Transitioning Survivors of Central Nervous System Tumors: Challenges for Patients, Families, and Health Care Providers

Journal of Pediatric Oncology Nursing
26(5) 280–294
© 2009 by Association of Pediatric
Hematology/Oncology Nurses
Reprints and permission: http://www.sagepub.com/journalsPermissions.nav
DOI: 10.1177/1043454209343209
http://jopon.sagepub.com

Debra Eshelman-Kent, MSN, RN, CPNP, Elizabeth Gilger, MSN, RN, CPNP, CPON, and Maureen Gallagher

Abstract

Survivors of central nervous system tumors (SCNST) are a growing group of cancer survivors who require risk-based, long-term health care due to the chemotherapy, surgery, and radiation they have received. Although treatment strategies are being developed to reduce morbidity and mortality, ultimately this subgroup of pediatric cancer survivors often faces moderate to severe late effects of their treatment. As a result, they will need lifelong health care that includes risk-based health care due to cancer treatment exposures as well as primary adult health care, including primary and secondary preventative care. The best way to accomplish lifelong health care for SCNST as they enter adulthood is not clearly defined. In this article, the authors plan to (1) present an overview of the complexities of health care problems that make transition challenging for SCNST; (2) review the evolving transition literature; (3) explore the barriers to successful transition; (4) discuss methods to facilitate transition; (5) describe approaches, strategies, and models for survivorship care in SCNST; (6) present issues for consideration when transitioning SCNST; and (7) provide information on transition-related resources.

Keywords

transition; late effects; survivorship; models of care

Exploring the topic of transition for survivors of central nervous system tumors (SCNST) is essential as treatment strategies for this population of pediatric cancer patients have improved, creating a larger number of survivors. Children with previously fatal central nervous system (CNS) tumors are often either being cured of their disease or living with stable disease. Pediatric cancer survival rates for all cancers have improved to about 80% (Nathan et al., 2007), and survival statistics for children with CNS tumors have also improved over time. The 5-year overall survival rate for patients diagnosed with a CNS tumor at less than 15 years of age has improved from 35% to 60% from the 1960s to the late 1980s, respectively. Survival rates for low-grade astrocytomas, the most common pediatric CNS tumor, have reached 80% to 90% (Benesch et al., 2006; Sonderkaer et al., 2003). More recent 2001 Surveillance, Epidemiology, and End Results (SEER) data show an overall CNS tumor survival rate of about 73% (Ries et al., 2004).

The idea of transitioning survivors of pediatric cancer to adult health care providers or to the adult setting is not unique, but it brings many challenges that may be magnified in the SCNST. In this article, we plan to (1) present a brief overview of the complexities of health care problems that make transition challenging for SCNST; (2) review the evolving transition literature; (3) explore the barriers to successful transition; (4) discuss methods to facilitate transition; (5) describe approaches, strategies, and models for survivorship care in SCNST; (6) present issues for consideration when transitioning SCNST; and (7) provide information on transition-related resources.

Advances in Treatment and Risk Factors for Late Effects

Increases in survival rates reflect technological and treatment improvements. Innovations in diagnostic imaging, neurosurgical technique, radiation therapy, and

Corresponding Author:
Debra Eshelman-Kent, RN, MSN, CPNP, ATP Five Plus Cancer Survivor Program, Division of Hematology/Oncology, Cincinnati Children's Hospital Medical Center, 3333 Burnett Avenue, MLC 11013, Cincinnati, OH 45229-3039
e-mail: Debra.kent@cchmc.org.

chemotherapy treatments have decreased morbidity and mortality in pediatric neurooncology patients. Magnetic resonance imaging (MRI) mapping that includes a functional MRI presurgery helps decrease surgery-related side effects. The role and increased use of conformal radiation, intensity-modulated radiation therapy (IMRT), proton beam radiotherapy, and intensity-modulated proton therapy (IMPT) are still being studied, and it is hoped that these new treatments will provide even greater promise of survival. Each form of radiotherapy has been able to decrease radiation fields, sparing normal brain tissue, as compared with conventional radiation therapy. In turn, it is expected that the late effects of therapy, including, but not limited to, neurocognitive deficits, endocrinopathies, ototoxicity, and secondary malignancies, should be reduced (Conklin, Li, Xiong, Ogg, & Merchant, 2008; Jain, Krull, Brouwers, Chintagumpala, & Woo, 2008; Kirsch & Tarbell, 2004; Wilson, McDonough, & Tochner, 2005). Risk-adapted therapies for newly diagnosed medulloblastoma patients are being studied in the hope of decreasing the neurocognitive effects of therapy (Mulhern et al., 2005). Apart from risk-adapted radiation therapy exposures, some studies are aimed at trying to decrease chemotherapy dosages and treatment duration (Partap & Fisher, 2007). The most commonly used chemotherapy agents for pediatric CNS tumors are vincristine, cytoxan, carboplatin, cisplatin, temozolomide, and lomustine. Each agent can cause potential late effects of therapy, including neuropathies, secondary malignancies, renal toxicity, ototoxicity, and infertility.

Dependent on tumor type, location, and age at diagnosis, pediatric patients with CNS tumors may receive single-modality or multimodality treatments. For many tumor types, the degree of surgical resection is a primary prognostic indicator. Therefore, neurosurgeons may be more apt to aggressively resect tumors. There are a wide range of neurosurgical complications. Posterior fossa syndrome (PFS), or cerebellar mutism syndrome, generally occurs 24 to 48 hours after posterior fossa surgery. It is characterized by mutism, hypotonia, ataxia, dysphagia, and emotional lability. Symptoms can be mild to severe, and as with intensity, the duration of symptoms varies. Most patients regain some degree of function; however, many exhibit late effects of PFS (Robertson et al., 2006). About 66% of patients diagnosed with low-grade astrocytomas treated with only surgery have some degree of long-term neurological deficit (Benesch et al., 2006; Sonderkaer et al., 2003). Cranial and craniospinal radiation has many well-known late effects, including endocrinopathies, neurocognitive deficits, ototoxicity, glaucoma, and secondary malignancies (Kirsch & Tarbell, 2004; Nathan et al., 2007). As stated above, chemotherapy is used in some types of CNS tumors, and its side effects vary widely.

Endocrine Late Effects

Endocrine late effects, common after cranial radiation and certain chemotherapy regimens, are a major concern for SCNST. The prevalence of endocrinopathy in patients with CNS tumors has been reported to be between 40% (Dickerman, 2007; Oberfield & Sklar, 2002) and 70% in the childhood brain tumor population (Sklar, 2002). These endocrinopathies require lifelong health care management, for which guidelines for care have been developed (Nandagopal, Laverdiere, Mulrooney, Hudson, & Meacham, 2008).

Multiple studies have explored endocrine late effects in SCNST. Radiation and chemotherapy, as well as the location of the tumor, determine the degree and type of endocrinopathy. The severe consequences of treatment can affect puberty, fertility, growth, and bone mass (Rutter & Rose, 2007). Endocrinopathies can be divided into the following categories: growth hormone deficiency, thyroid disorders, adrenal insufficiency, gonadotropin deficiencies, precocious puberty, and obesity/metabolic syndrome. Each will be described briefly below.

Growth Hormone Deficiency

Cranial radiation, a common treatment modality for children with CNS tumors, directly affects brain structures, including the complex structures of the hypothalamic–pituitary axis. The degree of side effects is related to the total dose of radiation given, the radiation fields included, and the duration of treatment. The hypothalamus is more radiosensitive and is damaged by lower doses of cranial radiation than the pituitary (Gleeson & Shalet, 2004). Growth hormone secretion is the most sensitive of the hypothalamic functions, and growth hormone deficiency can occur after doses as low as 18 to 25 Gy (Cohen, 2003). Growth hormone deficiency can have a profound impact on height and body mass and can cause metabolic abnormalities, for example, in lipid profile, glucose tolerance, and bone mineral density (Brougham, Kelnar, & Wallace, 2002). Adolescent and young adults with growth hormone deficiency have been found to have lower bone density (Luetjen & Moore, 2005).

Thyroid Disorders

Thyroid disorders occur from disruption of the hypothalamic–pituitary–thyroid axis or following direct damage to the thyroid gland itself. Disruption in the hypothalamic–pituitary axis occurs with radiation and is related to the dose of radiation as well as the length of time from irradiation (Gleeson & Shalet, 2004). Hypothyroidism, thyroid nodules, and secondary thyroid cancer are the consequences of radiation treatment

(Brougham et al., 2002). Thyroid dysfunction may occur in the first year after treatment or as long as 25 years after treatment (Oberfield & Sklar, 2002).

