (Reiss et al., 2005).

Many survivors and their families believed that finding adult providers who were just as knowledgeable of their needs as

their pediatric providers was difficult (Reiss et al., 2005). Survivors and families believed that pediatric services were better organized because one provider in one location generally provides services in the pediatric setting. Pediatric staff were noted to be more available for questions and support. Lastly, survivors reported minimal communication between their pediatric and adult providers (Reiss et al.).

Duffey-Lind et al. (2006) conducted a pilot study to identify the needs and concerns of survivors of pediatric cancer, their parents, and primary care physicians and recognized the unmet educational and psychological needs of this unique population. Survivors were very hesitant to discuss the potential of cancer recurrence and the possibility of late effects but did admit to current physical limitations. In contrast, parents were overly concerned about the potential for relapse and about their children's current health. Parents and survivors alike were confused about the distinction between screening for recurrence and screening for late-term effects. Many of the young adult survivors believed that their primary care physicians were lacking information regarding late effects and that they knew more than their current providers. If patients do not feel comfortable and safe with their primary care providers, they will be more hesitant to engage in the transition process.

The survivors also reported a range of emotional experiences during the transition period, ranging from fear of feeling abnormal in school to feelings of abandonment related to a downgrade of attention. Parents of survivors reported mostly negative emotions regarding completion of therapy related to fear of relapse. Survivors and parents believed that written information regarding their treatment, drugs, and psychological support, combined with face-to-face discussions with their providers, would ease their transition experience. Physicians stated that they would like general information on pediatric oncology as well as individual specific information (Duffey-Lind et al., 2006).

During the treatment of pediatric cancer, many parents decide to screen their children from the truth of their disease, sometimes omitting the words "cancer" and "chemotherapy." In addition, parents are the decision-makers for treatment plans, leading young adults to know little about the details of their treatment. Kadan-Lottick et al. (2002) conducted a cross-sectional telephone survey of 635 survivors aged 18 or older to assess their knowledge regarding aspects of their diagnoses and treatment. Only 72% of the participants accurately reported their diagnoses. Most troubling, when asked whether past therapy can cause health problems over time, only 35% responded correctly, whereas 46% stated that it could not and 19% did not know. Only 15% reported that they received written summaries of their diagnoses and treatment, and 12% did not know whether they had received such a summary. Successful transition of care is reliant upon the survivors of pediatric cancer becoming active, informed participants. This study demonstrated that important deficits exist that could prevent survivors from seeking the appropriate long-term follow-up care that they need. Pediatric survivors cannot be expected to be responsible for scheduling appointments, taking medications, and attending follow-up appointments if they don't have an accurate understanding of their own situations. Appropriate interventions are needed to correct existing deficits and ensure that future survivors transition into

### **Patient Barriers**

- Dependent behavior
- Immaturity
- Severe illness
- Disability
- Psychopathology
- Lack of trust in caregivers
- Poor adherence to treatment regimens

### **Family Barriers**

- Excessive need for control
- Emotional dependency psychopathology
- Overprotection of the young adult
- Heightened perception of disease severity
- Lack of trust in caregivers

### **Pediatric Caregiver Barriers**

- Economic concerns
- Emotional bonds with the patient and family
- Comfort with the status quo
- Distrust of adult caregivers, ambivalence toward the transition of care

### **Adult Caregiver Barriers**

- Economic concerns
- Lack of understanding and familiarity of disease
- Heightened perception of healthcare needs
- Lack of institutional support

## **Figure 5. Barriers to Transition**

*Note.* From "Delivering Long-Term Follow-Up Care to Pediatric Cancer Survivors: Transitional Care Issues," by J.P. Ginsberg, W.L. Hobbie, C.A. Carlson, & A.T. Meadows, 2006, *Pediatric Blood and Cancer*, 46(2), p. 170. Copyright 2006 by Wiley Liss. Adapted with permission.

survivorship with an increased awareness regarding their health risks (Kadan-Lottick et al.).

Scal (2002) explored the views of primary care providers regarding their efforts in transitional planning and issues and barriers they face in the transition process. Requests for nominations were sent to support groups in the Minnesota Children With Special Health Care Needs Program; primary care physicians were nominated to join the study because of their approach to facilitating transition. A total of 36 nominations were received, 13 completed surveys; 3 surveys were excluded because the providers did not work in a primary care setting; therefore, 10 completed surveys were the focus of the article.

