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Abstract

Although progress has been made in the treatment of childhood brain tumors, work remains to understand the complexities of disease, treatment, and contextual factors that underlie individual differences in outcome. A combination of both an idiographic approach (incorporating observations made by adult survivors of childhood brain tumors) and a nomothetic approach (reviewing the literature for brain tumor survivors as well as childhood cancer survivors) is presented. Six areas of concern are reviewed from both an idiographic and nomothetic perspective, including social/emotional adjustment, insurance, neurocognitive late effects, sexuality and relationships, employment, and where survivors accessed information about their disease and treatment and possible late effects. Guidelines to assist health care professionals working with childhood brain tumor survivors are offered with the goal of improving psychosocial and neurocognitive outcomes in this population.

Keywords

childhood brain tumors, pediatric cancer survivors, neurocognitive outcomes, psychosocial outcomes, interventions

Those who have worked in pediatric oncology over the past 2 decades have seen the tremendous progress made in the treatment of childhood cancer. Children diagnosed with cancer are living longer. For example, the 5-year survival rates for all childhood cancers increased from 58.1% in 1975-1977 to 79.6% in 1996-2003 (Ries et al., 2007). This is a dramatic change for a group of diseases that were almost universally fatal 30 to 40 years ago. The survival rates for children diagnosed with brain tumors—although not as striking—are improving. In the years between 1975 and 1984, 59% of children diagnosed with brain tumors achieved 5-year survival, whereas by 1985-1994, 67% of children with malignant brain tumors were still alive 5 years or more after diagnosis (Gurney, Smith, & Bunin, 2001).

As survival rates have improved, the focus on long-term and quality outcomes for survivors has increased. Improved treatments for pediatric cancers often come with a cost. Children diagnosed with brain tumors are often at higher risk than children with other forms of cancer because of the direct risk to the developing brain from the tumor, treatments, or sequelae of the disease and/or treatments. A number of factors influence neurobehavioral outcomes in childhood brain tumor survivors. The rapidly changing brains of young children are more vulnerable to cancer treatments than their older counterparts. The type and amount of treatment(s), the amount of time that has elapsed since treatment, the child's gender, the age at diagnosis, and associated neurological complications, such as hydrocephalus, seizures, sensory

or motor impairments, and genetic, health, or developmental problems, that the child may have had before treatment also affect outcomes. A total of 17% of a sample of 1607 pediatric brain tumor survivors diagnosed between 1970 and 1986 developed neurosensory impairments (Packer et al., 2003). In all, 49% of that sample of survivors developed problems with coordination (49%), motor control (26%), and/or seizures (25%).

Pediatric oncology health care providers have actively sought modifications in treatment protocols to balance the acceptable toxicity with improved response rates while minimizing long-term sequelae. For example, exposure to radiation has been delayed, eliminated, modified, or reduced, whereas chemotherapy agents have been selected with the goal of reducing long-term toxicity. Researchers have begun to explore the possibility of neuroprotective agents as well. In addition to altering treatment protocols to minimize late toxicities in children with cancer, our ability to measure their outcomes has improved as well. Improvements in methodology have contributed to the behavioral science knowledge base, which in turn, have provided data to guide treatment modifications. Samples are larger and often more differentiated than in past years, and more powerful computers have allowed for more sophisticated research designs that can

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incorporate the developmental questions unique to a pediatric population.

Health care providers working with children who have survived cancer continue to note the wide variation in individual neurobehavioral outcomes. The factors that determine individual variance in neurobehavioral outcomes are not yet well understood. In a commentary article on neurobehavioral outcomes in pediatric cancer, Brouwers (2005) suggests that in the coming years, we may see “fewer patients studied more intensively, and a greater emphasis on the individual and individualized approaches” (p. 81).

In the literature of neurobehavioral outcomes in children with brain tumors, nomothetic approaches (which seek to describe relationships across a cohort of individuals) predominate. However, idiographic approaches (which seek to describe the individual as set apart from other individuals) may be helpful as well. A recent example of such an approach incorporated focus groups and in-depth interviews to study 14 childhood cancer survivors as they transitioned from adolescence to adulthood (Boydell, Stasiulis, Greenberg, Greenberg, & Spiegler, 2008). Idiographic approaches such as this may better help us understand individual differences in how survivors characterize the “goodness” of their outcomes or the quality of their lives. Anecdotally, the variability in outcomes is illustrated by a recent interview with two survivors: one is a graduate student in biotechnology at a prestigious university and pursuing a career in medicine, whereas the other survivor’s mother needed to correspond with the author because he was unable to write. Although the survivor’s cognitive abilities were significantly limited, his mother described him as happy and reported how much he enjoyed his job, his collection of old movies, and his interactions with family and community members. Both of these survivors have gone on to have quality lives. As providers attempt to define “good outcomes” and “quality of life” for childhood cancer survivors, a combination of both nomothetic and idiographic approaches may prove to be the most informative.

To this end, a small group ($n = 11$) of adult survivors of childhood brain tumors was invited for an informal discussion at Children’s Hospitals & Clinics of Minnesota. The gathering was informal (not part of a research study) to allow participants to offer their unique perspectives on the survivor’s experience and to help providers understand the issues that were important to them. The goal of the gathering was to hear informally from a group of survivors about their concerns and experiences. The team consisted of a neuropsychologist who facilitated the group and 2 advanced practice pediatric oncology nurses who were also available to address specific medical questions from the participants. We were interested in how the concerns of our survivors compared with those identified in the research. We hoped to use that knowledge to

develop strategies to provide better care to our patients with brain tumors.

