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The Long and Winding Road: Transitions in Care for the Childhood Cancer Survivor

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1.1 Introduction

For young people and their families, undergoing cancer treatment is an experience characterized by transition--“transition” being defined as passage from one state, stage, subject, or place to another [1]. The major transitions associated with cancer treatment are readily identifiable and familiar to clinicians. For most patients, these include the transition from development of symptoms to diagnosis of cancer, from diagnosis to the initiation of treatment, from completion of treatment to initial follow-up, and from initial follow-up to long-term cancer survivorship (Fig. 1.1).

For some patients, transition may also include development of relapse, and, for too many, end-of-life care. Effective management of these cancer-related transitions requires strong communication skills and anticipatory guidance born of familiarity with the underlying cancer and treatment regimen, as well as the typical clinical course.

In pediatric and adolescent oncology, however, these transitions do not occur in isolation, but rather against a backdrop of the patient’s normal physical, emotional and social development. The successive transitions of developmental maturation that begin during infancy and continue through older adolescence not only influence each patient’s response to cancer-related transitions, but also cause patients to require support during the cancer experience in order for healthy adulthood to be achieved.

One additional transition of survivorship, which arguably represents a unique convergence of both cancer-related and normal developmental components, is the one which occurs between older adolescence and young adulthood. In no other transition do we encounter the simultaneous complexities of established treatment-related health problems, emerging risks, need for ongoing medical surveillance, change from pediatric to adult-focused health care services, threats to maintaining health insurance, completion of

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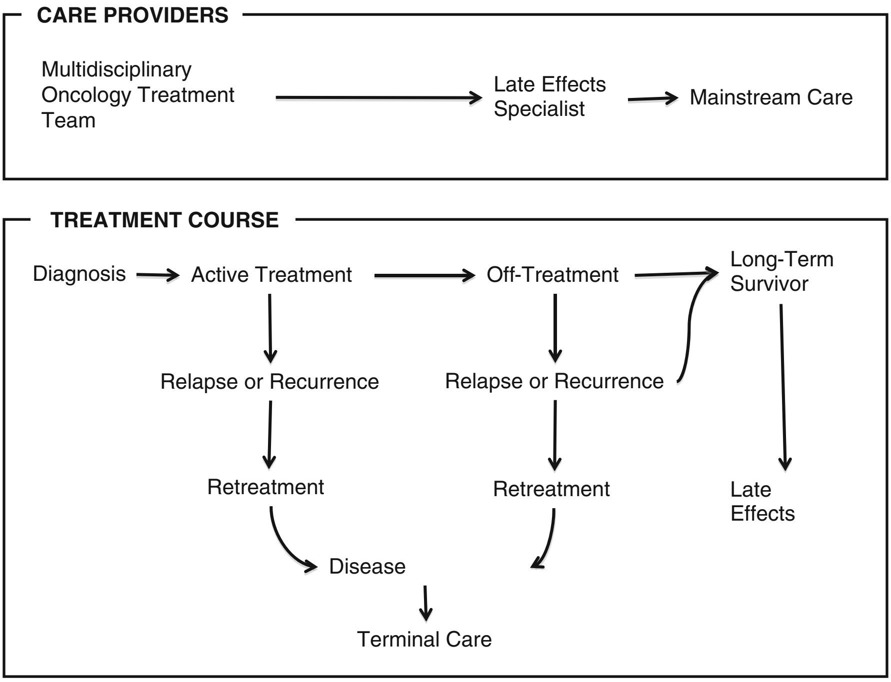


Fig. 1.1 Major transitions associated with cancer treatment. Reproduced with permission from MacLean et al. Cancer 1996; 78(6)

formal education, entrance to the work force, the achievement of personal independence, and redefinition of familial and societal roles, to name a few. With more and more young people surviving childhood cancer than ever before, the need for workable approaches to health care transition in young adulthood has never been greater.

The purpose of this chapter is to provide an overview of the major transitions experienced by children and adolescents undergoing management of their cancer, especially during the long-term follow-up phase. Key issues and potential interventions for each are discussed. The principles and practice of health care transition for young adult survivors of childhood and adolescent cancer are emphasized.