Adrenal Insufficiency

Adrenal insufficiency occurs with radiation doses greater than 50 Gy (Rutter & Rose, 2007). In one study, 19% of children treated with cranial radiation for brain tumors (that did not involve the hypothalamic–pituitary axis) developed insufficiency over a 15-year period. Adrenocorticotrophic hormone deficiency was identified in 38% of children with embryonal brain tumors receiving craniospinal, conformal radiation and high-dose chemotherapy (Laughton et al., 2008).

Gonadal Dysfunction

Survivors of CNS tumors are at risk for gonadal dysfunction and gonadal failure secondary to chemotherapy and radiation. The gonads have 2 main roles: The first is the production of testosterone or estrogens, and the second is production of sperm and ova. Both of these gonadal roles are influenced by the function of the hypothalamic–pituitary axis (Gleeson & Shalet, 2004). A number of chemotherapies are identified as being gonadotoxic, including procarbazine, cisplatin, cyclophosphamide, melphalan, and chlorambucil (Brydoy, Fossa, Dahl, & Bjoro, 2007). Brydoy et al. (2007) reported that any insult that reduces the number of follicles leads to an increased risk of ovarian failure or menopause before age 41. In males, secondary hypogonadism has been reported in survivors who had received 40 to 60 Gy of cranial irradiation (Schmiegelow et al., 2001).

Precocious Puberty

Precocious puberty is defined as onset of puberty before age 8 in girls and age 9 in boys. Lower doses of cranial radiation (18 Gy) can cause precocious puberty (Sklar, 1997). Female gender and young age at treatment are considered risk factors (Gleeson & Shalet, 2004). Most patients who experience premature sexual maturation have also been found to be growth hormone deficient (Sklar, 1997).

Obesity Metabolic Syndrome

Survivors of CNS tumors are at risk for obesity. This important health risk may be due in part to high-dose glucocorticoids during treatment, radiation to the hypothalamic–pituitary axis, and neurological complications. In a retrospective study of 675 children diagnosed and treated for primary brain tumors, body mass index (BMI) increased based on age at tumor diagnosis. Risk factors identified included hypothalamic location, tumor histology consistent with hypothalamic involvement, and extent of surgery. Hypothalamic endocrinopathies were associated with increased BMI (Lustig et al., 2003).

Cardiovascular Late Effects

Although the majority of the literature about late effects in SCNST focuses on endocrinopathies and neuropsychological outcomes, attention to cardiovascular outcomes is emerging. Radiation to the CNS is a key offender for cardiovascular risk, causing the aforementioned hypothalamic–pituitary axis dysfunction, which is closely linked with the potential for cardiovascular disease. For example, radiation-induced growth hormone deficiency may exacerbate an overweight or obesity problem, compounding the risk for dyslipidemia (Garmey et al., 2008; Gurney et al., 2003; Heikens et al., 2000; Link et al., 2004). As previously described, SCNST may also be at risk for metabolic syndrome, a clustering of cardiovascular risk factors such as obesity, insulin resistance, elevated blood pressure, and dyslipidemia, which may further increase the likelihood of poor cardiovascular outcomes (Talvensaari & Knip, 1997; Talvensaari, Lanning, Tapanainen, & Knip, 1996). Cardiovascular risk can be expected to be further compounded if SCNST exhibit neurological or musculoskeletal late effects that contribute to survivors' inability to exercise (Kavey et al., 2007).

Although strokes and blood clots have been reported to be rare outcomes in SCNST, a large cohort study of SCNST reports at least a 3-fold higher risk of these adverse events in survivors who had received chemotherapy, radiation, and surgery than in those who had received surgery and radiation without chemotherapy (Gurney et al., 2003). Late-occurring stroke has been reported in survivors who received cranial radiation doses of greater than 30 Gy, with the highest risk for late-occurring stroke in survivors who received greater than 50 Gy(Bowers et al., 2006). In another study of over 1600 survivors of brain tumors, 18% reported one or more cardiovascular conditions, including stroke, blood clots, or angina-like symptoms (Gurney et al., 2003). An additional risk factor to the heart is radiation to the spine (thoracic and cervical) in excess of 30 Gy (Adams, Hardenbergh, Constine, & Lipshultz, 2003; Jakacki, Goldwein, Larsen, Barber, & Silber, 1993).

Chemotherapy exposure effects of agents typically used in CNS treatment protocols are less well-defined for the cardiovascular system. Heavy-metal chemotherapy such as cisplatin, (Platinol-AQ) and carboplatin (Paraplatin) may put SCNST at risk for dyslipidemia, which could be exacerbated by coexistent morbidities such as a personal

or family history of dyslipidemia, overweight, and obesity (Meinardi et al., 2000; Raghavan, Cox, Childs, Grygiel, & Sullivan, 1992).

Neurological and Neurocognitive Late Effects

As previously described, risk factors for neurological late effects vary widely. The greatest risk factors include the extent and location of tumor resection, age at treatment (younger age at treatment is higher risk), time since completion of therapy (longer time since therapy is higher risk), and total doses of radiation (higher radiation doses and larger fields are higher risk). The resultant neurological and neurocognitive late effects vary considerably among survivors. Motor and sensory deficits including paralysis, movement disorders, and ataxia may impair mobility and create a risk for falls. Other problems such as seizures, eye problems (eg, ocular nerve palsy, nystagmus, papilledema, and optic atrophy), hydrocephalus/shunt malfunctions, and spinal cord damage (eg, neurogenic bladder/bowel, incontinency) have also been reported (Cassidy, Stirling, May, Picton, & Doran, 2000; Khan et al., 2005; Khan, Boop, Onar, & Sanford, 2006; Khan, Marshman, & Mulhern, 2003; McGirt et al., 2008). Neurocognitive dysfunction is expressed as learning deficiencies, diminished IQ, and behavioral changes. The scope of these neurocognitive problems has been reported elsewhere (Anderson & Kunin-Batson, 2009; Conklin et al., 2008; Jain et al., 2008; Mitby et al., 2003; Mulhern et al., 2005; Mulhern, Merchant, Gajjar, Reddick, & Kun, 2004; Ness et al., 2008; Palmer, Reddick, & Gajjar, 2007; Ris, 2007; Schultz et al., 2007; Sonderkaer et al., 2003; Zebrack, Gurney, et al., 2004).

Dental Late Effects

Dental abnormalities are varied and are primarily caused by chemotherapy at a young age and radiation to vital dental structures. Salivary gland dysfunction, tooth/root agenesis, enamel abnormalities, root thinning/shortening, a propensity for caries and periodontal disease have been reported (Yeazel et al., 2004). Propensity for caries may be increased by dexterity issues and neurocognitive impairment, which can contribute to lack of understanding of the importance of dental hygiene.

Sensory Late Effects: Vision and Hearing

SCNST are at risk for changes in vision as a direct result of radiation doses to eye structures and changes in hearing due to radiation and chemotherapy risk factors. Visual late effects include cataracts, orbital hypoplasia, lacrimal duct atrophy, retinopathy, glaucoma, optic nerve damage, and xerophthalmia (Gordon, Char, & Sagerman, 1995; Romestaing & Hullo, 1997). Ototoxicity can occur at doses of 30 Gy, but the highest risk is in patients with doses greater than 50 Gy. The risk may be compounded if the radiation doses are combined with other ototoxic agents (eg, Cisplatinum, aminoglycosides). Hearing late effects include tympanosclerosis, otosclerosis, tinnitus, and conductive and sensorineural loss (Johannesen, Rasmussen, Winther, Halvorsen, & Lote, 2002; Merchant et al., 2004). Conductive hearing loss often occurs early and is transient, whereas sensorineural hearing loss has been reported to be a delayed response to fractionated radiotherapy and is permanent (Hua, Bass, Khan, Kun, & Merchant, 2008).

Psychosocial Late Effects

As with other childhood cancer survivors, survivors of pediatric CNS tumors face other obstacles, encompassing insurance, quality of life, and psychosocial issues. Overall, CNS tumor survivors, more than any other survivor group, can be functionally impaired at the emotional, physical, social, and neurocognitive levels. Apart from the medical aspects of care for SCNST, late effects of tumors and treatments often affect independence, employment status, and social functioning. Various articles published by the Childhood Cancer Survivor Study (CCSS) have looked at different functional status aspects (Ness et al., 2008; Oeffinger et al., 2006; Pang et al., 2008; Schultz et al., 2007; Zebrack, Gurney, et al., 2004; Zeltzer et al., 2008). A CCSS health-related quality-of-life study noted that, as a whole, CNS tumor survivors did not expect high life satisfaction like the other groups studied (Zeltzer et al., 2008).