Most of the primary care physicians first became aware of transitional care issues because of parents' or patients' requests, not as a result of institutional policy or clinical guidelines. Primary care physicians identified two important issues crucial to transitional health: (a) Adolescents and young adults should be able to describe in detail signs and symptoms of their conditions that require urgent medical attention, and (b) they should understand the effects that their medical conditions have on their sexuality and reproductive health. Figure 6 lists other important areas essential to transition that were addressed by the primary care physicians. Respondents suggested that the key to successful transitions is to view transition as a continuum, start early, work as a team, emphasize to all involved the importance of having an adult healthcare provider, and "use common sense." Most concerning was the rather small number of nominations

that were received, perhaps indicative of the lack of transition services provided by primary care physicians in the United States (Scal, 2002).

## **Implications for Practice and the Role of Nursing**

Shared decision-making is a crucial part of communication needed for a successful transition. Geenen et al. (2003) assessed parental and providers' perceptions regarding providers' level of involvement in healthcare transition and the extent to which it is the provider's responsibility to participate in transitional care. Surveys were mailed to parents of children with special healthcare needs (N = 2,397) and physicians who provide their care (N = 409). A total of 753 parent surveys and 141 physician surveys were returned. The survey included 13 different activities that physicians can participate in to ease the transition into adulthood. For each activity, parents were asked how important the area was for their children, how much their physicians helped in that area, and the extent to which it was the physician's responsibility to provide care in that area. The survey was modified for the physicians to assess their levels of involvement in those areas and to what extent they felt it was their responsibility.

Transition areas that were most important to parents are listed in Table 2. Physicians reported that they should begin to teach adolescents to manage their health at approximately 9.5 years, whereas parents said at 12.3 years. Providers also reported more involvement with transitional care activities than parents' perceptions of their involvement. Sixty-three percent of providers reported time restrictions as a barrier to spending time on transitional care issues. Forty-three percent reported that they needed additional training, and 37% reported lack of financial reimbursement. Parents reported that having an individual who could develop a healthcare plan, act as a liaison between pediatric and adult providers, and have time to spend with the families would be most beneficial. They also stressed the need for increased training of professionals in transition-related care. In the study, physician and parent responses were not matched.

The study supported the need for shared decision-making and suggests the need for healthcare professionals to discuss with parents what they expect of physicians during transition

- Access to insurance
- Support organizations
- Description of the roles of the primary care physician and specialty physicians
- Individualized care plans
- Ability to identify emergency health services
- Awareness of the impact of drug and alcohol use
- A substantial relationship with a caring adult
- Understanding of the importance of an adult healthcare provider

## **Figure 6. Needs Among Individuals With Special Healthcare Needs to Enable Successful Transitions**

*Note.* Based on information from Scal, 2002.



**Table 2. Parents' Importance Ratings for Transition Activities**

RANK	ACTIVITY
1	Taking care of my child's general health
2	Taking care of my child's disability
3	Coordinating my child's health with other health professionals
4	Helping my child get health insurance
5	Helping me find a healthcare provider when my child becomes an adult
6	Teaching my child to manage own health
7	Working with the school to coordinate care
8	Discussing with my child how to take care of his or her health to be successful at work
9	Connecting my child with other services in the community
10	Screening my child for mental health problems
11	Talking to my child about drugs and alcohol
12	Talking to my child about sexual issues
13	Helping my child apply for or keep Social Security income

*Note.* From "Understanding the Role of Health Care Providers During the Transition of Adolescents With Disabilities and Special Health Care Needs," by S.J. Geenen, L.E. Powers, & W. Sells, 2003, *Journal of Adolescent Health*, 32(3), p. 228. Copyright 2003 by Elsevier. Adapted with permission.

planning. The study also demonstrated that physicians and parents agree that it is not the physician's responsibility to ensure that adolescents maintain continuous health insurance (Geenen et al., 2003).

Betz (2007) outlined five components needed for successful healthcare transitions, similar to the ones identified by Scal (2002): (a) transfer of care from pediatric primary care providers and specialists to adult providers, (b) access to continuous and uninterrupted health insurance coverage, (c) access to knowledge and skills necessary to manage daily regimen independently, (d) learning to identify and advocate for accommodations when needed, and (e) being referred to appropriate agencies and resources according to individual need. The five principles should serve as the foundation for transitions in pediatric cancer survivors.

