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Parent perspectives on the educational barriers and unmet needs of children with cancer

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Abstract

Childhood cancer challenges academic success and school engagement, yet little research has described these hardships. This study documented parental perspectives of the educational barriers and unmet needs of youth treated for cancer ($n = 102$). Treatment-related physical sequelae were noted as common problems interfering with school attendance and engagement. One-fourth of parents reported worse academic performance since diagnosis; however, many never had their child evaluated (63.3%) or enacted formalized educational accommodations (55%). Findings reflect educational challenges across the continuum of cancer care and survivorship, and highlight the importance of education of school staff on both acute and long-term effects of cancer treatment.

Successfully progressing through school is one of the most important tasks of childhood and early adulthood. Managing the academic and social tasks associated with each phase of school is crucially important to cognitive and social development and long-term health and psychosocial outcomes (Lent, Hackett, & Brown, 1999). Childhood cancer can disrupt this developmental process by interfering with school engagement and negatively impacting academic achievement (Katz & Madan-Swain, 2006). Maintaining pre-illness academic achievement and participation in school-related activities is an important goal for youth with cancer and has been related to enhanced quality of life (Katz & Madan-Swain, 2006; Katz, Varni, Rubenstein, Blew, & Hubert, 1992). Furthermore, evidence from epidemiological studies indicates that certain at-risk survivor groups achieve diminished educational attainment compared to the general population (Kuehni et al., 2012; Lancashire et al., 2010). With survival rates for childhood cancer currently exceeding 80% (Howlader et al., 2011), the importance of understanding the school experiences and academic needs of youth treated for cancer has never been higher. Little research, however, has documented the specific types of educational needs across the continuum of childhood cancer care.

Childhood cancer can affect school experiences across the continuum of treatment, from diagnosis to long-term survivorship. On the first end of the continuum, children and

adolescents who are in treatment for their cancer experience acute medical sequelae, such as short-term treatment toxicities and poor immune system functioning, that increase absenteeism (Eiser & Vance, 2002; Gerhardt et al., 2007) and inhibit effective learning and academic performance. Absenteeism is an important issue since it presents multiple challenges to children's development, including declines in academic achievement, disconnection with school, and increased social difficulties (Tadmor, Rosenkranz, & Ben-Arush, 2012). Furthermore, children with cancer who are more integrated into school are more likely to perceive cancer-related stressors as less stressful, have friends, and display positive thinking and enhanced self-image (Hockenberry-Eaton, Manteuffel, & Bottomley, 1997).

At the other end of the continuum, children who are far removed from active cancer treatment may experience long-term sequelae from their disease and treatment, such as permanent sensory deficits (e.g., vision and hearing loss; Oeffinger et al., 2006) or neurocognitive late effects (Hocking & Alderfer, 2012), that can impact school engagement and academic achievement. Children with central nervous system (CNS) disease and CNS-directed treatments, including those children with brain tumors, acute lymphoblastic leukemia (ALL), and any child treated with bone marrow transplant, are at increased risk for neurocognitive late effects secondary to their disease and treatments that disrupt brain development (Hocking & Alderfer, 2012). For these survivors, declines in IQ and deficits in attention, processing speed and memory have been documented (Kadan-Lottick et al., 2010; Peterson et al., 2008; Robinson et al., 2010). Neurocognitive sequelae are not limited to children with ALL or brain tumors, however, as young children with non-CNS cancers demonstrate impairments in cognitive and language development compared to healthy controls (Bornstein et al., 2012). In sum, children with cancer experience multiple challenges that could negatively affect school functioning and increase the need for accommodations for physical, social, and cognitive issues during and after treatment (Gurney et al., 2009), yet the specific ways in which cancer and treatment limit engagement across diagnoses and the extent to which youth access school services have not been adequately described.