Letters were sent to potential participants inviting them to a group discussion about their experiences as childhood brain tumor survivors. Only adult survivors (older than 18 years) who lived in the state of Minnesota were asked to participate. In addition, letters were sent only to individuals with a minimum of 5 years survivorship. Dinner was provided to facilitate participation at an evening event, but participants did not receive any financial compensation. The particular group of adult survivors who participated had experienced heterogeneous tumor types (including medulloblastomas [4/11], astrocytomas [3/11], PNET [3/11], and unknown [1/11]) and were of a variety of ages (mean = 28.4 years; range 23-33 years). Their tumors were diagnosed between 1978 and 1995, and treatment exposures varied, including surgical resection, chemotherapy, and radiation (mean region dose = 5080 cGy; range = 1500-9000 cGy). These survivors reported various levels of physical and/or cognitive difficulties ranging from none or mild to significant problems. No more specific information was collected, nor were any medical records or neuropsychological testing records reviewed because this was an informal gathering.

Participants were invited to share background information about themselves and their diagnosis and treatment. An outline of possible concerns was provided, but participants were also encouraged to raise new topics. Over the course of the evening, survivors expressed concern across 6 different areas: social/emotional adjustment, insurance, neurocognitive late effects, sexuality and relationships, employment, and where survivors accessed information about their disease, treatment, and possible late effects. These survivors’ concerns (an idiographic approach) will be contrasted with what is reported in the literature (a nomothetic approach) with the hope of providing a broader understanding of the issues that survivors of pediatric brain tumors face in adulthood.

Survivors’ Concerns

Social/Emotional Adjustment

Survivors in this group acknowledged many difficulties in their emotional adjustment to having survived childhood cancer. One reported having “severe anxiety about dealing with doctors—it’s like PTSD.” Another mentioned hating the smell of hospitals. One individual cited trying to make his doctor’s appointments for early mornings, so he didn’t have to agonize all day wondering if his cancer had returned. Others mentioned their anxiety flaring up around times they were being monitored to make sure their cancer had not recurred (eg, magnetic resonance imaging appointments).

This is consistent with a growing body of literature reporting high rates of posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS) in young adult survivors of childhood cancer (Hobbie et al., 2000; Rourke, Hobbie, & Kazak, 2002). Clinical rates of PTSD have been reported to affect approximately 1 in 5 young adult survivors (Barakat, Alderfer, & Kazak, 2006).

PTSD and PTSS symptoms affect the larger family system as well. Some of the survivors in our group reported feeling like they were unable to share any health issues with their parents "because they'll worry." One individual noted that even mentioning to her mother that she had a headache could set off alarm bells. Reports from the literature confirm this as well, with rates of moderate to severe PTSS reported for 44% of mothers and 35% of fathers of childhood cancer survivors (Kazak et al., 2004). A recent study, however, reported that their group of parents of children with cancer did not demonstrate any evidence of increased PTSS compared with parents of healthy children (Jurbergs, Long, Ticona, & Phipps, 2009). However, they noted that parents of children who had experienced a relapse reported higher levels of PTSS than parents of children who had not relapsed. Survivors in our group also acknowledged a persistent feeling of guilt about having put their families and siblings through the ordeal of childhood cancer and its aftermath. This has been reported in other groups of adult survivors of childhood brain tumors as well (Prouty, Ward-Smith, & Hutto, 2006).

Although many studies show that the majority of long-term childhood cancer survivors are psychologically well and do not report symptoms of distress, risks may be compounded for survivors of brain tumors given their greater likelihood of experiencing physical, cognitive, and psychosocial limitations (Zebrack et al., 2004). In a group of 2979 survivors of childhood cancer and 649 of their siblings, survivors of central nervous system (CNS) tumors (along with survivors of leukemia or neuroblastoma) were at increased risk for adverse behavioral and social outcomes (Schultz et al., 2007). Treatment with cranial radiation was a specific risk factor. One explanation for these problems may be due to declines in survivors' neurocognitive functioning (particularly in those brain tumor survivors treated with cranial radiation). However, the factors that predict behavioral outcomes in children with brain tumors may be different from those that predict neuropsychological outcomes. Carlson-Green, Morris, and Krawiecki (1995) reported that in their group of 63 children with heterogeneous brain tumors, family variables (eg, family stress, marital status) were better predictors of behavioral outcomes, whereas a combination of both family (eg, socioeconomic status [SES], maternal stress, marital status) and treatment variables (time since treatment, number of

treatment modalities) better predicted neurocognitive outcomes. The authors suggested that the traditional view of using only medical and treatment variables to predict neurocognitive outcomes may be too narrow.

Children treated for CNS malignancies—particularly those with cognitive impairments—have been reported to be more socially isolated based on teacher-report, peer-report, and self-report (Vannatta, Gartstein, Short, & Noll, 1998). Increased physical limitations, neurosensory issues, missed school days, and/or reduced participation in social activities may exacerbate brain tumor survivors' social difficulties. Survivors of posterior fossa tumors who received cranial radiation have been reported to have difficulties with social skills and attention (Mabbott et al., 2005). Children with brain tumors also may be at higher risk for social problems as compared with other children with chronic illness. Social functioning and facial expression recognition skills in survivors of heterogeneous pediatric brain tumors were reported to be significantly impaired across multiple measures when compared with children with juvenile rheumatoid arthritis (Bonner et al., 2008).

Changes in physical appearance may also contribute to social difficulties in brain tumor survivors. There are few studies that have examined this issue of physical disfigurement, but moderate to severe disfigurement has been identified as a risk factor for decreased social competence in a group of children with brain tumors (Mulhern, Carpentieri, Shema, Stone, & Fairclough, 1993). However, no one in our small group reported this kind of difficulty.