1.2 Developmental Aspects of Transition

Cancer commonly affects growth and development, either directly in physical changes or through parenting and peer experiences. Physicians and other health care professionals taking care of childhood cancer survivors should have an understanding of major developmental tasks of childhood in order to normalize the cancer experience in an age-appropriate way [2, 3]. Providing appropriate support for those tasks differs somewhat according to the type of transition. As summarized in Table 1.1, during transitions associated with diagnosis and treatment, the focus for all age groups is to support patients and families through crises characterized by sudden and dramatic change, unfamiliar situations, uncertain outcomes and frightening possibilities.

In contrast, during transitions associated with survivorship, especially during late long-term follow-up, the focus switches to assisting patients and families with understanding and coming to terms with the persisting health problems and/or future risks resulting from cancer treatment. In both transitions, explanations should become more detailed, commensurate with the patient's and the family's cognitive capacity and degree of involvement in medical decision-making. In pediatric oncology, clinicians are faced with the interesting challenge

Table 1.1 Developmental stages of childhood and their correlates for transitional care

		Correlates for transitional care	
Developmental stage	Selected developmental features [3]	Diagnosis and treatment phase	Survivorship phase
Preschool (2–5 years)	Acquisition of language and motor skills	Arrange child life interventions to minimize procedure-related anxiety	Child too young to understand the need for long-term follow-up
	Formation of simple concepts of reality	Facilitate child's understanding that illness is not a punishment	Direct anticipatory guidance about late effects towards the parents
	Emotional connection with other people Cognitive features of magical thinking, egocentrism and dominance of perception	Advise parents that being calm may be more comforting than explanations like "this will make you better"	Mention eventual transition to adult-focused providers
Middle childhood (6–12 years)	Expansion of child's world outside the home	Provide simple explanations to child regarding diagnosis and necessary treatments	Provide simple explanation to child relating prior illness to the need for continued follow-up
	Ability to get along with other children	Maintain educational progress through hospital-based school activities and school reentry programs	Continue to educate parents on late effects, health and wellness
	Development of concrete operational thinking	Encourage child's involvement in simple treatment choices (e.g., flavor of medications)	Mention eventual transition to adult-focused providers
	Acquisition of adult concepts and communication (writing, reading, calculating)	Advise parents against over protectiveness and encourage normal disciplining	Advise parents against over protectiveness and encourage normal disciplining Encourage parents to allow children to have increasing responsibilities at home and an increasing role in decisions
Early adolescence (10–13 years)	Development of formal logical operations	Provide straightforward but more detailed explanations of diagnosis and treatment	Provide straightforward but more detailed explanations about follow-up care
	Awareness of changing body and interest in opposite sex	Provide support to reduce social isolation and depression through interventions such as child life therapy	Encourage increased participation in medical decision making and personal health choices
	Reduced interest in family-centric activities Increasing peer-identification	Supplement parental support with organized peer-support activities	Initiate discussions about eventual transition to adult providers

(continued)

Table 1.1 (continued)

		Correlates for transitional care	
Developmental stage	Selected developmental features [3]	Diagnosis and treatment phase	Survivorship phase
Middle adolescence (14–16 years)	Importance of physical attractiveness, popularity and self-esteem	Direct conversations towards the adolescent with active involvement in decision-making	Direct the conversation towards the adolescent with active involvement in decision-making
	New understanding of abstract concepts and consequences	Provide support for body image issues, self esteem	Reserve 1-on-1 time with teen for a portion of each clinic visit
	Reorientation of primary relationships from family to peer groups	Provide support to reduce social isolation and depression through adolescent support groups and teen-friendly facilities	Discuss prevention of high risk behaviors (smoking, alcohol, drug use, unprotected sex)
	Start of dating	Stress importance of adherence to therapy	Discuss targets for transition readiness and provide rationale for transition to adult focused providers
Late adolescence (17–20 years and beyond)	Development of personal independence, core values, ethical principles and philosophy of life	When feasible, offer flexibility in treatment schedule to accommodate important social events, e.g., graduation	Encourage a primary role for older adolescent during clinic visits
	Attainment of emotional independence	Offer internet access in hospital rooms for social networking	Provide information related to reproductive health and sexuality
	Development of intimate relationships	If desired by patient, include significant other during clinic visits	Continue education about importance and rationale for life long follow-up
	Emerging importance of career decisions as related to self-concept and emerging societal role	Help parents realize the need for adolescent's privacy and developing autonomy	Encourage pursuit of higher education and provide information on survivor focused scholarships and resources
	Preparation for occupation	Stress importance of adherence to therapy	Emphasize importance of preparing for employment with insurance benefits to cover continued follow-up care Help them understand insurance options available for cancer survivors Assess transition readiness (see Fig. 1.2) and coordinate transition to adult setting

of caring for older long-term survivors who were treated as young children, yet never developed insight into and understanding of their cancer and its treatment. They return year after year with little knowledge as to why they are in the cancer clinic. As these survivors mature into adolescence, it is essential they receive sufficient information about their cancer, its treatment, and the resulting health implications, in order to prepare them properly for health care transition.