Second Malignant Neoplasms

Second malignant neoplasms (SMN) are the most serious late effect of treatment because a new malignancy warrants consideration for additional cancer treatment. The largest study published in the United States using SEER data (1973-2002) accounts for relatively large numbers of survivors who are aging into their 30s and 40s and who were treated with both older and more contemporary therapy (Inskip & Curtis, 2007). Childhood cancer patients whose initial treatment included radiotherapy or chemotherapy, or both, were at a higher risk of developing a new solid cancer than those not receiving this therapy (Inskip & Curtis, 2007). The identified 6-fold increased risk of developing a new cancer relative to the general population is similar to that reported by other large cohort studies (Garwicz et al., 2000; Neglia et al., 2006; Olsen et al., 1993). Another international study that

assessed the risk of SMN other than CNS neoplasms observed 43 non-CNS SMNs in 8341 CNS cancer survivors, with a median age at occurrence of 20 years, and the median interval between CNS cancer and SMN was 8.8 years (Maule et al., 2008).

Late-Effect Population-Based Studies

As described in the preceding paragraphs, SCNST face numerous potential late toxicities from their disease or treatment. One can appreciate the magnitude and breadth of these health-related problems by examining the literature from several large population-based studies. In a population-based retrospective cohort study of childhood cancer survivors, Geenan et al. (2007) established total burden scores of adverse health outcomes, using a well-established Common Toxicity Criteria for Adverse Events (CTCAE v3.0) and medical assessment data. The authors concluded that more than 80% of SCNST had a medium, high, or severe burden score of adverse events. In another study, childhood cancer survivors were significantly more likely to report adverse health status across various health domains (general health, mental health, activity limitations, and functional impairment) than were their siblings. When comparing SCNST survivors with leukemia survivors, SCNST were more likely to report increased adverse health status (Hudson et al., 2003).

Two large cohort studies of childhood cancer survivors in the United States and the United Kingdom shed more light on the extent of late effects childhood cancer survivors face years after treatment, presumably during the time when transition to adult providers should be occurring. Although these 2 cohort studies are not specific to SCNST, they were included as part of the cohort and did experience late effects. In the first, Oeffinger et al. (2006) reported that the cumulative incidence of a self-reported chronic health condition reached 74% thirty years after diagnosis, with a cumulative incidence of 42.4% for severe, disabling, or life-threatening conditions or death due to a chronic condition. In the second cohort study, Reulen et al. (2007) reported that survivors of childhood cancer had scores that were comparable to UK norms for mental component scores, but SCNST scored significantly below UK norms on physical component summary scores and were substantially more limited in specific daily activities.

Transition and Risk-Based Care Definitions

For the purposes of our article, "transition" is defined as the purposeful, planned movement of at-risk young adult SCNST from child-centered (pediatric oncology) to adult-oriented health care systems; this is an adaptation of a definition reported in The Society of Adolescent Medicine's position paper (Blum et al., 1993). Risk-based care is defined as cancer survivor health care that takes into consideration specific surgical, chemotherapy, and radiation exposures.

Transition Background

Transition has increasingly become a major topic of research and interest in pediatrics over the past 2 decades. The increased life expectancy of children with a variety of chronic diseases or disorders (eg, cystic fibrosis, Down syndrome, sickle cell disease, spina bifida, congenital heart disorders, endocrine disorders, juvenile idiopathic arthritis, epilepsy, and pediatric malignancies) as well as those who have received transplants presents the challenge of moving survivors from child-oriented to adult-focused care while simultaneously working toward the goal of maintaining positive health outcomes in an uninterrupted manner. Although the idea of transition and the age limits of pediatrics began appearing in the literature in the 1970s and early 1980s (Carroll et al., 1983; Jennison et al., 1972; Litt, 1998), the concept of transition was highlighted in 1984 with a conference convened by US Surgeon General C. Everett Coop. This novel transition conference was later expanded on after endorsement of the concept by several organizations in position papers and consensus statements, including those by the American Academy of Pediatrics (AAP), the American Academy of Family Physicians, the American College of Physicians, the American Society of Internal Medicine, and the Society for Adolescent Medicine (Blum et al., 1993). In 1989, another conference, titled "Growing Up and Getting Medical Care: Youth With Special Health Care Needs," set forth a national agenda by creating the goal of a seamless health care system that would allow young people with special health care needs to move from child-centered to adult-centered services (Blum, 2002). The lofty goal established by the Maternal and Child Health Bureau for the year 2010 iterated that "all youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence." Survivors of CNS tumors fit the Maternal and Child Health Bureau's definition of a child with special health care needs because they have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions that require health and related services beyond what is generally required by children (McPherson et al., 1998). Schidlow and Fiel (1990) brought the concept of "life beyond pediatrics" to the chronic disease literature with their work with the cystic fibrosis population. We have made progress in exploring

how best to achieve the lofty goal of transition for pediatric cancer survivors, but clearly more work is needed in this area, especially for the medically complex SCNST (Duffey-Lind et al., 2006; Freyer & Brugieres, 2008; Ginsberg, Hobbie, Carlson, & Meadows, 2006; Oeffinger & Eshelman, 2005; Oeffinger & McCabe, 2006; Oeffinger, Nathan, & Kremer, 2008; Skinner, Wallace, & Levitt, 2006, 2007; Viner, 2003).

Barriers to Transition

Transition barriers have been reported in the literature for children with chronic illnesses and special health care needs. Since SCNST fulfill the criteria of special health care needs, presumably these barriers are applicable to SCNST. Categorically, these transition barriers have been expressed from several perspectives, including those of the patient/family, the health care providers (pediatric-specialty-based and adult providers), and the health care system (Binks, Barden, Burke, & Young, 2007; Scal & Ireland, 2005; Tong & Kools, 2004; Tsamasiros & Bartsocas, 2002; Vinchon & Dhellemmes, 2007; White, 2002).

Patient/Family–Related Barriers

Survivors of CNS tumors have very complex medical histories and are at risk for moderate to severe late effects of their treatment (Geenen et al., 2007; Hudson et al., 2003; Oeffinger et al., 2006). Cognitive dysfunction may limit a survivor's ability to develop the skills needed to navigate the complexities of the adult health care system (Mulhern et al., 2004). Survivor and family knowledge deficits regarding the cancer diagnosis and the late effects of treatment may inhibit personal advocacy for health care needs, jeopardize communication with providers, and result in a barrier to positive health care outcomes (Kadan-Lottick et al., 2002; Zebrack, Eshelman, et al., 2004). Additionally, survivors and their families have long-standing, trust-based relationships with their oncology and subspecialty multidisciplinary team members, who have provided both physical and psychosocial support during stressful times, leaving little incentive for them to move away from a caring, safe, accommodating family-centered care environment to an adult-focused environment, where trust needs to be reestablished (AAP, 1996; Blum, 1995; Blum et al., 1993; McDonagh, 2007; McDonagh & Viner, 2006; Reiss, Gibson, & Walker, 2005; Rosen, 1993, 1994; Scal, 2002). Some survivors/families may feel isolated or rejected or may fear loss of control when faced with engaging an unfamiliar new health care provider or team of providers (AAP, 1996; Betz, 1998; Rosen, 1994; Sawyer, Blair, & Bowes, 1997; Viner, 2003). Another barrier is "cost," both financial and emotional. The emotional aspects of living with a cancer diagnosis can affect survivors and their families psychosocially in any and all areas of family functioning and dynamics and are similar to those one would expect when surviving through a potentially fatal diagnosis. Financial costs for families as a result of the cancer treatment include declining rates in private insurance coverage offered by employers, soaring costs of insurance, coverage limitations, and disparities in government-sponsored insurance plans across states. These place significant economic strain on families and ultimately create obstacles that affect health care (Newacheck, 2007; Okumura, McPheeters, & Davis, 2007). Some survivors have been forced to choose between maintaining a job and unemployment (Hoffman, 1999). Anecdotally, some survivors have chosen unemployment because the limits on their income would make them ineligible for government-sponsored insurance plans and health care services they deem necessary.

Health Provider Barriers

Pediatric oncology providers. Resounding in the general transition literature as one of the greatest barriers to effective transition is the inability of child-centered health care professionals to let go of their relationships with their patients (Callahan, Winitzer, & Keenan, 2001; Fox, 2002; McDonagh, 2005; McDonagh & Kelly, 2003; Reiss et al., 2005; Rosen, 1994; Sawyer et al., 1997; Viner, 2003). Medical expertise in pediatric oncology and/or the inability to find an adult provider whose skills one can have confidence in sometimes provides justification for maintaining a survivor in the pediatric setting. (Aziz, Oeffinger, Brooks, & Turoff, 2006; Fox, 2002; Reiss et al., 2005; Scal, 2002; Viner, 2003). Physician leaders who specialize in late effects reported in one study that it was difficult to establish and maintain communication with individual community physicians about each survivor, resulting in attrition by loss to follow-up (Aziz et al., 2006).