Specific treatments such as cranial radiation may also affect survivors' ability to fully negotiate the social problem-solving demands of everyday life. The late effects of cranial radiation therapy (CRT) are thought to inhibit normal brain volume development in young children (Reddick et al., 2005), and the loss of white matter may contribute to the gradual neurocognitive decline often seen in children with brain tumors (Mulhern et al., 2001). In their study of children treated for medulloblastomas, Reddick et al. (2005) reported that aggressive therapy was associated with lower volumes of normal appearing white matter (NAWM), which is known to be associated with significant risk of cognitive deficits and slowed processing speeds.

It has been suggested that the slow processing speed seen in some survivors treated with radiation may affect their ability to quickly process social nuances in interactions or communications. This may limit their social effectiveness; for example, not being able to quickly "get" jokes told to them by a peer (Armstrong, 2005). Slow processing speeds may also affect learning, the ability to take in and digest information, and to make good judgments. Using a prospective longitudinal

research design, a recent study of children with brain tumors treated with radiation reported that the children's parents rated them as having poor communication skills using the Vineland Scales of Adaptive Behavior (Chai, 2007). Poor communication skills would also be expected to negatively affect social development.

At the extreme end of survivors struggling with emotional issues are those who have considered or committed suicide. Although suicide among childhood cancer survivors is a rare event, one study reported an increased risk of suicide in a large, population-based cohort of heterogeneous childhood cancer survivors in the United States (Howard, Inskip, & Travis, 2007). The median duration between initial cancer diagnosis and suicide was 10 years, and the median age at suicide was 26.8 years, with risk comparable for males and females. Risk for patients diagnosed with cancer during early adolescence (ages 10-14 years) and later adolescence (15-20 years) was higher than those diagnosed at younger ages (0-4 or 5-9 years). Risk was not higher for patients initially treated with radiation as compared with those who did not receive radiotherapy as part of their initial treatment.

In a smaller study of 226 adult survivors of childhood cancer (mean age = 28 years) evaluated in a survivor clinic, more than 1 out of 8 reported having suicidal thoughts or previous attempts to take their lives many years after they were treated (Recklitis, Lockwood, Rothwell, & Diller, 2006). Only 11 were significantly depressed based on self-report rating scales. Data analysis showed that factors associated with more suicidal symptoms included younger age at diagnosis, greater time since diagnosis, and cranial radiation. Participants were more likely to report suicidal symptoms if they felt depressed or hopeless, experienced pain, had physical limitations, or were concerned about their appearance. Although brain tumor survivors were excluded from this sample because they were followed in a different clinic, one would expect suicidal symptoms and completed suicide rates to be higher in brain tumor survivors given the aggressiveness of their therapy, possible treatment with radiation (and its subsequent effects on growth retardation, physical disfigurement, and impairments in neurocognitive functions) as well as neurosensory or motor issues.

In contrast, some studies have found positive outcomes for childhood brain tumor survivors and our group was no different. All the survivors attending our group indicated that they would not want to change their experience of having had cancer, as it was part of what defined who they had become. "It has made me a stronger and more compassionate person," and "I look at it positively and focus on the good things" were two of the comments shared. Survivors (and to some extent, their parents) have indicated that they have experienced a positive

reordering of life's priorities, increased resilience, and improved relationships with family and others (Zebrack & Chesler, 2002). Although the idea that the experience of traumatic events may have both positive and negative outcomes is not new (Frankl, 1963; Parkes, 1971), the concept of posttraumatic growth (PTG) in families of children diagnosed with cancer is only beginning to be explored. In their group of adolescent survivors and their parents, Barakat et al. (2006) noted that the majority reported changes for the better in how they treated others and how others treated them.

Insurance

Participants in our brain tumor survivors' group mentioned a variety of insurance concerns. Some had experienced denials because of preexisting conditions, and others mentioned the expense of having to pay more for their insurance premiums or having enormous deductibles. Survivors also mentioned how insurance expenses prevented them from moving ahead in other areas of their adult life; for example, saving for the down payment on a house or putting away money for retirement.

Empirical evidence of system-based obstacles (ie, lack of third-party reimbursement) for medically indicated psychological services in pediatric brain tumor patients was reported in a study published in 2006 by Taylor et al. The authors reviewed insurance claims covering 263 866 persons. From that sample, 209 patients with pediatric brain tumor diagnoses were extracted and compared with pediatric patients treated for other primary diagnoses. In this particular sample, the authors reported a discrepancy between reimbursement for CPT codes associated with medically indicated neuropsychological testing and psychological therapy for patients treated for brain tumors as contrasted with patients diagnosed with attention-deficit/hyperactivity disorder (ADHD), learning disabilities, or autism spectrum disorders. Even with a medical diagnosis, survivors of childhood brain tumors may not be reimbursed as much as children with other disorders, which may limit their ability to access needed therapy interventions and/or neurocognitive assessment.

Neurocognitive Late Effects

Survivors in our brain tumor focus group discussed their concerns about the process of getting evaluated for learning problems and their experience of having learning difficulties. One noted that "getting tested for learning disabilities made me feel dumb." Some reported that they had to work harder or longer than their peers and that the amount of studying came at the expense of extracurricular or social involvement.

It is estimated that learning difficulties may affect as many as 50% of childhood cancer survivors (Armstrong, Blumberg, & Toledano, 1999), and perhaps a larger percentage of brain tumor survivors. Mitby et al. (2003) reported that nearly 25% of survivors of childhood cancers received special education services as compared with 8% of a sibling control group. Again, one would expect the number of brain tumor survivors needing special education services to be even higher. One of the most comprehensive studies on the outcomes of childhood brain tumor survivors suggested that survivors' lives were primarily affected by the intellectual impact as well as the psychological/emotional impact of both the disease and its treatment (Lannering, Marky, Lundberg, & Olsson, 1990). Research on children with brain tumors (Carlson-Green et al., 1995) as well as with traumatic brain injuries (Taylor et al., 2001) suggest that contextual factors such as family stress and SES may affect neurocognitive outcomes in survivors as much as the medical/treatment factors.