1.3 The Transition from Completion of Cancer Treatment to Initial Follow-Up

This period encompasses the end of treatment until approximately 24 months after completion of treatment, during which most survivors are at the highest risk for relapse. The primary focus during this transition is to assist the patient in returning to baseline function. Ironically, toward the latter phases of treatment, many older patients develop a certain comfort level in receiving chemotherapy, especially if it is tolerated reasonably well and no relapse has occurred. The transition to end of therapy may elicit anxiety and fears related to relapse, for which many families feel unprepared [4].

One way to aid families in navigating this transition is to have a formal conference with them at the end of treatment [5]. This conference should involve at least the patient, parents and/ or significant others, the primary oncologist, and ideally the primary nurse and social worker. During this end of treatment conference, the team should briefly summarize the cancer diagnosis, the treatment received, immediate plan for follow-up, surveillance and other health recommendations. Many families are relieved to discover that they are not now “on their own,” but that cancer treatment is followed by a formal phase of surveillance with systematic monitoring initially for relapse, and then later for long-term health and well-being. Straightforward conversation about the risk and typical patterns, the timing and symptoms of relapse, when to call the oncology clinic and the specific plan for surveillance will help reduce anxiety. Parents and patients should be briefly re-educated about the relevant, major long-term effects of treatment and need for continued follow-up. This presents an excellent opportunity to introduce the concept of lifelong survivorship care and the long-term follow-up program, if such a program exists in the institution. Parents should be encouraged to re-establish their child’s care with the child’s primary care provider, whom they should now contact for any health issues except those clearly related to the cancer. Specifying when to resume childhood immunizations and normal activity should be discussed. A copy of the treatment summary and follow-up plans should be provided to the older patient, parents and the primary care provider as a roadmap or guideline for future healthcare. Names and updated contact information for organizations providing further information and support to survivors may be provided.

1.4 The Transition from Initial to Long-Term Follow-Up Care

The transition period begins approximately 2 years post-cessation of cancer treatment and continues onwards. This transition is, for most patients, open-ended in the sense that life-long surveillance is recommended for most childhood cancer survivors. The separation between initial and subsequent periods of follow-up care is not uniformly distinct, as the risk for late relapse differs by cancer diagnosis. Indeed, for institutions where referral to cancer survivorship programs occurs relatively early, long-term follow-up services can overlap and should continue parallel with disease-directed surveillance for some period of time. The primary focus of this transition is to establish the practices for risk-based monitoring and to provide related health education to the survivor and family. Whereas the major risk during the initial period of follow-up is relapse, the major risk during this later period is disengagement from medical care and failure to remain in structured follow-up.

1.4.1 Late Effects and the Need for Survivorship Care

While the incidence of childhood cancer has increased gradually over the past three decades, mortality due to childhood cancer has steadily decreased [6]. In 2005, an estimated 328, 652 childhood cancer survivors were alive in the United States [7]. The prevalence of childhood cancer survivors has been estimated to be approximately 1 in 640 among Americans aged 20–39 years [8]. These figures will undoubtedly increase in the future as survival continues to improve.

Many survivors remain at increased, life-long risk for clinically significant complications of their cancer therapy. These are commonly referred to as “late effects,” defined as any chronic or late-occurring outcome, physical or psychosocial, that persists or develops 5 years after the cancer diagnosis [8]. In an analysis of self-reported data from 10,397 survivors and 3,034 siblings, investigators from the Childhood Cancer Survivor Study (CCSS) found that the risk for a chronic or life-threatening health problem was 3.3 and 8.2 times higher, respectively, in survivors compared with their siblings. The cumulative incidence of one or more chronic health conditions reached 73.4 % 30 years after the cancer diagnosis, with a cumulative incidence of 42.4 % for conditions graded as severe, disabling, or life-threatening [9]. A study involving 1,315 survivors from the Netherlands reported similar findings [10]. The excess risk does not appear to reach a plateau with time [9, 10]. Data from the CCSS indicate that all-cause mortality is 8.4 times higher among survivors compared with the United States (US) population 25 years following cancer diagnosis [11]. Although recurrent/progressive disease accounted for most deaths, second or subsequent cancers and cardio-pulmonary late effects were noted to become important contributors over time [11]. Selected late effects by organ system, their risk factors and recommended surveillance tests are outlined in Table 1.2.