Research on the neurodevelopmental issues in childhood cancer has focused on the neurocognitive late effects of ALL or brain tumor survivors (e.g., Robinson et al., 2010) and the long-term educational attainment of survivors (e.g., Kuehni et al., 2012). The prevalence and impact of academic difficulties for all children treated for cancer are not well-understood. Further, the ways in which schools are addressing school functioning of children with cancer have not been described beyond examination of factors related to more positive school reintegration (Bruce, Chapman, MacDonald, & Newcombe, 2008; Pini, Gardner, & Hugh-Jones, 2013) and testing specific school reintegration programs (Annett & Erickson, 2009; Katz et al., 1992). Additionally, few studies have sought parental perceptions of their child's school functioning and unmet needs. Obtaining the perspectives of these important stakeholders is a vital step in developing programs to enhance collaborations across the families, medical staff, and schools to improve the educational experiences of children with cancer.

Recently developed standards for the psychosocial care of children with cancer identify school reentry support for all families (Thompson et al., 2015) and routine neuropsychological evaluations of children treated for central nervous system disease (Annett, Pate, & Phipps, 2015) as essential services that should be offered at all cancer centers. Increased understanding of the school experiences and educational needs of this at-risk group might lead to greater efforts to adhere to these standards of care (Annett et al., 2015; Thompson et al., 2015) and advancements in interventions to ameliorate these difficulties during cancer treatment and into survivorship. To address this issue, we sought the perspectives of parents in our Cancer Center at The Children's Hospital of Philadelphia using a modified version of the Hematology/Oncology Psycho-Educational (HOPE) Needs Assessment (Peterson, Palermo, Swift, Beebe, & Drotar, 2005). The aims of this study were to (a) describe parent perceptions of school problems and barriers to school engagement, the types of resources accessed, and unmet academic needs of youth in our cancer center, and (b) examine rates of difficulties, resources accessed, and needs by cancer type and school grade.

Method

This descriptive study was part of a larger quality improvement project to enhance school reintegration services and was reviewed and approved by the Quality Improvement committee of the Division of Oncology at The Children's Hospital of Philadelphia. The institutional review board then approved analysis and dissemination of the data. Due to the quality improvement nature of the project, information on the specific demographics and medical history of the participants were not collected.

Participants and recruitment

Participants included 102 families of children receiving oncology care over a period of 6 months. Graduate research assistants approached parents of children pre-kindergarten through college about participating in this study in outpatient and inpatient settings. Parents of children who were too young to be in pre-school or who were post-college and those who could not read or write in English did not participate. The majority of children with cancer were either in pre-kindergarten through fifth grade (33.0%) or in sixth through twelfth grade (53.4%) and in public school (64.1%). Participant cancer diagnoses generally were divided evenly across liquid-based diseases (e.g., Leukemia /Lymphoma or LL; 34.0%), brain tumors (BT; 24.3%), and non-CNS solid tumors (ST; 20.6%). See Table 1 for more information on participant characteristics.

Measures

Educational needs and challenges—A modified version of the HOPE Needs Assessment (Peterson et al., 2005) was used to assess the types of difficulties experienced by children with cancer, the types of current educational services received, and areas of outstanding need. The HOPE Needs Assessment, originally developed for sickle cell disease, is an 18-item questionnaire that asks questions related to academic performance, problems that interfere with school, interactions with school-based personnel, history of educational or neuropsychological testing, and use of educational services. The

questionnaire was modified from the original version in order to be more relevant for a pediatric cancer population, to obtain information on the involvement of school personnel in facilitating school reintegration, and to ascertain how schools addressed special needs related to cancer and treatment. Appendix A contains the modified HOPE Needs Assessment used in this study and indicates which items were retained from the original version and which items were added.

Data analyses—Parental responses to the HOPE Needs Assessment were described using percentage rates (Aim 1). Chi-square analyses were used to compare responses to specific items (change in academic performance, parental concern about child's education, teacher concerns, barriers to school participation, completion of a comprehensive evaluation, and usage of special education services/accommodations) by disease group, school grade group, and type of schooling (public v. non-public; Aim 2). Effect sizes are reported using Cramer's V , where 0.1, 0.3, and 0.5 indicate small, medium, and large effects, respectively (Cohen, 1988).