It has been challenging to unravel the specific effects of different treatments for pediatric brain tumors and no single profile of neuropsychological impairment has been identified to date. However, some evidence for the syndrome of nonverbal learning disabilities in a sample of children with brain tumors has been reported (Buono et al., 1998). Brain tumor survivors with nonverbal learning disabilities may find themselves having a poor sense of direction, difficulty knowing how to "lay out" written math problems, or issues of planning and organizational skills. Other studies have shown that visual-spatial skills may be affected by the disease or its treatment (Copeland, deMoor, Moore, & Ater, 1999; Levisohn, Cronin-Golomb, & Schmahmann 2000), such that brain tumor survivors may have difficulty recognizing, organizing, interpreting, and/or remembering visual images. This can affect their ability to learn and recall letters and words, numbers and symbols, as well as diagrams, maps, and charts.

Treatments for brain tumors typically involve multiple modalities, including a combination of surgery, chemotherapy, and radiation. Protocols may change before studies on neurocognitive outcomes are published. Similarly, the tests used to document neurocognitive outcomes may change as the child is followed over time or as they are updated and renormed. In a review of 22 studies representing 544 patients with brain tumors ranging in age from birth to 22 years, Mulhern, Hancock, Fairclough, and Kun (1992) concluded that younger children (<4 years) who received cranial radiation were at the highest risk for intellectual declines. Although this study was completed more than 16 years ago, more recent studies continue to underscore these findings (Mulhern, White, et al., 2004; Palmer, Wilburn, Reddick, & Gajjar, 2007).

Neurocognitive issues affect a wide range of functional areas, and specific identification of those problems

may provide direction for specific interventions. Whereas earlier studies focused exclusively on using IQ scores as outcomes, neuropsychological assessment of oncology patients has become more sophisticated over the years to allow researchers to identify specific components of cognitive functioning and how they might be affected either by the disease or by its treatments. For example, the intellectual declines observed in children with brain tumors treated with CRT appear to be the result of a failure to learn and acquire new information, rather than a loss of previously learned information as would be observed in a dementia process (Mulhern, Merchant, Gajjar, Reddick, & Kun, 2004). Similarly, data from a study of 27 children treated with CRT for acute lymphoblastic leukemia (ALL) with demographically matched controls suggested that deficits in processing speed and working memory following CRT may be responsible for the declines observed in IQ (Schatz, Kramer, Ablin, & Matthay, 2000). However, findings from our own research on children with brain tumors have suggested that the number of different treatments a child undergoes may be a better predictor of outcomes than merely the presence or absence of radiation therapy (Carlson-Green et al., 1995).

Difficulty with focus and attention are often noted in survivors of pediatric brain tumors but are not typically accompanied by the hyperactivity or impulsivity seen in children with classic ADHD. Survivors may struggle to sustain their attention to tasks, select relevant from irrelevant stimuli (eg, being able to ignore irrelevant information embedded in a math word problem), shift their attention from one task to another, and process information in a time-efficient manner. It is not unusual for survivors to find that it takes them longer to complete tasks or homework as compared with their peers. This was noted by individuals in our survivors group who also mentioned the impact this had on their social lives. Disruption to white matter integrity and utility also may underlie these processing problems (Palmer et al., 2007). Attentional abilities—but not memory—explained a significant amount of the relationship between volumes of NAWM and IQ in a sample of pediatric brain tumor survivors (Reddick et al., 2003). In an archival sample of 22 children treated with cranial radiation for 3rd ventricle or cerebellar tumors, the amount of time since radiation treatment was found to directly decrease children's auditory attention scores (Papazoglou, King, Morris, Morris, & Krawiecki, 2008). Reduced attention span also was found to be associated with poorer parent ratings of children's adaptive scores in the area of self-help or "daily living" scores.

A study of adult survivors of pediatric brain tumors suggested a possible link between disruption in frontal lobe white matter integrity and executive skills in brain tumor survivors treated with cranial radiation (Mumaw,

King, Mao, Morris, & Krawiecki, 2008). Executive dysfunction can impair a survivor's ability to control and regulate other behaviors and to anticipate and adapt to changing situations. Problems in these areas have significant implications for survivors' daily functioning across a wide array of tasks.

Problems with memory are reported as well. Brain tumor survivors may experience difficulty in their ability to attend to, register, and encode new information in memory, as well as their ability to access stored memories and retrieve them on demand. Particular risk factors for memory problems include treated with cranial radiation, history of hydrocephalus, and a brain tumor (Reimer, Mortensen, & Schmiegelow, 2007). Difficulty with the retrieval of learned information (both verbal and visual material) was noted in a sample of 16 patients (ages 6-15 years) treated for craniopharyngiomas with surgery only (Carpentieri et al., 2001). It also has been suggested that the efficiency of working memory processes (the ability to hold information "online" for the purposes of completing a task) is reduced following CRT or treatments for ALL (Schatz et al., 2000). Such difficulties might contribute to a survivor's inability to carry out a math problem with multiple steps or to do mental math problems. Children treated for brain tumors have been found to be at high risk of having specific arithmetic deficits (Buono et al., 1998).

Sleep issues in this population may also affect daytime attention and concentration as well as cognitive efficiency. A retrospective case series review of 14 children with CNS neoplasms referred to a sleep clinic for clinical evaluation was conducted between 1994 and 2002 (Rosen, Bendel, Neglia, Moertel, & Mahowald, 2003). The most common sleep complaint in this group of children was excessive daytime sleepiness (EDS) present in 9 of the 14 children. This subset of children had sustained damage to the hypothalamic/pituitary regions of their brains, but the particular cause (eg, tumor, surgery, hydrocephalus, or radiation) did not appear to be significant.