There is expert consensus that most childhood cancer survivors should remain in structured, lifelong follow-up due to increased risk for late effects, impaired health status, and premature death. To assist in this task, the Children’s Oncology Group (COG) has developed risk-based, exposure-indexed clinical practice guidelines for late effects surveillance [12]. The guidelines are intended to increase awareness about the potential late effects and to standardize the follow-up care of survivors provided by pediatric oncology, subspecialty, and primary care clinicians. Individual guidelines are updated regularly and, along with corresponding patient/family educational materials, may be downloaded from the COG website [13]. Research is underway to validate these guidelines and determine their clinical utility. Similar guidelines have been developed by other international cooperative pediatric oncology groups [14–16].

1.4.2 Role of the Cancer Survivorship (Long-Term Follow-Up) Clinic

The American Academy of Pediatrics (AAP) has recommended that pediatric cancer treatment centers offer a mechanism for the long-term follow-up (LTFU) care of successfully treated patients, either at the original treatment center or with a specialist familiar with the potential adverse effects of cancer treatment [17]. The main goals of LTFU clinic are to provide surveillance for late effects, identify and address medical and psychosocial issues, provide health education and health promotion interventions to modify risk, and conduct longitudinal research (Table 1.3).

Various effective models exist for delivering LTFU care [18]. Most LTFU clinics are staffed by nurse practitioners, a social worker, and a physician with expertise in childhood cancer survivorship. LTFU clinic staff should also have referral access to other specialists such as psychologists, nutritionists, genetic counselors, cardiologists, endocrinologists, fertility specialists, and orthopedic surgeons. However, given that a recent survey of COG centers found that only 59 % have a dedicated LTFU clinic, many institutions provide survivorship care by the same treating oncologist [19]. In programs offering an LTFU clinic, comprehensive survivorship evaluation is resource-intensive, beginning with generating a detailed cancer treatment history, performing a complete physical assessment, preparing a treatment summary and survivorship care plan, and educating the survivor and family about health risks, behavior and promotion.

Referral to LTFU clinic generally represents the “official” transition to long-term follow-up care.

Table 1.2 Overview of selected late effects in childhood cancer survivors

Organ system	Late effect	Risk factors	Surveillance
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	Growth chart
	Gonadal failure	RT, alkylators	Testosterone, estradiol, FSH, LH
Cardiovascular	Cardiomyopathy	Anthracyclines, RT	Serial echocardiography
	Coronary artery disease	RT	Clinical history
	Carotid artery narrowing	RT	Carotid artery ultrasound
Pulmonary	Pulmonary fibrosis, restrictive or obstructive lung disease	Bleomycin, busulphan, lomustine, carmustine, RT	Chest X-ray, pulmonary function testing
Genitourinary	Reduced GFR	Cisplatin, RT	Serum creatinine
	Tubular dysfunction	Cisplatin, ifosfamide	Serum electrolytes, Mg, Phos
	Hemorrhagic cystitis, bladder fibrosis	Cyclophosphamide, ifosfamide, RT	Urinalysis
Reproductive	Infertility	Alkylators, RT	Clinical history, specialty assessment
Gastrointestinal	Cirrhosis	RT	Liver function test
	Chronic enterocolitis	RT	Clinical history
	Strictures	Surgery	Clinical history
Musculoskeletal	Osteopenia/osteoporosis	Corticosteroids, methotrexate	Bone density measurement
	Osteonecrosis (AVN)	Corticosteroids	Clinical examination, MRI
	Altered bone growth	RT	Clinical examination
Eyes	Cataract	Corticosteroids, RT	Regular eye examination
Auditory	Hearing loss, tinnitus	Cisplatin, RT	Audiological evaluation
Oral	Dental caries, dry mouth, dental maldevelopment	RT	Regular dental examination
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
Secondary neoplasms	Melanoma, breast carcinoma, thyroid carcinoma, sarcoma, bowel cancer, brain tumor	RT	Site specific surveillance
	Acute myeloid leukemia/ myelodysplastic syndrome	Etoposide, anthracyclines, RT	CBC