Results

Table 2 presents frequencies of problems identified, resources accessed, and unmet needs for the total sample as well as delineated by cancer type.

Problems identified

Almost a quarter of the parents reported a negative change in academic performance since diagnosis. The rate of parents noting negative changes did not differ significantly based on cancer type, $\chi^2(9) = 6.68$, $p = .67$, Cramer's $V = 0.15$, 95% CI $[-0.50, 0.34]$, grade level $\chi^2(3) = 3.18$, $p = .37$, Cramer's $V = 0.19$, 95% CI $[-0.21, 0.39]$, or type of schooling $\chi^2(3) = 4.84$, $p = .18$, Cramer's $V = 0.24$, 95% CI $[0.03, 0.43]$. Parents noted absenteeism (24%), changes in concentration/memory (20%), and neurological conditions (e.g., seizures, Posterior Fossa syndrome) secondary to the cancer or cancer treatment (16%) as reasons for these negative changes. Only parents of children with BTs attributed their child's lower performance to neurological conditions, while parents of children with LL and ST identified absenteeism (8.6% of each group) and changes in attention/concentration (5.7% of each group).

Approximately 30% of the parents in the sample reported having concerns about their child's education. The rate of parental concerns differed significantly by cancer type $\chi^2(3) = 8.14$, $p = 0.04$, Cramer's $V = 0.29$, 95% CI $[0.10, 0.46]$, with parents of children with BTs and STs more likely to report concerns. The rate of parental concerns also differed by grade level $\chi^2(1) = 4.87$, $p = 0.03$, Cramer's $V = 0.23$, 95% CI $[0.27, 0.42]$. Compared to parents of children in preschool through fifth grade (17.6%), parents of children in sixth through twelfth grade (40%) were more likely to report concerns. About 17% of the parents reported that teachers have raised concerns about their child's functioning; this rate did not differ by cancer type, $\chi^2(3) = 2.96$, $p = 0.40$, Cramer's $V = 0.17$, 95% CI $[-0.03, 0.36]$, or grade grouping, $\chi^2(3) = 2.61$, $p = 0.46$, Cramer's $V = 0.16$, 95% CI $[-0.04, 0.35]$. The rate of parental or teacher concerns about participants' education did not differ based on type of

schooling, $\chi^2(1) = 0.48$, $p = 0.49$, Cramer's $V = -0.07$, 95% CI $[-0.14, 0.28]$, and $\chi^2(1) = 0.97$, $p = 0.32$, Cramer's $V = 0.11$, 95% CI $[-0.11, 0.31]$, respectively.

Parents noted significant barriers that interfere with school functioning, including a high number of missed school days and difficulties participating in school and school-related activities. Neither of these barriers differed significantly in terms of cancer type, $\chi^2(15) = 20.04$, $p = 0.17$, Cramer's $V = 0.27$, 95% CI $[0.07, 0.45]$, and $\chi^2(6) = 3.56$, $p = 0.73$, Cramer's $V = 0.14$, 95% CI $[-0.07, 0.33]$, respectively, or type of schooling, $\chi^2(5) = 8.71$, $p = 0.12$, Cramer's $V = 0.32$, 95% CI $[0.12, 0.50]$ and $\chi^2(2) = 2.18$, $p = 0.34$, Cramer's $V = 0.16$, 95% CI $[-0.06, 0.37]$, respectively. The most frequent problems interfering with participation in school and school-related activities were fatigue (total sample = 22.3%, BT = 24%, LL = 22.9%, ST = 22.9%), physical limitations contributing to decreased ability to engage in school-related activities (e.g., gym class, sports, band, school dances, etc.; total = 20.6%, BT = 20%, LL = 17.1%, ST = 28.6%), and gastrointestinal problems (total = 9.8%, BT = 8%, LL = 14%, ST = 8.6%). The number of problems experienced that interfered with school ranged from 0–5 and did not differ based on cancer type, $\chi^2(15) = 9.77$, $p = 0.83$, Cramer's $V = 0.27$, 95% CI $[-0.03, 0.52]$.