Fine motor speed slowing and/or dyscoordination can be observed acutely during treatment with particular chemotherapies (eg, vincristine neuropathies) as well as in the long term. In particular, individuals with posterior fossa brain tumors may be affected in this area as well because of the location of the tumor. These difficulties can also contribute to slow processing speed on written tasks, as well as difficulties with or a reluctance to do paper-pencil tasks.

Relationships and Sexuality

Participants in our brain tumor survivors' group expressed concerns about the risk of parenting a child who might develop cancer, even though intellectually they knew that the risks were not any greater. A possible

reluctance to have children might also be a self-limiting factor in survivors' willingness to enter into long-term relationships. One participant even noted that her sibling was ambivalent about having her own children because of the fear of "going through it all again."

Developing the capacity for sustained relationships and possibly entering into marriage or partnerships are important milestones for the transition from adolescence to adulthood. The Childhood Cancer Survivors Study (CCSS) followed 10 425 survivors treated in the United States and Canada (Rauck, Green, Yasui, Mertens, & Robison, 1999). They reported that children who survive cancer have a slightly lower rate of marriage when they reach adulthood than the general population, although the rate varies somewhat by sex and race. A total of 90% of female cancer survivors aged 40 and above were ever married compared with 91.3% in the general population. Among males in the same age group, 92% of survivors were married compared with 86% in the general population. Those with CNS tumors in the CCSS study were less likely to have married than those with other cancer diagnoses and those of similar age in the general population. Mostow, Byrne, Connelly, and Mulvihill (1991) reviewed 342 cases of children who survived brain tumors as compared with sibling controls. They reported that a majority of the men (56%) and one quarter of the women (25%) had never married (compared with 9% and 15% of the male and female sibling controls, respectively). In contrast, participants in the CCSS had lower divorce and separation rates than did controls (Rauck et al., 1999).

The timing of the cancer diagnosis may also play a role in how issues play out in the arena of relationships and sexuality. In a cohort of 60 childhood cancer survivors, psychosexual problems were frequently reported (Van Dijk et al., 2007). A total of 20% of survivors felt a limitation in their sexual life because of their illness; with older survivors feeling "less experienced" than age-matched peers, and their overall appraisal of their sexual quality of life was less positive. Survivors treated in adolescence were reported to have a delay in achieving psychosexual milestones, leading the authors to suggest that treatment in adolescence may be a risk factor for sexual problems in adult survivors of childhood cancer. Given the higher possibility of cognitive, physical, or neurosensory complications in survivors of childhood brain tumors, the risk for sexual problems might be even higher.

Employment

Although all the survivors in our small focus group were employed, not all were in their desired kinds of jobs. One mentioned that although he was cognitively competent to work as a nursing assistant, he had insufficient stamina and physical strength to do the work. Others

noted energy span issues, which were reported to affect both work and school.

Results of the CCSS, which assessed more than 10 300 survivors, found the highest rates of unemployment in CNS tumor survivors treated with more than 39 Gy radiation (Pang et al., 2008). Because this is also the group at higher risk for long-term cognitive sequelae, it suggests that for some survivors, cognitive limitations may affect their ability to find gainful employment. The CCSS study also found higher unemployment rates for survivors who were female or who were less than 4 years old at the time of their diagnosis, presumably because they may have been more cognitively affected by their treatments at a young age. The survivors averaged a 5.6% unemployment rate, whereas their sibling controls had only a 1.2% unemployment rate. Future studies will look at the type of employment survivors are engaged in, their job satisfaction, and possible reasons for unemployment, which should be elucidating, given some of the comments made by survivors in our brain tumor group. A few in our group of survivors, however, mentioned that concerns about ongoing social issues, as well as cognitive issues, made them reticent about continuing their postsecondary education. They shared that the social difficulties they had experienced in high school had made them think twice about going to college.

Accessing Information

Various advocacy groups (eg, CureSearch, Childhood Brain Tumor Foundation, Beyond the Cure, Leukemia & Lymphoma Society, National Brain Tumor Foundation) have worked tirelessly to provide Web-based information to help childhood cancer survivors better manage their long-term care. Information about late effects as well as survivorship guidelines is available to those with computers and Internet access as well as through regional conferences and teleconferencing. The question that remains is whether or not this information is sufficiently accessed by or accessible to those to whom it is provided. A review of the literature did not find any studies addressing these questions.

In our small focus group, we were surprised that none of these brain tumor survivors were familiar with these or any other Web sites. However, this particular group had been treated between 1978 and 1995, before much of the large-scale efforts had been made to provide information electronically. Overall, our survivors relied on their parents to provide them with information about their treatments and other late effects. In a CCSS study of 635 adult survivors of childhood cancer assessing knowledge and understanding of their disease and treatment, the authors concluded that the survivors were largely deficient in understanding even basic aspects of their

diagnosis and what kinds of treatments they had had. The authors expressed concern that this knowledge deficit could impair survivors' ability to seek out and obtain appropriate follow-up care (Kadan-Lottick et al., 2002).

Improving Survivors' Psychosocial and Neurocognitive Outcomes

Improving Social/Emotional Adjustment

Across the board, participants in our brain tumor survivors' group acknowledged that social relationships improved with age and over time. One participant noted that the experience of going to college was "a real release because it was a break from those people who knew about the cancer." The social problems of childhood and adolescence were reported to get better with adulthood because adults were, in general, more compassionate and more understanding than were childhood peers. Barakat et al. (2006) reported that their group of adolescent survivors of cancer reported positive changes in how they treated others and how family members and others treated them. In our survivors' group, one noted that entering the workforce provided an important opportunity for social relationships to blossom; an observation that highlights the importance of making sure that survivors have opportunities for employment. Prior to that, however, health care providers need to make sure that children with brain tumors can maximize their educational psychological testing. Provision of training to help parents and older survivors with special education advocacy also could be helpful.