Adapted from Freyer DR. J Clin Oncol 2010;28:4810–4818

RT radiation therapy, *MRI* magnetic resonance imaging, *TSH* thyroid stimulating hormone, *FSH* follicle-stimulating hormone, *LH* luteinizing hormone, *GFR* glomerular filtration rate, *AVN* avascular necrosis, *CBC* complete blood count

When this should be initiated is a matter of varying practice and some debate. A survey of 24 comprehensive pediatric survivorship programs found that most patients were referred to LTFU clinics when they reached 5 years post-diagnosis and 2 years off therapy, whichever was later [20]. The rationale for this relatively late time point is that the risk for relapse is minimal for most

Table 1.3 Components and tasks of survivorship care [8]

Components of ideal system of survivorship care
1. Provide a range of direct services to survivors to identify, prevent, treat and manage late effects
2. Bridge the realms of primary and specialty health care with education and outreach
3. Coordinate medical care with educational and occupational services
4. Conduct research to better understand late effects and their prevention
Specific tasks of survivorship program
1. Educating and counseling survivors regarding the specific conditions to which they are susceptible and guidance of self-monitoring of late effects
2. Applying preventive approaches known to be effective for the general population, including encouragement of abstinence from tobacco, limited exposure to alcohol, sun protection, physical activity, maintenance of a healthy weight, consumption of fruits and vegetables
3. Providing psychosocial support services to survivors and their families
4. Providing reproductive and sexuality counseling
5. Providing genetic counseling for individuals with a hereditary cancer and their family members
6. Assistance with identifying and meeting financial challenges

pediatric cancers. One concern about such a late time point is that for cancers treated with relatively brief therapy (e.g., Wilms' tumor and Burkitt lymphoma), the period of elapsed time between end of therapy and referral for LTFU is relatively long, during which patients/families lose motivation to remain in surveillance. Consequently, this traditional time point is being reconsidered by some programs in favor of something earlier while patients are still engaged in disease-directed follow-up.

The transition to LTFU care is neither as predictable nor as automatic as might be assumed. Even well-established pediatric survivorship clinics within large cancer treatment programs at prominent hospitals do not necessarily capture all eligible survivors. The reasons for this have not been studied extensively, but one survey of survivorship programs suggests many factors. Institutional factors include inadequate resources and finances to sustain programs, low institutional commitment toward the provision of survivorship care, and a lack of capacity to care for the growing population of survivors. Factors arising from the survivor include lack of both interest and awareness of cancer-related risks [20]. Patients/families may also be reluctant to relinquish their relationship with their treating oncologist in order to see a new physician in LTFU clinic. In preparing them, physicians may well need to confront their own reluctance to "let go" of patients with whom they have bonded during treatment. Some patients may find it difficult to come to the same clinic where they experienced the trauma of cancer treatment. Because of this, it is ideal to hold LTFU clinic in a setting separate from the acute oncology clinic. Survivors and their families may lack financial resources or have to travel long distances to the LTFU clinics, as these are often located far from their local communities. Lack of health insurance coverage for surveillance tests may be an issue, although most states provide catastrophic health insurance programs that cover follow-up services up to 21 years of age.

1.5 The Transition from Child-Oriented to Adult-Focused Care

As promulgated by the Society for Adolescent Medicine, the now-classic definition of health care transition is the planned movement of adolescents and young adults with chronic physical and medical conditions from child- centered to adult-oriented health care systems [21]. Its overarching purpose is to provide continuous, well-coordinated care that is both medically and developmentally appropriate. As mentioned previously, the medical rationale for health care transition of childhood cancer survivors is the need for late effects surveillance. While health care transition is a concept now being applied broadly across most chronic diseases or conditions originating in childhood [22–24], cancer survivorship is different in that patients are considered cured, and may not have developed symptoms of late effects yet. This can cause many survivors to wonder why continued medical care is necessary. From a developmental perspective, while pediatric care tends to be nurturing and prescriptive, adult care is typically collaborative and empowering, perhaps more supportive of the emerging autonomy of an older adolescent/young adult. Communication should be directed toward the adolescent/young adult rather than the parent in order to address important issues such as sexuality, reproductive health, substance abuse and other risk-taking behaviors [21]. Most adolescent cancer survivors undergo the same developmentally appropriate shifts as their peers, including educational advancement, change in residence, re-orientation of primary relationships, need for employment and health insurance, and switch to an adult-focused health care provider [25]. It is important for health care transition to address these needs in a way that is relevant for childhood cancer survivors. Of particular importance is their understanding of the non-intuitive relationship linking education, employment and health insurance—the "survivorship triad." Adolescent survivors should be counseled to stay in school to reach the highest educational degree they can, which will assist them in securing employment that hopefully offers the health insurance necessary for them to obtain the life-long survivorship care they need.

