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I, Megan P. Elam , hereby submit this original work as part of the requirements for the degree of Doctor of Education in Special Education.

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Educational Issues of Children who are Chronically Ill: A Quantitative Analysis of Patients', Caregivers', and Educators' Beliefs

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Educational Issues of Children who are Chronically Ill: A Quantitative Analysis of Patients', Caregivers', and Educators' Beliefs

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By

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Abstract

There is a paucity of research evaluating the effectiveness of school intervention and school reentry programs with respect to meeting the perceived educational needs of the recipients. In an attempt to align the goals of these programs with the perspectives of stakeholders, this research examined the perspectives of such recipients at an urban pediatric hospital. This study was novel in its aim to capture perceptions of educational issues of chronically ill students of three key stakeholders in a patient's education: the patient, associated caregiver, and associated educator. Perceptions were categorized within five domains, including perceptions about student attendance, teacher knowledge, medical issues, peer issues, and academic performance. While the primary purpose of this research was to identify the perceived educational issues across these five domains according to chronically ill patients, their caregivers, and their educators, this study also examined secondary aims to determine if perceptions varied from one group of stakeholders to another and to determine if perceptions were impacted by a patient's specific oncologic diagnosis. A quantitative design was employed in which all participants completed a perceptions questionnaire at a single time point. Data was analyzed using descriptive statistics and MANOVA.

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It is with great humility that I finalize my dissertation with one of the most important components: the recognition of those who have influenced my journey. I have been fortunate to find myself surrounded by mentors, professors, colleagues, family, and friends who have challenged, supported, and inspired me through my doctoral studies. In writing this, I am reminded that this was never a solo expedition, and that a single page in my dissertation hardly seems enough to acknowledge the partnership and guidance of those who have shared in this with me.

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Chapter One: Introduction

Increasingly, as medical advances have extended lifespans of pediatric patients with cancer and other chronic illnesses, quality of life has become a focus for these children and their families (Shaw & McCabe, 2007; Bessell, 2001). Normalization after diagnosis encompasses a critical dimension of quality of life. As school represents normalcy for the child whose life has become far from routine, school participation and/or reentry are of particular concern for these students (Chesler & Barbarin, 1986). Furthermore, because school can play such a significant role in encouraging the return to normality, school participation and attendance are frequently encouraged by the various stakeholders devoted to the child's treatment and overall well-being (Chesler & Barbarin, 1986).

Unfortunately, the education of children with cancer and other chronic illnesses can frequently be made challenging by a multiplicity of issues and concerns. As Olson, Seidler, Goodman, Gaelic, and Nordgren (2004) indicate, "these children are likely to attend neighborhood schools, [yet] schools face challenges incorporating children with different illnesses into the classroom" (p. 53). Reentry is not the only consideration that must be evaluated to ensure educational success for these students. In addition to issues surrounding attendance, noteworthy concerns that may impact the child's education can be attributed to medical needs and safety in the school setting, academic performance, social and peer concerns, and teacher-related issues. These various factors demonstrate how "the complexity of illness management and disease sequelae can alter their school experience" (Olson et al., 2004, p. 53). To fully ensure educational success for a child who is ill, each of these dimensions must be understood by invested practitioners supporting the child and subsequently addressed through evidence-based interventions.

In addition to evidence-based, interventions designed to improve the educational quality of life for children who are ill must be comprehensive and multidimensional. Various stakeholders are involved in and impact the success of the educational process for these children – most significantly, the patient, the caregivers or parents of the patient, and the educators of the patient: "Reports suggest that school problems are centered not only in the ill child, but also in reactions of the child's teachers [and] parents"

(Chesler & Barbarin, 1986, p. 42). Kliebenstein and Broome (2000) elaborate on this dynamic by describing the ecological exchange in this process:

> From an ecological perspective, a child's health outcomes are viewed as the result of interactions between the child and the immediate environment, both of which change over time and are subject to influence from larger systems. (p. 579) […] Optimal coordination of care during the transition from the clinic or hospital to home and then reentry into the school setting must reflect the use of a structured framework that will guide the process. This framework should be based on principles of the ecological model, which recognizes the inextricable linkage between the child, family, health care provider, and the school. (p. 584)

Because these stakeholders each contribute in some way to educational outcomes, understanding the educationally-relevant concerns from the perspectives of each of these groups is essential for improving school and academic-related outcomes for students who are ill: "If all attempts to moderate the stress of school reentry are directed toward the sick child […], significant sources of stress will remain unaffected and interventions will be incomplete and ineffective" (Chesler & Barbarin, 1986, p. 42).