Adult health care providers. Adult health care providers have reported several barriers to successful transition. First is the burden of assuming care for medically complex survivors who themselves may lack an understanding of their disease or whose families may have knowledge deficits about their treatment (Callahan, Winitzer, & Keenan, 2001; Fox, 2002; Freyer & Kibrick-Lazear, 2006; Reiss et al., 2005; Scal, 2002). Medically complex health care problems, coupled with a provider's knowledge deficit and lack of training in pediatric CNS cancers and treatment, may present additional obstacles (Binks et al., 2007; Viner, 2003). Prolonged visits because of survivors' medical complexities, inappropriate compensation for care coordination, and lack of reimbursement for nonprocedural

services contribute to diminished motivation to provide care (White, 2002). Finally, the emotional bond that existed with the pediatric oncology provider may not exist with the new adult provider assuming care (Binks et al., 2007).

Health System–Related Barriers

There are many health system barriers for SCNST. Perhaps the most pressing barrier is that health care delivery systems have not kept up with the growing numbers of survivors of chronic diseases (White, 2002). Another deterrent to transition may be related to the structure of health services, particularly as it relates to accessibility. For example, gaps in communication and a lack of referral networks linking pediatric oncology providers and adult providers preclude easy access to services (Binks et al., 2007). Insurance issues including discontinuation of parental coverage because of survivors' age or the lack of adult health care providers who accept specific health insurance plans can become a barrier to accessing adult health care (White, 2002). Although it has been reported that adolescents with special health care needs benefit from insurance coverage through public plans more often than adolescents without special health care needs, the continuation of insurance coverage is often based on program eligibility criteria that are less generous for adults than they are for children; also, coverage varies from state to state in the United States (Okumura et al., 2007). Additionally, adult health care systems generally focus on the individual, and it requires some degree of advocacy skills to succeed in obtaining health care. These skills may be limited in SCNST for the reasons previously mentioned. For those SCNST who cannot live independently, health care privacy and guardianship issues may present problems in communication between health care providers and survivors. Cancer survivors in one study reported the following health system barriers: (1) lack of availability of services and providers knowledgeable about the problems of cancer survivors; (2) inability to find good, affordable care that provides access to needed specialists; and (3) inability to locate or obtain complete medical records (Zebrack, Eshelman, et al., 2004).

Methods to Facilitate Transition

For SCNST and their families, one can presume that a smooth, seamless transition to adult health care systems would prevent gaps in medical care, which is critical to successful outcomes. There have been many transition strategies and practices suggested in the literature, but to our knowledge, specific strategies for SCNST have not been clearly delineated, nor have outcomes and practices been evaluated. However, we believe that the general transition strategies suggested for cancer survivors and others with chronic diseases may be applicable to SCNST. The common themes for successful transition are (1) a thorough assessment and knowledge of the population being transitioned, (2) knowledge of individual survivors' unique health care requirements, (3) an assessment of the availability of resources in each transitionee's community, (4) education of key players on the health care team (including the SCNST and their families), and (5) thorough, reciprocal communication between the pediatric health care provider and the adult health care provider and survivor. It is important that the transition take place during a time of health stability, not during a health care crisis (Robertson, 2006), implying that the process needs to start early (Rosen, 1994). Methods to facilitate transition for cancer survivors can be found in Table 1. Transition-related resources, including tools such as Adolescent Autonomy Checklists and Health History Summaries, are available on the Internet, and some suggested sites are listed in Table 2.

Models of Care for SCNST as They Transition to Adult Providers

Little has been published about the availability of health-related services specific to adult SCNST. Evaluations of models of care for survivors are needed within the Children's Oncology Group (COG). However, a necessary first step is to identify the services that exist for SCNST. Bowers and his colleagues (personal communication, 2007) found that there was considerable variability among long-term follow-up (LTFU) programs for adult survivors of childhood brain tumors in institutional members of the COG, with the majority of institutions that responded reporting having a clinic or mechanism in place for follow-up for adult cancer survivors.

Several types of models described in the survivorship literature deserve consideration as potential options for health care for adult SCNST. Several examples of those programs are mentioned in the following sections, to illustrate models for adult survivorship services that exist across the United States. The examples cited are only a few of the existing programs in the COG for adult survivors of pediatric cancer.

Models for Adult Survivors of Pediatric Cancers

Transition to Individual Primary Care Providers

This model has been primarily described as the transition of a survivor from the multidisciplinary oncology/late-effects program in a pediatric institution to an

Table 1. Transition Methods

Methods to facilitate transition from acute care to LTFU
- Clearly explain the purpose of risk-based care
- Discuss long-term plans for follow-up through the survivor continuum
- Address emotional issues of survivorship
- Provide a summary of the cancer diagnosis and treatment
- Educate regarding risks and methods to reduce risk
- Foster self-care practices
- Promote positive decision-making skills for healthy lifestyles

Methods to facilitate transition from LTFU to adult care
- Survivor in an LTFU program
  - Develop a policy for the process of transition
  - Identify qualified and committed health care providers
  - Involve the survivor and the family in the process
  - Assess the expectations and health care beliefs of the survivor and the family
  - Emphasize the goals of risk-based health care
  - Highlight the importance of the survivor/family as the key providers of health care information
  - Focus on the survivor as self-advocate
  - Stress the ongoing communication between the LTFU team and new providers
  - Discuss the transfer of medical records and the oncology medical summary
- Survivors in general (and not in an LTFU program)
  - Use the LTFU community as activists for survivorship
  - Raise public awareness
  - Educate insurance companies and managed care organizations
  - Communicate with state and federal legislators

SOURCE: Oeffinger and Eshelman (2005). Reprinted with kind permission of Springer Science+Business Media.

identified adult practitioner or adult specialist known to the patient. The St Jude model is an example of transitional care that involves phased education and transition to survivors' primary care providers at a specified time after completion of treatment (Hudson et al., 2004). Risk-based care and primary care are managed by each survivor's adult health care provider.

Shared Care Models

Shared care models refer to care that is shared by 2 or more providers of different specialties, or different systems, separated by some boundaries (Oeffinger & McCabe, 2006). For example, in the case of SCNST, shared care may be between an endocrinologist and a primary care physician, between a pediatric oncologist and an adult family medicine specialist, or between various specialists (neurologists, ophthalmologists, etc) and primary care providers. In the United States and internationally, this model works well with patients with chronic diseases (Oeffinger & McCabe, 2006) and shows promise for improved patient outcomes in other chronic diseases (Valk et al., 2004). An evaluation of the shared care model for cancer survivors in the Netherlands showed that (1) survivors would see their primary doctor for a risk-based follow-up visit; (2) the family doctors, with good education, guidelines for follow-up care, and provision of medical records, were interested in sharing in survivor care; and (3) family doctors were satisfied with the shared care program, showing compliance by returning data forms about survivors' health outcomes (Blaauwbroek, Tuinier, Meyboom-de Jong, Kamps, & Postma, 2008). Shared care programs for adult survivors of pediatric cancers exist within the COG, using shared care between pediatric oncology providers and adult health care providers. Examples of these are described in the next sections.

One adult shared care survivorship program is the program at UT Southwestern (UTSW) and Children's Medical Center Dallas, called the After the Cancer Experience (ACE) Program. In this combined pediatric and young adult cancer survivor program, adult survivors receive shared, risk-based care from the late-effects oncology team and a single identified general internal medicine physician who directs care, within the boundaries of a single institutional system (UTSW). The pediatric oncology nurse practitioner is central in this model, serving as the identified link for the survivor between the pediatric institution and the adult institution (which are both teaching facilities within the same university system). One of the advantages to the survivor in this model is familiarity. The nurse practitioner(s) who followed the patient through the pediatric years is the same nurse practitioner following the survivor through the adult years. Although survivors have the option of maintaining their individual primary care physicians for provision of

Table 2. Transition-Related Internet Resources

Name	Web Site	Information
Health Care Transitions	http://hctransitions.ichp.edu	The focus of this site is transition for youth with disabilities and special health care needs. It has a Transition Digest Listserv for youth/young adults with disabilities. The site is supported by the Promising Practices in Health Care transition research project at the University of Florida.
Adolescent Health Transition Project	http://depts.washington.edu/healthtr/	This site is housed at the University of Washington, Seattle, and includes an Adolescent Autonomy checklist, Healthy Transition Summary templates in various languages, a transition timeline, as well as information for health care providers, educators, parents, and family.
Health and Ready to Work (HRTW) National Center	http://www.hrtw.org/index.html	HRTW is funded through the Maternal Child Health Bureau. The site includes a wide range of transitioning topics, screening and assessment tools, and transition planning manuals.
Family Village	http://www.familyvillage.wisc.edu/sp/TRANS.HTML	The site provides resources about specific diseases, an extensive listing of transition and Internet resources for people with cognitive disabilities, their families, and supportive personnel. The site links to research, statistics, and surveys.
Parent Advocacy Coalition for Educational Rights (PACER)	http://www.pacer.org	The site has transition-to-work videos regarding transition, health, and vocational planning.
National Information Center for Children and Youth with Disabilities (NICHY)	http://www.nichcy.org	The site specializes in disability and disability-related services, individualized education plans, family issues, disability organizations, parent groups, and state-related services.

cancer-related risk-based care, many will elect to continue their general preventive adult health care *and* cancer-related risk-based care within the confines of the internal medicine practice, enhancing the holistic care of the survivor. Charting system access for the nurse practitioner in the adult institution affords smooth transition of data to an LTFU database. SCNST who are followed in the ACE Program and who require additional subspecialist care outside the expertise or comfort level of the internal medicine physician are generally referred to these providers within the same health care system (UTSW) if insurance coverage permits, thereby facilitating communication between all team members and enhancing easy access to health records. Similar to the ACE Program are the Survivors Taking Action and Responsibility Program at Northwestern University in Chicago, which uses an internal medicine physician, and the cancer survivor program at Memorial Sloan Kettering in New York, which uses a family practice physician.