Resources accessed

As shown in Table 2, the majority of parents (65%) reported having regular conversations with school personnel about their child's special needs related to cancer and treatment. However, only about a quarter of children had been tested in the past for learning difficulties. This finding did not differ significantly based on disease type, $\chi^2(3) = 5.14$, $p = 0.16$, Cramer's $V = 0.23$, 95% CI $[0.03, 0.41]$, or type of schooling $\chi^2(1) = 0.17$, $p = 0.68$, Cramer's $V = 0.04$, 95% CI $[-0.17, 0.25]$. Regarding usage of special education programs, 38.8% of the sample reported not having either a 504 Plan or an Individualized Education Plan (IEP), and the rates of 504 Plans or IEPs did not differ based on cancer type, $\chi^2(6) = 2.35$, $p = 0.89$, Cramer's $V = 0.11$, 95% CI $[-0.09, 0.31]$, and $\chi^2(6) = 6.35$, $p = 0.39$, Cramer's $V = 0.19$, 95% CI $[-0.02, 0.38]$, respectively. Additionally, there were no differences between participants attending public school compared with non-public school on rates of 504 plans (41.0% in public v. 21.9% in non-public, $\chi^2(2) = 4.44$, $p = 0.11$, Cramer's $V = 0.22$, 95% CI $[0.02, 0.40]$) or IEPs (32.7% in public v. 32.1% in non-public, $\chi^2(2) = 0.48$, $p = 0.79$, Cramer's $V = 0.08$, 95% CI $[-0.14, 0.29]$). However, parents of children in sixth through twelfth grade (48.0%) were significantly more likely to report having homebound services than parents of children in preschool through fifth grade (12.1%), $\chi^2(2) = 11.46$, $p < 0.01$, Cramer's $V = 0.37$, 95% CI $[0.17, 0.54]$.

Unmet needs

In addition to asking parents about specific areas of outstanding need (see Table 2), the responses of parents who reported concerns about their child's education were examined to identify potential unmet needs. Of those parents with concerns, 63.3% of them had not had their child formally evaluated for learning problems. Additionally, 55% of this group of parents with concerns reported not having either a 504 Plan or an IEP.

Discussion

The objective of this study was to describe parental perceptions of the school experiences, the educational needs, and the barriers to academic success and positive school functioning of children treated for cancer. Results from this study reflect a theme of persistent educational challenges across the continuum of cancer care and survivorship. Parents reported needs and barriers for a variety of reasons, including those typically associated with active cancer treatment (e.g., absenteeism, fatigue, gastrointestinal issues) and those related to neurocognitive late effects (e.g., changes in concentration, memory) generally seen several years after the conclusion of treatment. Findings suggest that youth treated for BTs or STs and those attending secondary school (i.e., middle and high school) are at greater risk for parent-reported educational concerns. Additionally, the challenges parents reported reflect issues that are broader than pure academic functioning, including reduced participation in school-related activities (e.g., gym, after-school activities), and highlight the impact of childhood cancer on many relevant domains of school functioning.

Independent of diagnosis, 25% of parents in this cohort reported negative changes in academic performance, with absenteeism being the most common reason identified by parents for this change. Absenteeism is a challenge experienced across childhood cancer diagnoses and is a significant barrier to academic success. In addition to increased difficulty gaining content knowledge due to reduced academic exposure, absenteeism interrupts the natural development and maintenance of social relationships (Shiu, 2001). Medical teams, school personnel, and families should work together to minimize missed school and make reasonable modifications to encourage school attendance as much as possible.

Almost one-third of parents reported having concerns about their child's education, with parents of children with BTs and STs more likely to report concerns. In this sample, parents of children with BTs identified difficulties with attention or concentration and neurological conditions that impact academic performance. These findings are consistent with a large literature demonstrating that children who received CNS-directed therapies (e.g., brain surgery, cranial radiation) for BTs generally have a decreased rate of acquiring new skills/learning over time compared to healthy peers (Hocking & Alderfer, 2012) and emphasize the importance of long-term surveillance of neurocognitive functioning for children treated for CNS tumors as a standard of care (Annett et al., 2015).