Health care transition generally occurs in the age range of 18–21 years. This is also the age when most pediatric hospitals begin to have difficulty serving the needs of adult patients, due to child-oriented facilities and lack of convenient access to adult-focused specialists. Recent surveys reveal considerable variation in timing of transition among pediatric centers [19]. Some have drawn support for delaying transition until the mid- to late-twenties, derived from recent evidence that neurobiological maturation in brain regions responsible for risk-assessment, motivation and choice is not complete until that time [26]. Relatively little is known about what factors contribute to successful health care transition, particularly for childhood cancer survivors. Through focus group interviews of adolescents with special health care needs, their parents and providers, Reiss and Gibson identified the following factors as being important: (1) having a future-focused orientation throughout care; (2) viewing transition positively as a normal milestone of late adolescence; (3) starting the transition process early; (4) fostering personal and medical independence by promoting early involvement of the child in medical decision making; and (5) maintaining continuous, uninterrupted health care insurance if possible [27]. Inasmuch as most children with cancer become long-term survivors, it is appropriate to make first mention of health care transition even as early as the initial family conference at diagnosis, and to revisit the topic at end of therapy and upon referral to LTFU clinic.

Although health care transition is best conceived as a gradual process, eventually care must be transferred to the new provider and setting. At this "transition visit," at least four broad goals must be accomplished: (1) assessment of readiness for transition; (2) education of the survivor/family on essential skills needed in the adult health care system; (3) preparation of an updated health care summary, including past cancer treatment, current and potential health problems, and recommended late effects surveillance (Survivorship Care Plan); and (4) communication with the new adult-focused provider(s) including a clear transfer of responsibility for follow-up.

1.5.1 Transitional Care Models for Young Adult Survivors

A variety of models are in use for care of young adult survivors. No single care model is "best" for all settings. In designing a transitional care program, institutions should consider models that make the most of their strengths and resources while adapting best to limitations. More research is needed to define "best practices" in this area. In general, existing programs fall into three broad categories: (1) Cancer Center-based; (2) Community-based; or (3) Hybrid [18].

Cancer Center-Based Model. In this model, adult-focused care continues to be provided within the same cancer center or health system where treatment was given. This model is more prevalent in institutions where both children and adults are treated. In a recent survey of COG institutions, this was the most common model used for care of adult survivors [19]. In this model, the post-transition team includes an adult-focused primary care provider (internist, family medicine, medicine/pediatrics), and/or medical oncologist, plus pediatric survivorship specialists. Thus, this model involves transition to adult services but not transfer of care. An advantage of this model is continuity of providers and medical records. A disadvantage is that survivors may be required to travel long distances. Further, survivors at low risk of developing late effects may not need this degree of resource intensity.

Community-Based Model. In this model, survivorship care is provided by a community-based primary care provider [18]. Here, there is both transition and transfer of care. When properly executed, this model involves the treatment center providing an identified primary care provider with a formal Survivorship Care Plan (as described above). Advantages of this model include geographic convenience, an emphasis on wellness/prevention that characterizes primary care, and integration of cancer survivorship into routine health care. The chief disadvantage is that the primary care provider may have a relative lack of medical expertise in late effects.