Another shared care program is the Living Well After Cancer (LWAC) Program at the University of Pennsylvania, a program that addresses medical and quality-of-life issues for adult survivors of pediatric cancers. Based on time-from-diagnosis and age criteria, survivors are considered for transition from the Cancer Survivorship Program at the Children's Hospital of Philadelphia (CHOP) to the LWAC Program. Introduction of the concept of transition occurs early, oncology treatment summaries and information about the program are provided, and specific treatment protocol information is shared with the new providers in the LWAC Program. Reciprocal follow-up information is returned to CHOP to update each survivor's status after the survivor's visit. Collaborative efforts in research help overcome the barrier of loss of outcome data in this population (Ginsberg et al., 2006).

Another method for shared care of adult SCNST is used in the ATP Five Plus Cancer Survivor Program at Cincinnati Children's Hospital Medical Center, where adult survivors are followed at the pediatric institution, with an adult oncologist from the neighboring adult university system attending clinics on specified days to direct risk-based care. Patients are encouraged to maintain their relationship with their primary health care providers as transition to adult services for subspecialty care is being initiated.

Shared Care Among Specialty Services

Some adult brain tumor treatment programs in adult facilities may share clinical faculty and research interests with oncologists in affiliated pediatric institutions. As a result of these relationships, access to adult health care services may be available for SCNST.

Joint Care

Joint care is defined as a transition time frame established between pediatric oncology providers and a specific adult care provider for a specified period of time to increase the comfort level of the survivor and family being transitioned. For example, first, transition is discussed and methods to facilitate transition are enacted, including preparation and education. Then, the survivor sees the oncology care provider and adult health care provider at the same clinic visit for the first visit or first several visits.

Risk Stratification Models

In an era of dwindling resources and an ever-increasing number of survivors, attention is justifiably being paid to the appropriate provision of care that is economically responsible and to those for whom care is most needed. As a result, risk-stratified approaches to cancer survivor care are being suggested, with survivors who received more intensive chemotherapy and radiation being at highest risk and therefore presumably most in need of resources (Oeffinger et al., 2008; Oeffinger & Eshelman, 2005; Oeffinger & McCabe, 2006; Skinner et al., 2007; Viner, 2003; Wallace et al., 2001). In the case of risk stratification models, SCNST would likely fall in the higher-risk categories, requiring more frequent routine care than lower-risk survivors, who may require follow-up every 2 to 3 years. This further highlights the need for exploration and evaluation of models of care that emphasize fiscally responsible resource utilization, measurement of health outcomes, and maintenance of survivor and provider satisfaction.

Issues in Transitioning SCNST

Should SCNST Be Transitioned to Adult Providers for Risk-Based (Exposure-Related) Care?

Clearly, adults cannot be followed indefinitely in a pediatric institution. However, the question of who should provide risk-based care to this population continues to plague care providers. It is not in a survivor's best interest to be followed by pediatric providers, who are limited in their knowledge about the effects of aging and the intricacies of managing aging organs and adult diseases. Conversely, it is not ideal to have survivors followed by adult providers, who have limited expertise in the late effects of therapy for the treatment of brain tumors. In cases where the survivorship program is located in an adult health care system, survivors can continue to receive their risk-based care in hospital-based cancer centers. Critics of this model believe that this setting overmedicalizes survivors, focusing on the illness concept rather than prevention and wellness, and does not promote the normal development of the tasks of adulthood. However, LTFU follow-up programs focus on education, empowerment through knowledge of risk factors (eg, oncology medical summaries of treatment), promotion of healthy-living strategies, self-assessment practices (eg, teaching breast self-examination), and earlier intervention if needed. Ultimately, it does not matter where the care is provided, so long as the emphasis is on health promotion and health maintenance to maximize health care outcomes for individual survivors.

If Survivors Are Referred to Adult Providers, Will Oncology Research Be Jeopardized?

Current therapy protocols are altered based on many factors, including the late effects experienced by the previous generation of oncology patients. For example, total cumulative anthracycline exposure and risk for cardiotoxicity have been identified, leading to reductions in total doses in frontline therapies. Leaders in survivorship have developed guidelines based on the knowledge gained from studying the outcomes of survivors (www.survivorshipguidelines.org). Ongoing collection of outcome data is crucial because of the unknown risks to aging organs from chemotherapy and radiation exposure. If SCNST are transitioned to adult providers outside the catchment area of pediatric oncology research, then there is a risk of loss of outcome data, if mechanisms are not in place to secure these data or if survivors are not invited to participate in ongoing research. Additionally, outcome data could be further compromised if SCNST drop out or are lost to follow-up, making efforts to design successful plans for the delivery of care extremely important. Therefore, it is imperative that we build collaborative relationships with adult care providers to ensure that we can study survivors as they enter the later decades of life and continue to inform our practice for future generations.

Discussion

Transition to adult care providers is possible and necessary for SCNST. However, to achieve successful transition, leaders in cancer survivorship programs need to clearly assess the accessibility, availability, and interest of adult services; weigh the advantages and disadvantages of those services for their survivors; assess survivor expectations and desires; explore financial and health system resources; secure lines of communication; maintain collection of outcome data; and advocate legislatively for this unique population. Clearly there is no

"one-size-fits-all" model. When considering follow-up models, the leaders of cancer survivor programs need to be ever vigilant of the ultimate outcome—that is, maximizing each survivor's health care potential and assisting survivors to successfully reintegrate into a full, productive life. Constant evaluation and reassessment of what works and what does not, how specific models affect outcome, the costs incurred in program development and maintenance and the publication of pertinent findings about outcomes are critical. Education about risk-based care for SCNST, their families, and future health care providers is paramount to the success of this transition process.

Declaration of Conflicting Interests

The authors declared no conflicts of interest with respect to the authorship and/or publication of this article.

Funding

The authors received no financial support for the research and/or authorship of this article.

References

Adams, M. J., Hardenbergh, P. H., Constine, L. S., & Lipshultz, S. E. (2003). Radiation-associated cardiovascular disease. *Critical Reviews in Oncology/Hematology, 45,* 55-75.

American Academy of Pediatrics, Committee on Children with Disabilities and Committee on Adolescence. (1996). Transition of care provided for adolescents with special health care needs. *Pediatrics, 98*(6, Pt. 1), 1203-1206.

Anderson, F. S., & Kunin-Batson, A. S. (2009). Neurocognitive late effects of chemotherapy in children: The past 10 years of research on brain structure and function. *Pediatric Blood & Cancer, 52,* 159-164.

Aziz, N. M., Oeffinger, K. C., Brooks, S., & Turoff, A. J. (2006). Comprehensive long-term follow-up programs for pediatric cancer survivors. *Cancer, 107,* 841-848.

Benesch M, Lackner H, Sovinz P, et al. (2006). Late sequela after treatment of childhood low-grade gliomas: a retrospective analysis of 69 long-term survivors treated between 1983 and 2003. *Journal of Neuro-Oncology*. 78: 199-205.

Betz, C. L. (1998). Facilitating the transition of adolescents with chronic conditions from pediatric to adult health care and community settings. *Issues in Comprehensive Pediatric Nursing, 21,* 97-115.

Binks, J. A., Barden, W. S., Burke, T. A., & Young, N. L. (2007). What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Archives of Physical Medicine & Rehabilitation, 88,* 1064-1073.

Blaauwbroek, R., Tuinier, W., Meyboom-de Jong, B., Kamps, W. A., & Postma, A. (2008). Shared care by paediatric oncologists and family doctors for long-term follow-up of adult childhood cancer survivors: A pilot study. *Lancet Oncology, 9,* 232-238.

Blum, R. W. (1995). Transition to adult health care: Setting the stage. *Journal of Adolescent Health, 17,* 3-5.