Parents of children with STs in this sample expressed concerns related to their child's education at the same rate as parents of children with BTs. This finding suggests the importance for hospital- and school-based personnel to closely monitor the educational experiences of this group. Children treated for STs often undergo intensive treatment regimens that can include surgical resections and amputations, high dose chemotherapy, and radiation therapy. Such treatments might increase their risk for physical and functional difficulties that impact school functioning and social engagement. For example, adult survivors of non-CNS STs treated in childhood reported high rates of hearing loss, and the presence of hearing loss increased the risk for not graduating high school (Brinkman et al., 2015). Treatments that result in significant scarring or impact physical mobility (e.g., amputation) also may impact school functioning.

About 43% of parents reported that their child experiences difficulties participating in school or school-related activities due to their cancer. Fatigue and gastrointestinal symptoms, and a decreased ability to engage in school-related activities (e.g., gym class, team sports) due to physical limitations, interfered with full school participation. These concerns did not differ based on cancer type and suggest that school-related challenges are not confined to only those youth with disease affecting the CNS.

Despite the documented challenges for children with cancer across multiple academic domains, only 25% of the sample had been evaluated for learning problems. Additionally, of those parents with concerns about their child's education, the majority of those children had not been evaluated (63.3%) and did not have either a 504 Plan or an IEP (55%). While neuropsychological evaluation is a recommended standard of care for childhood cancer survivors (Annett et al., 2015), these evaluations may not occur standardly due to competing time commitments, insurance coverage, and access to a neuropsychologist. Efforts are needed that increase the regularity of neuropsychological evaluations in order to facilitate parent-school communication. Potential strategies to reach these goals include regular, brief screenings conducted in oncology clinics that focus on areas of neurocognitive vulnerability, including attention, working memory, and processing speed (Annett et al., 2015).

The number of parents with concerns whose child does not have a 504 Plan or IEP is somewhat surprising. Although the time frame for returning to school and obtaining accommodations varies based on a child's age and medical course, seeking appropriate accommodations or services early on in cancer treatment is important to minimize the time spent without supports or accommodations and continue progress in school. Oftentimes parents are unfamiliar with how to access school services and are overwhelmed with the high demands at the start of treatment. Current standards of care indicate that a hospital-based team member with requisite skills and knowledge should coordinate communication between families and school in order to develop recommendations or accommodations to support the child's school experience (Thompson et al., 2015). Such support has been shown to increase parental satisfaction with their child's academic course and decrease stress (Northman, Ross, Morris, & Targuini, 2014). As a result of this study's findings, an educational liaison was hired at our Cancer Center to help families advocate for appropriate services and accommodations.

The findings from this study should be interpreted within the context of its limitations. First, this study did not employ a comparison group (e.g., healthy control or other chronic illness) to examine whether rates of concerns or unmet needs were different for children treated for cancer. A comparison group would have provided context for these findings, particularly given that more than a third of the sample attended school in a non-public school setting, which is higher than national averages. However, prior studies have not reported on the type of school (e.g., public v. private) that children treated for cancer attend, making it unclear whether the ratio seen in the current study is high or not. Additionally, type of schooling was not related to any outcomes of interest.

Second, this study relied on parental report for all data and did not include school personnel-reported data on academic functioning, perception of academic needs, and social

functioning. Seeking additional information on social functioning and participation in school activities would provide a more comprehensive understanding of the reintegration of children treated for cancer into school. Finally, due to the nature of the data collection methods, no information on pre-cancer diagnosis educational history, cancer treatment history and time since diagnosis, or issues that might affect parent report (e.g., social support) was collected, thereby preventing exploration of associations between such correlates and the findings. Time since diagnosis would be an important variable to explore in terms of its association with academic needs and functioning. Future studies could investigate whether there are differential outcomes in terms of academic achievement and social engagement for children who received comprehensive neuropsychological evaluations or school reintegration services versus those who have not.