Cancer camp experiences (eg, CBTF's Heads Up Conference at Camp Mak-A-Dream) were uniformly noted by our brain tumor survivors to have been very positive as they provided opportunities to be with other individuals who truly understood them. This has been reported in the literature as well (Meltzer & Rourke, 2005). Providing patients and families with information about these kinds of supportive camps can be very helpful. An informal benefit of our survivors' group meeting was that many of the participants stayed past the ending time to chat with each other, and some exchanged contact information with plans to get together or to provide support in different ways.

In our clinical neuropsychology practice, we have informally shared observations from older survivors with patients and their families at the beginning of their brain tumor journeys. Newly diagnosed parents and older patients have reported it to be helpful to have the benefit of a "long-range perspective" from other patients. In that respect, families may appreciate referrals to in-hospital programs that match them with parents who have been through the brain tumor experience or referrals to organizations such as the WE CAN program for patients in California (http://www.wecan.cc/We_Can/Home.html) or programs such as the Children's

Brain Tumor Foundation's "Parent to Parent" program (http://www.cbtf.org/cms/parent_parent_p2p_network).

Reports from the research literature indicate that the general well-being of survivors of childhood brain tumors may be improved by psychosocial support interventions that promote the development of social and vocational skills at particular time frames (Zebrack et al., 2004). Social skills interventions have been offered specifically to children with brain tumors. A highly structured intervention group targeting boys with brain tumors that used a parallel group for parents was reported by the recipients to be efficacious (Die-Trill et al., 1996). Preliminary findings from a more recent pilot program with brain tumor survivors are encouraging (Barakat et al., 2003). Multisite, randomized, controlled studies were recommended as the next step. In the absence of such programs in their communities, health care professionals may recommend patients to work individually with psychologists or work with families to see if social skills or friendship groups might be available in their communities or in the patient's school.

Educating families (parents and siblings) about PTSD and PTSS symptoms and normalizing the experience may be an important first step to encouraging them to seek treatment for problematic intrusive memories, avoidance, or arousal resulting from the cancer experience.

In our practice, discussion of these issues is routine during initial and follow-up consultations for neuropsychological follow-up. In our experience, it is not uncommon for parents to express a sigh of relief or to comment that they thought they were "going crazy." Identification of the PTSD or PTSS issues is the first step. The next step is learning how best to support those individuals who would benefit from intervention.

The Surviving Cancer Competently Intervention Program (SCCIP) integrates cognitive-behavioral and family therapy approaches in a four-session, 1-day program suitable for adolescent survivors and their parents and siblings (Kazak et al., 1999). In this particular treatment model, ongoing cancer-related symptoms (eg, intrusion symptoms, arousal, avoidance) were identified, and therapists worked with individuals to reframe their beliefs about the experience to facilitate a more adaptive outcome. This program has been demonstrated to significantly reduce symptoms of PTSS, particularly for survivors and fathers. Continuing education for patients and their families about PTSS and PTSD issues is imperative. Health care professionals working with pediatric brain tumor patients should encourage their institutions and behavioral science colleagues to offer intervention programs such as SCCIP. It is helpful for health care providers to have a working relationship with psychology/behavioral science colleagues who have experience working with PTSD or PTSS issues related to cancer, where they could refer identified patients, parents, or siblings.

Health care professionals need to consider how to evaluate brain tumor survivors for behavioral, emotional, and social difficulties during clinical encounters. However, providers will need training to assess survivors in a complete and efficient manner. It has been noted that health care practitioners may be less accurate in identifying the presence of internalizing symptoms (such as anxiety or depression) as compared with externalizing symptoms such as acting out (Schultz et al., 2007). This suggests that using brief self-report questionnaires assessing symptoms of anxiety or depression or working on teams with psychology/behavioral sciences colleagues may be a better option. Psychologists are also good resources for helping oncology staff identify the specific questionnaires or modalities (eg, paper and pencil or computer based) that will work best for a particular setting or population of patients. The results cited earlier on suicidal ideation and attempts (Howard et al., 2007; Recklitis et al., 2006) underscore the importance of incorporating resources devoted to psychosocial concerns into long-term follow-up programs for survivors.

The use of complementary and alternative medicine (CAM) treatments in the United States is reported to be high, particularly among individuals with cancer (Eisenberg et al., 1993). Mind-body therapies (such as meditation, hypnosis, yoga, mindfulness training, Qigong, Tai Chi art, and music therapies) are one area of CAM approaches that may be a means of connecting brain tumor survivors and their families to psychosocial supportive services. As the group of brain tumor survivors becomes more diverse over time, access to a broader range of interventions may be particularly important for individuals from different cultures. Use of mind-body therapies is reported to be particularly high in some minority subgroups such as African Americans (Mackenzie, Taylor, Bloom, Hufford, & Johnson, 2003). Such individuals may feel more comfortable seeking services from sources other than or in addition to more traditional Western health care providers (Monti, Sufian, & Peterson, 2008). Although the data on the efficacy of some of these therapies are inconclusive at the present time, their potential benefits suggest possible consideration.

Improving Access to Insurance

Reducing insurance barriers for childhood cancer survivors is a challenge because of the current structure of the health care system in the United States. Nonetheless, some small victories have been won. In 2006, the state of Connecticut passed a legislation requiring private and state insurance companies to cover neuropsychological testing for children diagnosed with cancer (P.A. 06-131: An Act Concerning Developmental Needs of Children and Youth

With Cancer), when ordered by a licensed physician (<http://www.jud2.ct.gov/lawlib/newslog/newlegis.htm>). Similar efforts are reported to be underway in other states as well. Health care providers can encourage their patients to challenge insurance denials and work with psychology/behavioral science colleagues to find ways to get needed services covered. It remains to be seen whether or not the Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA) will result in any changes for childhood brain tumor patients' ability to access psychological and neuropsychological services.