Blum, R. W. (2002). Introduction. Improving transition for adolescents with special health care needs from pediatric to adult-centered health care. *Pediatrics, 110*(6, Pt. 2), 1301-1303.

Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., et al. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health, 14,* 570-576.

Bowers, D. C., Liu, Y., Leisenring, W., McNeil, E., Stovall, M., Gurney, J. G., (2006). Late-occurring stroke among long-term survivors of childhood leukemia and brain tumors: a report from the Childhood Cancer Survivor Study. *J Clin Oncol, 24*(33), 5277-5282.

Brougham, M. F., Kelnar, C. J., & Wallace, W. H. (2002). The late endocrine effects of childhood cancer treatment. *Pediatric Rehabilitation, 5,* 191-201.

Brydoy, M., Fossa, S. D., Dahl, O., & Bjoro, T. (2007). Gonadal dysfunction and fertility problems in cancer survivors. *Acta Oncologica, 46,* 480-489.

Callahan, S. T., Winitzer, R. F., & Keenan, P. (2001). Transition from pediatric to adult-oriented health care: A challenge for patients with chronic disease. *Current Opinion in Pediatrics, 13,* 310-316.

Carroll, G., Massarelli, E., Opzoomer, A., Pekeles, G., Pedneault, M., Frappier, J. Y., et al. (1983). Adolescents with chronic disease. Are they receiving comprehensive health care? *J Adolesc Health Care, 4*(4), 261-265.

Cassidy, L., Stirling, R., May, K., Picton, S., & Doran, R. (2000). Ophthalmic complications of childhood medulloblastoma. *Medical and Pediatric Oncology, 34,* 43-47.

Cohen, L. E. (2003). Endocrine late effects of cancer treatment. *Current Opinion in Pediatrics, 15,* 3-9.

Conklin, H. M., Li, C., Xiong, X., Ogg, R. J., & Merchant, T. E. (2008). Predicting change in academic abilities after conformal radiation therapy for localized ependymoma. *Journal of Clinical Oncologist, 26,* 3965-3970.

Dickerman, J. D. (2007). The late effects of childhood cancer therapy. *Pediatrics, 119*(3), 554-568.

Duffey-Lind, E. C., O'Holleran, E., Healey, M., Vettese, M., Diller, L., & Park, E. R. (2006). Transitioning to survivorship: A pilot study. *Journal of Pediatric Oncology Nursing, 23,* 335-343.

Fox, A. (2002). Physicians as barriers to successful transitional care. *International Journal of Adolescent Medicine and Health, 14,* 3-7.

Freyer, D. R., & Brugieres, L. (2008). Adolescent and young adult oncology: Transition of care. *Pediatric Blood Cancer, 50*(Suppl. 5), 1116-1119.

Freyer, D. R., & Kibrick-Lazear, R. (2006). In sickness and in health: Transition of cancer-related care for older adolescents and young adults. *Cancer, 107*(Suppl. 7), 1702-1709.

Garmey, E. G., Liu, Q., Sklar, C. A., Meacham, L. R., Mertens, A. C., Stovall, M. A., et al. (2008). Longitudinal changes in obesity and body mass index among adult survivors of childhood acute lymphoblastic leukemia: a report from the Childhood Cancer Survivor Study. *J Clin Oncol, 26*(28), 4639-4645.

Garwicz, S., Anderson, H., Olsen, J. H., Dollner, H., Hertz, H., Jonmundsson, G., et al. (2000). Second malignant neoplasms after cancer in childhood and adolescence: A population-based case-control study in the 5 Nordic countries. The Nordic Society for Pediatric Hematology and Oncology. The Association of the Nordic Cancer Registries. *International Journal of Cancer, 88,* 672-678.

Geenen, M. M., Cardous-Ubbink, M. C., Kremer, L. C., van den Bos, C., van der Pal, H. J., Heinen, R. C., et al. (2007). Medical assessment of adverse health outcomes in long-term survivors of childhood cancer. *Journal of American Medical Association, 297,* 2705-2715.

Ginsberg, J. P., Hobbie, W. L., Carlson, C. A., & Meadows, A. T. (2006). Delivering long-term follow-up care to pediatric cancer survivors: Transitional care issues. *Pediatric Blood Cancer, 46,* 169-173.

Gleeson, H. K., & Shalet, S. M. (2004). The impact of cancer therapy on the endocrine system in survivors of childhood brain tumours. *Endocrine-Related Cancer, 11,* 589-602.

Gordon, K. B., Char, D. H., & Sagerman, R. H. (1995). Late effects of radiation on the eye and ocular adnexa. *International Journal of Radiation Oncology Biology Physics, 31,* 1123-1139.

Gurney, J. G., Kadan-Lottick, N. S., Packer, R. J., Neglia, J. P., Sklar, C. A., Punyko, J. A., et al. (2003). Endocrine and cardiovascular late effects among adult survivors of childhood brain tumors: Childhood Cancer Survivor Study. *Cancer, 97,* 663-673.

Heikens, J., Ubbink, M. C., van der Pal, H. P., Bakker, P. J., Fliers, E., Smilde, T. J., et al. (2000). Long term survivors of childhood brain cancer have an increased risk for cardiovascular disease. *Cancer, 88*(9), 2116-2121.

Hoffman, B. (1999). Cancer survivors' employment and insurance rights: A primer for oncologists. *Oncology (Williston Park), 13,* 841-846.

Hua, C., Bass, J. K., Khan, R., Kun, L. E., & Merchant, T. E. (2008). Hearing loss after radiotherapy for pediatric brain tumors: Effect of cochlear dose. *International Journal of Radiation Oncology Biology Physics, 72,* 892-899.

Hudson, M. M., Hester, A., Sweeney, T., Kippenbrock, S., Majcina, R., Vear, S., et al. (2004). A model of care for childhood cancer survivors that facilitates research. *Journal of Pediatric Oncology Nursing, 21,* 170-174.

Hudson, M. M., Mertens, A. C., Yasui, Y., Hobbie, W., Chen, H., Gurney, J. G., et al. (2003). Health status of adult long-term survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Journal of American Medical Association, 290,* 1583-1592.

Inskip, P. D., & Curtis, R. E. (2007). New malignancies following childhood cancer in the United States, 1973-2002. *International Journal of Cancer, 121,* 2233-2240.

Jain, N., Krull, K. R., Brouwers, P., Chintagumpala, M. M., & Woo, S. Y. (2008). Neuropsychological outcome following intensity-modulated radiation therapy for pediatric medulloblastoma. *Pediatric Blood Cancer, 51,* 275-279.

Jakacki, R. I., Goldwein, J. W., Larsen, R. L., Barber, G., & Silber, J. H. (1993). Cardiac dysfunction following spinal irradiation during childhood. *Journal of Clinical Oncology, 11,* 1033-1038.

Jennison, M. H., Coleman, A. B., Feiertag, R. B., Kugel, R. B., Forsyth, W. B., Rinker, A. et **al.** (1972). Age limits of pediatrics. *Pediatrics, 49,* 463.

Johannesen, T. B., Rasmussen, K., Winther, F. O., Halvorsen, U., & Lote, K. (2002). Late radiation effects on hearing, vestibular function, and taste in brain tumor patients. *International Journal of Radiation Oncology Biology Physics, 53,* 86-90.

Kadan-Lottick, N. S., Robison, L. L., Gurney, J. G., Neglia, J. P., Yasui, Y., Hayashi, R., et al. (2002). Childhood cancer survivors' knowledge about their past diagnosis and treatment: Childhood Cancer Survivor Study. *JAMA, 287*(14), 1832-1839.

Kavey, R. E., Allada, V., Daniels, S. R., Hayman, L. L., McCrindle, B. W., Newburger, J. W., et al. (2007). Cardiovascular risk reduction in high-risk pediatric patients: A scientific statement from the American Heart Association Expert Panel on Population and Prevention Science; the Councils on Cardiovascular Disease in the Young, Epidemiology and Prevention, Nutrition, Physical Activity and Metabolism, High Blood Pressure Research, Cardiovascular Nursing, and the Kidney in Heart Disease; and the Interdisciplinary Working Group on Quality of Care and Outcomes Research. *Journal of Cardiovascular Nursing, 22,* 218-253.

Khan, R. B., Boop, F. A., Onar, A., & Sanford, R. A. (2006). Seizures in children with low-grade tumors: Outcome after tumor resection and risk factors for uncontrolled seizures. *Journal of Neurosurgery, 104*(Suppl. 6), 377-382.

Khan, R. B., Hunt, D. L., Boop, F. A., Sanford, R. A., Merchant, T. E., Gajjar, A., et al. (2005). Seizures in children with primary brain tumors: Incidence and long-term outcome. *Epilepsy Research, 64,* 85-91.