The prevalence of neurocognitive sequelae in children treated for cancer warrants research employing multiple methodologies to understand the school functioning of this group. In this study, parents completing the HOPE Needs Assessment reported concerns related to worsening academic performance, high-lighted the impact of missed school and physical sequelae on full school participation and underscored the need for more comprehensive screening for potential learning difficulties. The totality of educational issues experienced in this sample may partly explain the lower rates of full-time employment among adult survivors of childhood cancer when compared to sibling controls (Gurney et al., 2009). Understanding the types of needs, who is experiencing them and what is currently being done to address them is essential to programmatic efforts to ameliorate these difficulties and to justify the need for hospital-based school reintegration services.

Implications for practice

This study identified several barriers/needs with clinical implications that warrant attention from hospital and school personnel. First, parents of children with BTs and STs were more likely to express concerns regarding their child's educational experiences, and the findings suggest that these concerns are not being adequately addressed. Hospital-based providers should closely monitor the school experiences and challenges of children treated for STs, as this is a likely under-recognized risk group. Parents of children with BTs reported attention/concentration problems and neurological difficulties. While current recommendations emphasize the importance of regular neuropsychological assessment of children treated for CNS tumors (Annett et al., 2015), only a small percentage of families endorsing concerns reported having a full neuropsychological assessment or an established 504 plan or IEP. Increased screening and support for families and schools from hospital-based school reintegration personnel are needed. Second, regarding absenteeism, findings underscore that critical role of pro-active programming overseen by a school reintegration team that involves the family, treatment team, and school staff can insulate the child from negative outcomes associated with missed learning and school disengagement (Katz et al., 1992). Additionally, new programs and technologies that facilitate remote participation in the academic environment during periods of missed school warrant further evaluation. Finally, these data highlight the importance of recognizing the impact of decreased involvement in extracurricular activities (e.g., school sponsored social events such as dances, music/sports events) for children with cancer in addition to concerns with academic performance.

Effective symptom management for all childhood cancers should be included as a key component of school reintegration efforts and long-term educational planning.

Appendix A

Oncology Education/School Needs Assessment

*Retained question from HOPE Needs Assessment (Peterson et al., 2005)

**New question

-
- 1.* What is your child's current grade? _____
 - 2.* Has your child ever been held back? Yes /No If yes, what grade? _____
 - 3.** Check one: public school _____ private school _____ home schooled _____
 - a. If off treatment, is your child's school aware of his/her cancer history? Yes /No /NA
 - 4.** What is your child's cancer diagnosis? _____
 - 5.** Does your child get most of his/her treatment: inpatient _____ outpatient? _____?
 - 6.* How would you describe your child's academic performance at school? Now? Before the diagnosis?

 - 7.* Do you have concerns about your child's education? Yes /No
 - 8.* Have teachers raised concerns regarding your child's academic performance or behavior at school? Yes /No

 - 9.** Do you have regular conversations with school personnel about your child's special needs related to cancer and treatment? Yes /No

- If yes, with whom do you speak (e.g., school nurse, guidance counselor, principal, teacher) and how often do you speak with them (e.g. once a week, once a month)?
- 10.* How many days was your child absent from school in the last year due to his/her cancer? 1. 1–7 days _____ 8–14 days _____ 15–20 days _____ 20+ days _____
 - 11.* Does your child experience any difficulties participating in school-related activities because of cancer (e.g. fatigue, pain)? Yes /No
 - 12.* Has your child ever been tested for learning problems? Yes /No

If yes, where? _____ Date _____
 - 13.** Does your child have attention problems or been diagnosed with ADHD? Yes /No
 - 14.** How does the school address your child's special needs related to cancer and treatment?
 - a. Does your school provide assignments when child is in the hospital or unable to attend school? Yes /No
 - b. Does your school use SKYPE to allow your child to 'attend' class or to communicate with your child about school assignments? Yes /No
 - c. Does your child have an Individual Education Plan (IEP) Yes /No
 - d. Does your child have a 504 Plan? Yes /No
 - e. Does your child have a Gifted Individual Education Plan (GIEP)? Yes /No
 - f. Does your child have homebound tutoring? Yes /No
- If yes to 14f, does your child's school allow your child to attend school as health allows and still receive some homebound tutoring? Yes /No
- 15.** If your child does receive special school services, who is the person responsible for coordinating them (e.g., special education teacher, guidance counselor, school psychologist)?