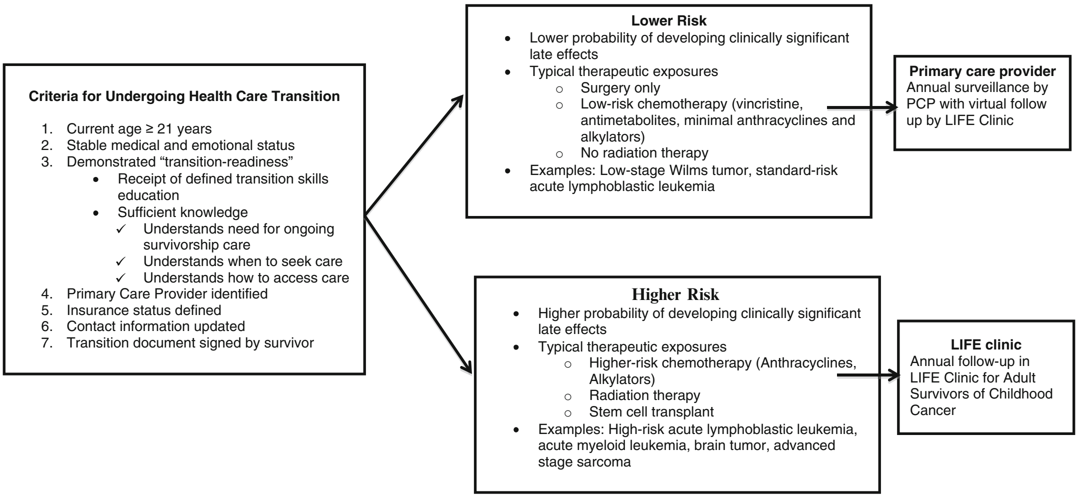
Hybrid Model. In this model, a combined approach is used that involves both the community-based primary care provider and the cancer treatment center. Survivors undergo transition and transfer of care, but in this case a robust linkage is maintained between the pediatric survivorship center and the primary care provider. A formal Survivorship Care Plan is provided to the primary care provider who assumes responsibility over late effects monitoring. Ideally in this model, the primary care provider maintains regular interactions with the survivorship center to report on the survivor's status and receive updates on changing follow-up guidelines. In theory, the Hybrid Model offers the advantages of both the Cancer Center-based and Community-based Models but offsets the disadvantages of each. Delivery of survivorship care by the primary care provider is appealing because CCSS data have shown better utilization of general medical care than cancer center care among young adult survivors [28]. Additionally, a recent study from the Netherlands showed that a coordinated program involving the childhood cancer treatment center and family physicians resulted in good outcomes and provider satisfaction [29].

A variant of the Hybrid Model, called the Risk-Stratified Model, is utilized in the LIFE Cancer Survivorship and Transition Program at Children's Hospital Los Angeles (CHLA). In this model, the site of post-transitional survivorship care is determined by the classification of survivors according to risk for developing clinically significant late effects. As shown in Fig. 1.2, transition-ready survivors are classified as either Lower or Higher Risk using adapted criteria [30, 31].

At 21 years of age, Lower Risk survivors undergo transition to their primary care providers to continue life-long follow-up as specified in their Survivorship Care Plan. Lower Risk survivors are contacted annually by the LIFE Program to ascertain current health status and adherence to recommended surveillance ("virtual follow-up"). Those deemed to be Higher Risk return annually to the LIFE Clinic for Adult Survivors of Childhood Cancer, a collaborative pilot initiative involving adult-focused providers held at a community-based adult cancer center. In this model, all survivors undergo transition, but full transfer of care occurs only for those classified as Lower Risk. Transition-related outcomes data are now being collected to evaluate the efficacy and satisfaction with this model. One anticipated benefit is rational, risk-based utilization of valuable survivorship resources.

1.5.2 Barriers to Transition of Young Adult Survivors

No discussion of health care transition for young adult survivors of childhood cancer is complete without mention of the sometimes formidable



*See text for additional details

Fig. 1.2 Risk-stratified model for transition of young adult survivors used by the LIFE Cancer Survivorship and Transition Program at Children's Hospital Los Angeles

barriers encountered at the level of the survivor, health care provider and medical systems (Table 1.4). While some have been the subject of research, others remain clinical observations and impressions.

Barriers Related to the Survivor. Certain negative perceptions and lack of relevant health-related knowledge may interfere with follow-up. These factors include a lack of awareness about long term risks and need for continued monitoring [32, 33], reluctance to terminate long-standing relationships with their pediatric oncology providers, and the challenge of building relationships in new health care settings [27]. Additionally, the perceived stigma of a cancer history and the emotional difficulty of continuing to discuss the cancer experience may contribute [34]. There is some evidence to suggest that targeted interventions aimed at improving survivor knowledge might result in improved adherence to recommended late effects screening. Seventy-two survivors of Hodgkin lymphoma who were at increased risk of breast cancer or cardiomyopathy but had not undergone recommended screening during the previous 2 years were mailed a one-page survivorship care plan containing applicable surveillance recommendations [35].