Khan, R. B., Marshman, K. C., & Mulhern, R. K. (2003). Atonic seizures in survivors of childhood cancer. *Journal of Child Neurology, 18,* 397-400.

Kirsch, D. G., & Tarbell, N. J. (2004). New technologies in radiation therapy for pediatric brain tumors: The rationale for proton radiation therapy. *Pediatric Blood Cancer, 42,* 461-464.

Laughton, S. J., Merchant, T. E., Sklar, C. A., Kun, L. E., Fouladi, M., Broniscer, A., et al. (2008). Endocrine outcomes for children with embryonal brain tumors after risk-adapted craniospinal and conformal primary-site irradiation and high-dose chemotherapy with stem-cell rescue on the SJMB-96 trial. *Journal of Clinical Oncology, 26,* 1112-1118.

Link, K., Moell, C., Garwicz, S., Cavallin-Stahl, E., Bjork, J., Thilen, U., et al. (2004). Growth hormone deficiency predicts cardiovascular risk in young adults treated for acute lymphoblastic leukemia in childhood. *J Clin Endocrinol Metab, 89*(10), 5003-5012.

Litt, I. F. (1998). Age limits of pediatrics, American Academy of Pediatrics, Council on Child Health, Pediatrics, 1972;49:463. *Pediatrics, 102*(1 Pt 2), 249-250

Luetjen, T., & Moore, W. V. (2005). Bone density after completion of growth hormone treatment for growth failure. *Journal of Pediatric Endocrinology & Metabolism, 18,* 1053-1061.

Lustig, R. H., Post, S. R., Srivannaboon, K., Rose, S. R., Danish, R. K., Burghen, G. A., et al. (2003). Risk factors for the development of obesity in children surviving brain tumors. *Journal of Clinical Endocrinology Metabolism, 88,* 611-616.

Maule, M., Scelo, G., Pastore, G., Brennan, P., Hemminki, K., Pukkala, E., et al. (2008). Risk of second malignant neoplasms after childhood central nervous system malignant tumours: An international study. *European Journal of Cancer, 44,* 830-839.

McDonagh, J. E. (2005). Growing up and moving on: transition from pediatric to adult care. *Pediatr Transplant, 9*(3), 364-372.

McDonagh, J. E. (2007). Transition of care from paediatric to adult rheumatology. *Archives of Disease in Childhood, 92,* 802-807.

McDonagh, J. E., & Kelly, D. A. (2003). Transitioning care of the pediatric recipient to adult caregivers. *Pediatr Clin North Am, 50*(6), 1561-1583, xi-xii.

McDonagh, J. E., & Viner, R. M. (2006). Lost in transition? Between paediatric and adult services. *British Medical Journal, 332*, 435-436.

McGirt, M. J., Chaichana, K. L., Atiba, A., Attenello, F., Yao, K. C., & Jallo, G. I. (2008). Resection of intramedullary spinal cord tumors in children: Assessment of long-term motor and sensory deficits. *Journal of Neurosurgery: Pediatrics, 1,* 63-67.

McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W., et al. (1998). A new definition of children with special health care needs. *Pediatrics, 102*(1, Pt. 1), 137-140.

Meinardi, M. T., Gietema, J. A., van der Graaf, W. T., van Veldhuisen, D. J., Runne, M. A., Sluiter, W. J., et al. (2000). Cardiovascular morbidity in long-term survivors of metastatic testicular cancer. *Journal of Clinical Oncology, 18,* 1725-1732.

Merchant, T. E., Gould, C. J., Xiong, X., Robbins, N., Zhu, J., Pritchard, D. L., et al. (2004). Early neuro-otologic effects of three-dimensional irradiation in children with primary brain tumors. *International Journal of Radiation Oncology Biology Physics, 58,* 1194-1207.

Mitby, P. A., Robison, L. L., Whitton, J. A., Zevon, M. A., Gibbs, I. C., Tersak, J. M., et al. (2003). Utilization of special education services and educational attainment among long-term survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Cancer, 97,* 1115-1126.

Mulhern, R. K., Merchant, T. E., Gajjar, A., Reddick, W. E., & Kun, L. E. (2004). Late neurocognitive sequelae in survivors of brain tumours in childhood. *Lancet Oncology, 5,* 399-408.

Mulhern, R. K., Palmer, S. L., Merchant, T. E., Wallace, D., Kocak, M., Brouwers, P., et al. (2005). Neurocognitive consequences of risk-adapted therapy for childhood medulloblastoma. *Journal of Clinical Oncology, 23,* 5511-5519.

Nandagopal, R., Laverdiere, C., Mulrooney, D., Hudson, M. M., & Meacham, L. (2008). Endocrine late effects of childhood cancer therapy: A report from the Children's Oncology Group. *Hormone Research, 69,* 65-74.

Nathan, P. C., Patel, S. K., Dilley, K., Goldsby, R., Harvey, J., Jacobsen, C., et al. (2007). Guidelines for identification of, advocacy for, and intervention in neurocognitive problems in survivors of childhood cancer: A report from the Children's Oncology Group. *Archives of Pediatrics & Adolescent Medicine, 161,* 798-806.

Neglia, J. P., Robison, L. L., Stovall, M., Liu, Y., Packer, R. J., Hammond, S., et al. (2006). New primary neoplasms of the central nervous system in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Journal of the National Cancer Institute, 98,* 1528-1537.

Ness, K. K., Gurney, J. G., Zeltzer, L. K., Leisenring, W., Mulrooney, D. A., Nathan, P. C., et al. (2008). The impact of limitations in physical, executive, and emotional function on health-related quality of life among adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Archives of Physical Medicine and Rehabilitation, 89,* 128-136.

Newacheck, P. W. (2007). Insurance matters: Adolescents with special healthcare needs. *Journal of Adolescent Health, 41,* 319-320.

Oberfield, S. E., & Sklar, C. A. (2002). Endocrine sequelae in survivors of childhood cancer. *Adolescent Medicine, 13,* 161-169.

Oeffinger, K. C., & Eshelman, D. A. (2005). Transition issues. In C. L. Schwartz, W. L. Hobbie, L. S. Constine, & K. S. Ruccione (Eds.), *Survivors of childhood and adolescent cancer: A multidisciplinary approach* (pp. 333-344). Heidelberg, Germany: Springer.

Oeffinger, K. C., & McCabe, M. S. (2006). Models for delivering survivorship care. *Journal of Clinical Oncology, 24,* 5117-5124.

Oeffinger, K. C., Mertens, A. C., Sklar, C. A., Kawashima, T., Hudson, M. M., Meadows, A. T., et al. (2006). Chronic health conditions in adult survivors of childhood cancer. *New England Journal of Medicine, 355,* 1572-1582.

Oeffinger, K. C., Nathan, P. C., & Kremer, L. C. (2008). Challenges after curative treatment for childhood cancer and long-term follow up of survivors. *Pediatric Clinics of North America, 55,* 251-273.

Okumura, M. J., McPheeters, M. L., & Davis, M. M. (2007). State and national estimates of insurance coverage and health care utilization for adolescents with chronic conditions from the National Survey of Children's Health, 2003. *Journal of Adolescent Health, 41,* 343-349.

Olsen, J. H., Garwicz, S., Hertz, H., Jonmundsson, G., Langmark, F., Lanning, M., et al. (1993). Second malignant neoplasms after cancer in childhood or adolescence. Nordic Society of Paediatric Haematology and Oncology Association of the Nordic Cancer Registries. *British Medical Journal, 307*, 1030-1036.

Palmer, S. L., Reddick, W. E., & Gajjar, A. (2007). Understanding the cognitive impact on children who are treated for medulloblastoma. *Journal of Pediatric Psychology, 32,* 1040-1049.

Pang, J. W., Friedman, D. L., Whitton, J. A., Stovall, M., Mertens, A. C., Robison, L. L., et al. (2008). Employment status among adult survivors in the Childhood Cancer Survivor Study. *Pediatric Blood Cancer, 50,* 104-110.

Partap, S., & Fisher, P. G. (2007). Update on new treatments and developments in childhood brain tumors. *Current Opinion in Pediatrics, 19,* 670-674.

Raghavan, D., Cox, K., Childs, A., Grygiel, J., & Sullivan, D. (1992). Hypercholesterolemia after chemotherapy for testis cancer. *Journal of Clinical Oncology, 10,* 1386-1389.

Reiss, J. G., Gibson, R. W., & Walker, L. R. (2005). Health care transition: Youth, family, and provider perspectives. *Pediatrics, 115,* 112-120.

Reulen, R. C., Winter, D. L., Lancashire, E. R., Zeegers, M. P., Jenney, M. E., Walters, S. J., et al. (2007). Health status of adult survivors of childhood cancer: A large-scale population-based study from the British Childhood Cancer Survivor Study. *International Journal of Cancer, 121,* 633-640.