16.** If your child graduated from high school:

a. Did he/she enter college? Yes /No

b. If in college, is he/she assessing special services through the college's Office of Disabilities? Yes /No

17.** If you have children other than your child with cancer, have they had any difficulties in school (e.g. problems remembering and completing assignments, comments from teachers regarding their behavior, drop in grades)? Yes /No

If yes, please indicate the age and grade of your other child(ren) and the types of concerns.

18.** Are there specific ways our team can help you with your child's education or these school concerns?

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Table 1.Participant demographics ($n = 102$)

Measure	<i>n</i>	%
Current grade		
Pre-K to 5th grade	34	33.0
6–12th grade	55	53.4
College	11	10.7
Post-college	1	1.0
Not reported	2	1.9
Cancer type		
Brain tumor	25	24.3
Leukemia/Lymphoma	35	34.0
Non-central nervous system solid tumor	35	20.6
Unknown cancer type	5	7.8
Not reported	3	2.9
Type of schooling		
Public school	66	64.1
Private school	22	21.4
Home schooled	7	6.8
Charter school	2	1.9
Public, private and home school	3	2.9
Not reported	3	2.9

Table 2.

Needs assessment results.

Item	Total sample		Brain tumor	Leukemia / Lymphoma	Non-CNS Solid
	N	%	N	N	N
Negative change in academic performance after diagnosis	25	24.5	6	10	8
Child has been retained	6	6	2	0	3
Parental concern about child's education ^{ab}	31	30.4	12	5	12
Teacher concern about child's education	17	16.7	5	8	3
Days absent last year due to cancer	5	4.9	1	0	3
None					
1–7 days	19	18.6	4	7	6
8–14 days	10	9.8	4	1	4
15–20 days	14	13.7	4	9	1
More than 20 days	46	45.1	9	15	20
Child experiences difficulties participating in school or school-related activities due to cancer	44	43.1	12	12	18
Number of problems identified that interfere with school					
1	23	22.5	7	4	11
2	12	11.8	3	3	6
3	7	6.9	2	3	2
4	1	0.9	0	1	0
5	1	0.9	0	1	0
Has regular conversations with school personnel	67	65.7	19	22	23
Tested for learning problems	26	25.5	10	8	6
Accommodations in place	31	30.4	11	11	7
Individualized Education Plan					
504 plan	32	31.4	9	10	11
Homebound tutoring ^c	32	31.4	6	13	9
Specific areas of outstanding need	11	10.8			
Help with obtaining accommodations					
Help with college admissions & scholarships	2	1.9			
More hospital-based instruction	5	4.9			
Help child reintegrate into school socially	2	1.9			
More hospital-based neuropsychological evaluations	1	0.9			
Provide information about treatment side-effects to school	5	4.9			

^aRate of parental concerns differed significantly by cancer type, $\chi^2(3) = 8.14$, $p = 0.04$, Cramer's $V = 0.29$, 95% CI [0.10, 0.46], with parents of children with brain tumors and solid tumors more likely to report concerns.

^bRate of parental concerns differed by grade grouping, $\chi^2(1) = 4.87$, $p = 0.03$, Cramer's $V = 0.23$, 95% CI [0.27, 0.42], with parents of children in sixth through twelfth grades more likely to report concerns than parents of children in preschool through fifth grade.

^cRate of parent-reported homebound services higher for parents of children in sixth through twelfth grade than parents of children in preschool through fifth grade, $\chi^2(2) = 11.46$, $p < 0.01$, Cramer's $V = 0.37$, 95% CI [0.17, 0.54].