Table 1.4 Barriers to transition of survivorship care

Survivor-related	Complex cancer treatment history
	Multiple long-term health risks
	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
	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
Health system-related	Lack of seamless referral networks linking pediatric and adult-oriented providers
	Lack of systemic training of health care professionals in post-translational health care
	Loss of health insurance needed for continuation of survivorship care in young adulthood and beyond

Adapted from Freyer DR. J Clin Oncol 2010;28:4810–4818

Their primary physicians were given patient-specific information. Within 6 months, 41 % of survivors completed the recommended mammogram and 20 % completed the echocardiogram. However, providing written directives may not be enough, as they can be easily misplaced or lost [36]. Electronic health records accessible by survivors or their care providers through secure internet portals, such as the innovative Passport For Care initiative [37], may address some of these issues.

Barriers Related to the Health Care Provider. Barriers related to the health care provider involve both the pediatric cancer specialist and the adult-focused physician. Among both pediatric oncology providers and survivors, there are concerns that adult-focused providers lack survivorship expertise [19, 32, 33]. A factor likely contributing to this is the current paucity of survivorship-related content in medical school curricula and primary care residency training, whereas pediatric oncology fellowship training in survivorship is improving [38]. At the same time, it is unclear how diligent pediatric cancer specialists have been in reaching out to develop collaborative relationships with those primary care providers due to their own reluctance to "let go" of survivors. The extent to which these factors actually are operative is not well understood, but the perceptions are pervasive [19].

This lack of survivorship expertise might be addressed in several ways. Fundamentally, clinical survivorship and health care transition must be addressed at multiple levels of education for health care professionals, particularly during residency training in the primary care specialties of family medicine, internal medicine and medicine-pediatrics. It also needs to be included as a topic in continuing medical education conferences and on-line courses, such as the "Focus Under Forty" series recently launched by the American Society of Clinical Oncology [39]. At the same time, it may be unrealistic to expect primary care providers to have sufficient expertise in caring for higher-risk survivors. As discussed earlier, one response might be for pediatric survivorship programs to stratify young adult survivors at the time of transition such that only those deemed to be at lowest risk for developing late effects are transitioned to primary care providers. Another is to make patient-specific surveillance recommendations available to both survivors and their primary care providers through a secure, interactive on-line resource that can be accessed in real time at the point-of-care, the prototype for this being Passport For Care [37]. Passport For Care could prove helpful even for some pediatric oncologists [40].

Barriers Related to Systems of Care. At least two important system-based issues serve as barriers to effective survivorship care. The first is a lack of survivorship care networks linking pediatric and adult-focused providers. A key element for facilitating this is a shared electronic medical record (EMR) containing relevant clinical detail for each patient. Since the type of EMR that bridges treatment centers and outpatient practices is usually provided by hospitals or health systems, its availability is dependent upon their strategic commitment in this area. As a partial or interim alternative, the Passport For Care initiative may be utilized [37].

The second issue, particularly pertinent in the US, is the lack of continuous health insurance coverage over the transitional age period. Data from the CCSS have documented that, compared with siblings, young adult survivors have less health insurance coverage and are more likely to report difficulties obtaining it [41]. This is, by no means a survivorship-specific issue, as young adults in general are the most under-insured segment of the US population [42]. For childhood cancer survivors, this may result in not receiving appropriate monitoring or management for late effects despite increasing risk. Typically, children with cancer are covered by Medicaid-funded state programs for catastrophic illness, but this coverage usually ends at 21 years of age, resulting in the "aging out" phenomenon commonly mentioned in transitional care literature from the US. For young adult survivors fortunate enough to qualify for coverage on their parents' private health insurance policy, a provision of the Patient Protection and Affordable Care Act passed in 2010 by the US Congress permits them to remain covered until 26 years of age [43].

1.6 Conclusion

The transitions during childhood cancer treatment take place against a backdrop of each patient's normal physical, emotional and social development. Understanding the major developmental tasks of childhood is essential in order to normalize the cancer experience in an age-appropriate way. Families often feel unprepared for end of cancer treatment and are relieved to discover that they will be systematically followed for relapse initially and long-term health and well-being later. Many survivors remain at increased life-long risk for clinically significant complications of their cancer therapy. The primary focus of long term follow up care is risk-based monitoring for late effects and provision of health information to the survivor and family. Transition of young adult survivors from the pediatric to adult-focused setting is a major challenge. Multiple transitional care models exist but formidable barriers may be encountered at the level of survivor, health care provider and medical systems. Understanding these barriers and developing strategies to overcome them are essential for successful health care transition of the young adult survivor of childhood cancer.

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