Ries, L. A. G., Eisner, M. P., Kosary, C. L., Hankey, B. F., Miller, B. A., Clegg, L., et al. (2004). *SEER cancer statistics review, 1975-2001.* Bethesda, MD: National Cancer Institute.

Ris, M. D. (2007). Lessons in pediatric neuropsycho-oncology: What we have learned since Johnny Gunther. *Journal of Pediatric Psychology, 32,* 1029-1037.

Robertson, L. (2006). When should young people with chronic rheumatic disease move from pediatric to adult-centred care? *Best Pract Res Clin Rheumatol, 20*(2), 387-397.

Robertson P.L., Muraszko K.M., Holmes E.J., et al. (2006). Incidence and severity of postoperative cerebellar mutism syndrome in children with medulloblastoma: a prospective study by the Children's Oncology Group. *J Neurosurg* (6 Suppl Pediatrics) 105: 444-451.

Romestaing, P., & Hullo, A. (1997). Late effects of radiation on the eye and ocular adnexa. *Cancer Radiotherapy, 1,* 683-691.

Rosen, D. S. (1993). Transition to adult health care for adolescents and young adults with cancer. *Cancer, 71*(Suppl. 10), 3411-3414.

Rosen, D. S. (1994). Transition from pediatric to adult-oriented health care for the adolescent with chronic illness or disability. *Adolescent Medicine, 5,* 241-248.

Rutter, M. M., & Rose, S. R. (2007). Long-term endocrine sequelae of childhood cancer. *Current Opinion in Pediatrics, 19,* 480-487.

Sawyer, S. M., Blair, S., & Bowes, G. (1997). Chronic illness in adolescents: Transfer or transition to adult services? *Journal of Paediatric Child Health, 33,* 88-90.

Scal, P. (2002). Transition for youth with chronic conditions: Primary care physicians' approaches. *Pediatrics, 110*(6, Pt. 2), 1315-1321.

Scal, P., & Ireland, M. (2005). Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics, 115,* 1607-1612.

Schidlow, D. V., & Fiel, S. B. (1990). Life beyond pediatrics: Transition of chronically ill adolescents from pediatric to adult health care systems. *Medical Clinics of North America, 74,* 1113-1120.

Schmiegelow, M., Lassen, S., Poulsen, H. S., Schmiegelow, K., Hertz, H., Andersson, A. M., et al. (2001). Gonadal status in male survivors following childhood brain tumors. *Journal of Clinical Endocrinology & Metabolism, 86,* 2446-2452.

Schultz, K. A., Ness, K. K., Whitton, J., Recklitis, C., Zebrack, B., Robison, L. L., et al. (2007). Behavioral and social outcomes in adolescent survivors of childhood cancer: A report from the childhood cancer survivor study. *Journal of Clinical Oncology, 25,* 3649-3656.

Skinner, R., Wallace, W. H., & Levitt, G. A. (2006). Long-term follow-up of people who have survived cancer during childhood. *Lancet Oncology, 7,* 489-498.

Skinner, R., Wallace, W. H., & Levitt, G. A. (2007). Long-term follow-up of children treated for cancer: Why is it necessary, by whom, where and how? *Archives of Disease in Childhood, 92,* 257-260.

Sklar, C. A. (1997). Growth and neuroendocrine dysfunction following therapy for childhood cancer. *Pediatric Clinics of North America, 44,* 489-503.

Sklar, C. A. (2002). Childhood brain tumors. *Journal of Pediatric Endocrinology & Metabolism, 15*(Suppl. 2), 669-673.

Sonderkaer, S., Schmiegelow, M., Carstensen, H., Nielsen, L. B., Muller, J., & Schmiegelow, K. (2003). Long-term neurological outcome of childhood brain tumors treated by surgery only. *Journal of Clinical Oncology, 21,* 1347-1351.

Talvensaari, K., & Knip, M. (1997). Childhood cancer and later development of the metabolic syndrome. *Annals of Medicine, 29,* 353-355.

Talvensaari, K. K., Lanning, M., Tapanainen, P., & Knip, M. (1996). Long-term survivors of childhood cancer have an increased risk of manifesting the metabolic syndrome. *Journal of Clinical Endocrinology Metabolism, 81,* 3051-3055.

Tong, E. M., & Kools, S. (2004). Health care transitions for adolescents with congenital heart disease: Patient and family perspectives. *Nursing Clinics of North America, 39,* 727-740.

Tsamasiros, J., & Bartsocas, C. S. (2002). Transition of the adolescent from the children's to the adults' diabetes clinic. *Journal of Pediatric Endocrinology & Metabolism, 15,* 363-367.

Valk, G. D., Renders, C. M., Kriegsman, D. M., Newton, K. M., Twisk, J. W., van Eijk, J. T., et al. (2004). Quality of care for patients with type 2 diabetes mellitus in the Netherlands and the United States: a comparison of two quality improvement programs. *Health Serv Res, 39*(4 Pt 1), 709-725.

Vinchon, M., & Dhellemmes, P. (2007). The transition from child to adult in neurosurgery. *Advances and Technical Standards in Neurosurgery, 32*, 3-24.

Viner, R. (2003). Bridging the gaps: Transition for young people with cancer. *European Journal of Cancer, 39,* 2684-2687.

Wallace, W. H., Blacklay, A., Eiser, C., Davies, H., Hawkins, M., Levitt, G. A., et al. (2001). Developing strategies for long-term follow-up of survivors of childhood cancer. *British Medical Journal, 323*, 271-274.

White, P. H. (2002). Access to health care: Health insurance considerations for young adults with special health care needs/disabilities. *Pediatrics, 110*(6, Pt. 2), 1328-1335.

Wilson V, McDonough J, Tochner Z. (2005). *J Pediatr Hematol Oncol*. 27: 444-448.

Yeazel, M. W., Gurney, J. G., Oeffinger, K. C., Mitby, P. A., Mertens, A. C., Hudson, M. M., et al. (2004). An examination of the dental utilization practices of adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Journal of Public Health Dentistry, 64,* 50-54.

Zebrack, B. J., Eshelman, D. A., Hudson, M. M., Mertens, A. C., Cotter, K. L., Foster, B. M., et al. (2004). Health care for childhood cancer survivors: Insights and perspectives from a Delphi panel of young adult survivors of childhood cancer. *Cancer, 100,* 843-850.

Zebrack, B. J., Gurney, J. G., Oeffinger, K., Whitton, J., Packer, R. J., Mertens, A., et al. (2004). Psychological outcomes in long-term survivors of childhood brain cancer: A report from the childhood cancer survivor study. *Journal of Clinical Oncology, 22,* 999-1006.

Zeltzer, L. K., Lu, Q., Leisenring, W., Tsao, J. C., Recklitis, C., Armstrong, G., et al. (2008). Psychosocial outcomes and health-related quality of life in adult childhood cancer survivors: A report from the childhood cancer survivor study. *Cancer Epidemiology Biomarkers & Prevention, 17,* 435-446.

Bios

Debra Eshelman-Kent, RN, MSN, CPNP, is an advanced practice nurse who has worked in the late-effects arena for the past 16 years. She has published and presented on survivorship issues, worked on the original task force responsible for the development of the *COG Late Effects Guidelines*, and has served in leadership positions in the Children's Oncology Group and the Association of Pediatric Hematology/Oncology Nurses. She is currently one of the nurse practitioners in the ATP Five Plus Long Term Cancer Survivor Clinic at Cincinnati Children's Hospital Medical Center.

Elizabeth Gilger, RN, MSN, CPON, CPNP, is an advanced practice nurse who has worked with pediatric oncology patients and families for the past 12 years. Since obtaining her MSN, she has focused on the care of patients with central nervous system tumors. She has presented and published on various pediatric oncology topics. She is one of the nurse practitioners in the neurooncology clinic at Cincinnati Children's Hospital Medical Center.

Maureen Gallagher is an advanced practice nurse who has worked with children and families with chronic care issues over the past 10 years. She has been involved in numerous projects providing family-centered care and developing programs for children with complex medical problems. She joined the neurooncology team at Cincinnati Children's Hospital Medical Center in 2006.

Continuing Education Credit

The *Journal of Pediatric Oncology Nursing* is pleased to offer the opportunity to earn pediatric hematology/oncology nursing continuing education credit for this article online. Go to www.aphon.org and select "Continuing Education." There you can read the article again or go directly to the posttest assessment. The cost is $15 for each article. You will be asked for a credit card or online payment service number.

The posttest consists of 11 questions based on the article, plus several assessment questions (e.g. how long did it take you to read the article and complete the posttest?). A passing score is 8 out of 11 questions correct on the posttest and completion of the assessment questions yields one hour of continuing education in pediatric hematology/oncology nursing for each article.

The Association of Pediatric Hematology/Oncology Nurses is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.