Improving Neurocognitive Outcomes

Unfortunately, specific interventions to address the neurocognitive sequelae of childhood cancer have been few and far between. As Brouwers (2005) points out, it remains unclear the extent to which neurocognitive declines may be the result of psychologic processes (eg, a specific disruption in a process that is necessary to facilitate future development [such as attention or memory]) or the result of biologic changes (eg, physiological changes resulting in neuronal damage or dysfunction). A better understanding of these factors may help guide future intervention methods. The Neurological Predictor Scale was developed as a means for quantifying a child's exposure to the risk factors associated with the diagnosis and treatment of a brain tumor (Micklewright, King, Morris, & Krawiecki, 2008). Although additional studies are needed, the authors demonstrated its usefulness in predicting variance in neurocognitive outcomes and statistically controlling for the influence of confounding variables. With some treatment settings having limited resources to refer children for neuropsychological testing, methods such as the Neurological Prediction Scale might be a quick method for oncology professionals to assess which patients might be at the highest need for assessment of possible neurocognitive problems.

Pharmacological interventions such as trials of methylphenidate (Mulhern, Khan, et al., 2004) have proved beneficial. Results of a multicenter, randomized, double-blind crossover study of the effects of methylphenidate on survivors of childhood brain tumors and ALL indicated that methylphenidate significantly reduced attentional and some social deficits among survivors of childhood brain tumors and ALL. There was no consistent statistical advantage for a moderate dose (0.6 mg/kg) over a low dose (0.3 mg/kg; Mulhern, Khan, et al., 2004). However, childhood brain tumor survivors had higher rates of premature discontinuation of medication because of side effects relative to childhood ALL survivors (Conklin et al., in press). This finding underscores

the need for careful monitoring by providers and education of parents regarding potential side effects.

As noted earlier, children treated for brain tumors can present with EDS (excessive daytime sleepiness), which can affect cognitive functioning. Rosen et al. (2003) reported that in their group of patients, symptoms of EDS were effectively controlled with modest doses of daytime stimulant medication and/or scheduled naps. Helping parents of children with brain tumors advocate for naps during the school day or an abbreviated school day (eg, the child attends morning academic classes and lunch with peers and then goes home to nap) may be an important intervention.

Cognitive rehabilitation may be an additional area of promise, but more work remains to be done (Butler & Copeland, 2002; Butler et al., 2008). Results of a phase III, multisite clinical trial of cognitive remediation program consisting of massed practice, strategy acquisition, and cognitive-behavioral interventions for 161 childhood cancer survivors aged 6 to 17 years and 54 controls was published recently (Butler et al., 2008). Participants completed 20 two-hour sessions of cognitive rehabilitation intervention over 4 to 5 months. However, compliance for this time-intensive intervention was an issue with only 60% completing all 20 sessions. Although trends were supportive of mild gains, there were no statistically significant differences in neurocognitive functioning. However, participants were reported to have statistically significant improvements in measures of academic achievement and manifested improved attention based on parent report, but not teacher report. The study's authors noted that future investigations should consider training parents and teachers to implement the strategies as well.

Ecological interventions are those strategies that seek to effect change in the survivor's environment or in the different systems (eg, home, school, community). For example, explaining neuropsychological late effects to patients, parents, and especially teachers may be a more cost-effective means of improving outcomes for this population than other types of intervention strategies. Bruce, Chapman, MacDonald, and Newcombe (2008) noted that strong communication among parents, schools, and health professionals is critical for improving survivors' outcomes and that more preparation of parents to learn advocacy skills would be beneficial. Carlson-Green, Oliver, Finkelstein, Liu, and Chen (2008) reported recently on 4 methods of providing information about neurocognitive late effects: in the context of a family retreat, a parent/teacher evening conference in a hospital, a training conference for teachers of children with medical disorders sponsored by a state Department of Education, and a day-long educational program for childhood cancer survivors organized by a national survivors'

group. Preknowledge and postknowledge surveys were collected from participants, and the different intervention methods were compared. Each intervention had its own strengths and weaknesses, but all were effective in delivering important information. In general, self-evaluation of knowledge postworkshop compared with preworkshop demonstrated significant improvements for both parents and teachers regardless of the format or setting. These preliminary results underscore the need and importance of providing education about neurocognitive and social/emotional late effects to parents and teachers of children with cancer. Brain tumor and other childhood cancer survivors who access special education services may experience improved quality of life and similar educational achievement as children who did not have cancer (Mitby et al., 2003). Access to special education services may also qualify survivors for transitional support until the age of 21 years. In our group of brain tumor survivors, county or school-based programs to help with transitional issues such as apartment living, balancing a checkbook, cooking, and so on were reported to have been positive ways to get specific skills sets that allowed them to function more like their peers.

Future work in this area may see more application of brain imaging procedures to allow for better tracking and prediction of the trajectories of development after treatment and/or response to therapeutic interventions. Biomedical and clinical research studies are also beginning to examine the relationship between physical exercise and cognitive function. Brain tumor survivors with physical, motor, or sensory impairments may not only have reduced cardiovascular fitness levels, but they may be prevented from benefiting from possible cognitive benefits of exercise as well (Ploughman, 2008). It has been stated that physical activity during childhood may optimize development in the brain cortex, possibly promoting lasting changes in brain structure and function (Hillman, Erickson, & Kramer, 2008). Promotion of physical activities in brain tumor survivors may not only benefit them cognitively but also may help reduce problems associated with obesity as well.