Betz and Redcay (2005) described the implementation and description of an advanced practitioner serving as a transition service coordinator for adolescents with special healthcare needs. Such a coordinator would serve as a direct link between the pediatric and adult healthcare worlds while promoting optimal healthcare goals. Pediatric providers offer family-centered care, whereas adult providers expect individuals to be self-sufficient and responsible for coordinating providers' recommendations and referrals. Advanced practice nurses can use their knowledge of the special healthcare needs of an individual to act as clinical expert, consultant, leader, researcher,

and educator. The role of a transitional service coordinator is versatile and appropriate in many clinical settings. The growing population of pediatric cancer survivors provides a new, wonderful opportunity for advanced practice nurses. Because transitional care models are in their earliest stages, advanced practice nurses can take an active role in developing their own responsibilities in an area that is lacking implementation into practice. Nurse practitioners have the ability to balance the delicate emotional, psychosocial, and medical needs of parents and children. They can serve as educators, coordinators, and resources to patients, parents, and pediatric and adult primary care physicians. As research has demonstrated, a lack of communication exists between providers and patients regarding expectations in transitional care, and patients and their families report that high-quality relationships with their providers are crucial for smooth transitions. Ideally, the most reliable way that survivors would not get lost to the adult medical world would be for each pediatric oncology practice to have a nurse practitioner whose role is to serve as coordinator, provide a medical summary, ensure that proper follow-up management is occurring, and act as a liaison between the pediatric oncologist and the adult primary care provider.

Major pediatric oncology centers need to develop position statements on the transition of care for childhood cancer survivors, similar to what has been done in other specific chronic diseases of childhood. The statements need to be detailed and specific for this population. In addition, further research and funding should be directed toward descriptive and comparative studies and be able to assess outcomes of different models (Freyer & Brugieres, 2008). Advanced practice nurses can act as educators for their fellow providers, providing disease-specific information and teaching about transitional care issues. They can have an integral role in the creation of continuing education programs for transitional care. They also should promote funding for evidence-based research in the pediatric and adult realms. Finally, they can become politically involved and advocate for legislature to ensure continuous health care for all survivors of pediatric cancer.

## Conclusion

Healthcare transition for survivors of pediatric cancer is not an event but rather a long-term developmental process that involves the patient, the family, pediatric and adult primary care providers, and the patient's oncologist. The process of transition should begin as early as possible, possibly at time of diagnosis, by allowing the parent to envision a future beyond the illness. A common theme similar in all articles, studies, and guidelines was that transition planning is still in its early stages; although it is recognized as a necessity, it is not implemented often. Transitional care for survivors of pediatric cancer should include risk-based follow-up care, health education, health promotion, surveillance for recurrent disease, reimmunization plans, and assessment of growth, development, and psychological health.

Techniques used when transitioning pediatrics to the adult world can be applied in a variety of settings. Survivors of adult cancers also may face challenges upon finding themselves no longer under the care of their "oncologists" and therefore be

less inclined to resume care with their primary care providers. Developing a structured system with the guidelines discussed in this article could benefit that population as well.

Widespread implementation of transitional care is dependent on funding for research studies to determine the most cost-effective transition programs, training for pediatric and adult healthcare providers in transitional care issues, and appropriate financial resources for the care itself. Until those goals are met, young adult pediatric cancer survivors must be educated to take an active role in their care by understanding their diagnoses, treatments, and risks for developing late effects. Advanced practice nurses and other nurses can take an active role, serving as coordinators for those services, being advocates for patients, and easing their transition into adulthood.

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This article has been identified as appropriate for a journal club. When you read this article, think about how you would change your current practice regarding osteoporosis in your patients. See the Evidence-Based Practice column in the February 2009 *Clinical Journal of Oncology Nursing* (Vol. 13, No. 1, pp. 109–112) on how to implement and participate in journal clubs. Photocopying of this article for discussion purposes is permitted.

1. What is the clinical practice question the authors are trying to address?
2. Is the purpose of the article described clearly?
3. Is the literature review comprehensive, and are major concepts identified and defined?
4. Do you see young adult survivors in your practice? What challenges do they face?
5. What are the challenges all patients face when ending active treatment?
6. Where are your patients' "medical homes"?
7. How do these clinical recommendations compare to your current practice and population?
8. What practice change recommendations will you consider making based on the evidence presented in this article?