Finally, sensitivity and understanding of survivors' neurocognitive issues and needs is imperative. When the neuropsychologist was organizing the evening event for survivors, it was noted that some of the respondents had difficulties in their attempts to respond. In preparing for this focus group, we had not anticipated the significant limitations some of the survivors were experiencing. For example, a few survivors left messages that seemed to have been written down beforehand and then read into the neuropsychologist's voice mailbox, and some survivors' parents responded to the mailings on behalf of their adult children.

Improving Relationships and Sexuality

Fertility preservation technology (eg, sperm banking, ova preservation) has become increasingly available to individuals at diagnosis, which may contribute positively to outcomes in this area. To date, we are not aware of any particular studies that specifically focus on improving relationship outcomes or sexuality in survivors of childhood brain tumors. Resources for survivors include books (eg, *Sexuality and Fertility After Cancer* by Schover, 1997) and a Web site resource for finding therapists accredited in understanding sexual issues (www.aasect.org).

Improving Employment

Brain tumor survivors' ability to access legal and advocacy support, as mandated in the United States by the Americans With Disabilities Act, also ensures that appropriate workplace accommodations are made for cancer survivors. Long-term follow-up and medical treatment and/or rehabilitation or intervention that addresses and alleviates cognitive and physical sequelae may enhance survivors' psychosocial functioning and reduce their distress. Health care professionals need to consider that individuals treated for their brain tumors when younger may need additional support in finding and keeping employment. Ensuring that children receive special education services when needed is one step toward making sure that they will be supported in their transition from school to work or postsecondary options.

The American Brain Tumor Foundation (www.abta.org) provides information on its Web site regarding work-related issues for survivors of brain tumors and employment rights under the tab "Care and Support." The Cancer Legal Resource Center is a joint program of the Disability Rights Legal Center and the Loyola Law School. The center offers a toll-free national telephone assistance line, which provides free and confidential information on cancer-related legal issues by calling 866-843-2572 or going to their Web site: cancerlegalresourcecenter.org. One publication of the National Coalition for Cancer Survivorship (1.800.NCCS YES) includes the following: "Working It Out: Your Employment Rights as a Cancer Survivor" by Barbara Hoffman, JD (2008). Health Care providers can help families access these and other resources by providing handouts during clinical follow-ups or providing information on their hospital Web sites.

Improving Access to Information

Brain tumor survivors need to have summaries of their diagnosis and treatments, as well as someone taking the

time to explain to them (as adults) about what happened to them when they were younger (and possibly before they remember). Armed with this information, many survivors will be better consumers of information about the late effects of their treatment.

Clinical practice guidelines have been developed to foster appropriate risk-based survivor care (Landier, Wallace, & Hudson, 2005). However, it is imperative that these guidelines are disseminated to improve risk-based care for cancer survivors. Improved marketing of these guidelines to primary care physicians as well as to patients is needed. Collaboration among the various organizations providing this information might also be a way to make limited resources stretch further. Gathering information from patients during clinical appointments about helpful resources in individual communities and sharing that information with others would also be beneficial in developing a list of local resources.

Survivors Speak Out

Although the treatment of childhood brain tumors has made progress over the years, a better understanding of the potential roadblocks between successfully completing treatment for childhood cancer and the experience of a "good outcome" or good "quality of life" is needed. Use of an idiographic approach, in which survivors speak for themselves, captures the richness and nuance of the individual experience. It also may prevent professionals from making assumptions about what constitutes "good outcomes," as survivors and their families may differ widely in their individual responses to the brain tumor experience. Individuals responded very positively to our request for survivors to tell us their stories, whether or not they were able to participate. Many indicated a sense of wanting to "give back" to the treating hospital as well as a desire to help those who were following in their footsteps. However, the nomothetic approach (in which averages across many survivors are summarized) provides a snapshot of a typical survivor and helps us understand on average what our brain tumor patients may and may not expect. Neuropsychological assessment of individual survivors also allows for a combination of these approaches to be used. The individual's strengths and weaknesses can be evaluated in the context of what is known about neuropsychological outcomes of particular tumors or treatments.

Although outcomes can vary greatly for survivors of childhood brain tumors, there is more awareness and assessment available for evaluating possible late effects, as well as options available for intervention. Work continues to focus on preventing and ameliorating psychosocial as well as neurocognitive late effects. Advocates are trying to improve insurance obstacles to survivors in various states. Recent studies are working to

identify and understand the factors involved in underemployment issues as well as relationship issues. Finally, there is much information available to survivors through various organizations, and the Internet has made this information more accessible to a variety of people. As time passes since their time of diagnosis and treatment, survivors and their families may begin to apply more positive interpretations and meaning to their cancer experience.

Although there are many strategies that can be offered to ameliorate potential problems and enhance the richness and fullness of their lives, much work remains for health care providers to target the particular subgroups of brain tumor survivors who might benefit from specific interventions offered at a given time (Zebrack & Zeltzer, 2003). Additional cultural, religious, financial, and racial sensitivity is important when working with diverse groups who may or may not respond to interventions such as traditional therapy versus mind-body approaches. The National Action Plan for Childhood Cancer recommends increasing and improving the ways in which children and adolescents are screened and treated for possible late effects (Arceci et al., 2002). Improved screening, education, and the ability to offer evidence-based interventions will go a long way toward improving the outcomes of childhood cancer survivors. In these difficult economic times, and with the insurance issues reported for children with brain tumors, health care and behavioral science professionals will need to be creative about ways to provide for survivors.

As we work with childhood brain tumor survivors and their families, we need to remind ourselves that they may define outcomes and quality of life in many different ways. Support should be provided in the ways in which families and patients define the need. Survivors and family members, as well as other important players such as educators, need ongoing and developmentally sensitive education about long-term effects as well as the options available to them. Collaboration among health professionals, specific disease support organizations, and collaborative groups, such as the Children's Oncology Group, will do much to ensure better outcomes for all survivors of childhood brain tumors.

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Bio

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