Problem Statement

A substantial barrier to supporting these children, their families, and educators effectively is rooted in the extant literature base. Evidence-based practice is essential, yet minimal data exists in this area to validate the interventions most effective in meeting the needs of children with an oncologic diagnosis with respect to education. The majority of literature examining education for children who are chronically ill is based on practitioner experience without documented empirical evidence. While reports founded on professional practice provide firsthand anecdotal substantiation, research-based evidence is far more powerful, and even necessary, to build a case documenting the problems these children experience and to subsequently tailor effective interventions that will support the patients, caregivers, and educators confronted with implications of pediatric chronic illness in the educational setting.

Perceptions studies are frequently used to understand the beliefs, concerns, and attitudes of individuals from the perspective of the individual. Evaluating the perceptions of patients with respect to

healthcare experiences has become both increasingly popular and increasingly essential in today's ever-changing healthcare system. Perceptions research can provide valuable insight into the needs of individuals and critical information related to problems and barriers surrounding a specific experience or service.

Patient perceptions. Few studies have examined the perceptions of educational issues for children with cancer from the perspective of the patient. Most literature describing educational issues of children with cancer has been presented from the perspective of those providing care for these children. Shaw and McCabe (2008) briefly outline school-related concerns from the perspective of pediatric patients based on their review of existing literature; their review captures responses which indicate that students who are ill value social support (including support from parents, teachers, and friends/peers), though they often feel excluded from social activities, and teachers frequently lack the knowledge to provide them appropriate support.

Caregiver perceptions. Olson et al. (2004) report that "school issues are listed by parents as one of the most important problems where they want assistance from their primary care providers" (p. 54) when their child faces a chronic medical diagnosis, yet parental perceptions of educational issues for children with cancer have been studied on a limited basis.

In 1986, Chesler and Barbarin studied the perceptions of 59 parents of school age children with cancer. Subjects in this study participated in an interview and completed a 6-page questionnaire to describe their child's diagnosis, school reentry process, school related problems and issues, school attendance, performance and motivation, and the helpfulness of the child's educators.

More than half of the families interviewed expressed problems related to their child's school return. Of the 59 parents interviewed, 22 (37%) indicated that teasing by peers had been problematic for their child, 18 (31%) indicated that missing much school was a concern, and seven of the 59 parents (12%) suggested that relations with teachers had been difficult. Notably, parent reports signal that absence alone is not a cause of other problems; that is, there was no difference noted in peer teasing and incidence of school-related problems between the children who did and did not miss significant amounts of school

related to their illness. Parents' concerns related to peer teasing were substantiated by evidence of classmates who treated their child "like a leper" (Chesler & Barbarin, 1986, p. 41). Parents perceived that the changes that their children underwent as a result of their medical treatment (including, for example, hair loss, weight gain, weight loss, and/or facial puffiness) left their child susceptible to rejection in social settings. Regarding teacher helpfulness, nearly half (45%) of parents interviewed perceived their child's educators and school staff to be unhelpful. Parents felt that teacher unhelpfulness over time translated into greater academic difficulty, particularly for students who struggled academically prior to their diagnosis.

Using a mixed-methods approach, Kliebenstein and Broome (2000) also studied the perceptions of parents regarding school reentry for children who are chronically ill. Twenty-one parents of children with a chronic illness participated in the interview process and completed a supplemental questionnaire. Content analysis of the responses revealed five themes of concerns related to the reentry process and their child's school issues after a chronic diagnosis: sharing the news, making the transition, watching the child, teaching the teachers, and working with the child. Parents frequently reported that school support contributed significantly to the reentry process, particularly at the time of initial reentry. These caregivers also emphasized the value of communication with the school regarding each aspect of the educational process to provide appropriate support for the child and family with respect to the child's illness.

In a brief report, Anthony, Gil, and Schanberg (2003) presented the findings of their study on the impact of parental perceptions of child vulnerability on school and social adjustment for children who are chronically ill. Sixty-nine parent-child dyads participated in the quantitative study, which utilized parental self-reports, child reports, and physician reports to measure the relationship between parental concerns and child adjustment. The authors described the link between parental influence and child adjustment as a delicate balance. Parental concerns about the child's health may restrict school participation, and parental anxiety related to the child's illness and perceived vulnerability may lead to "a maladaptive pattern of parent-child interactions and child behavior problems" (p. 185). Unexpectedly, though higher parental perceptions of child vulnerability correlated with increased social distress in children, study findings did not predict correlations between perceptions of child vulnerability and school absences.

According to Moore, Kaffenberger, Goldberg, Oh, and Hudspeth (2009), "because the parents' role is central to how the child manages treatment and school reentry, gaining the parent's perspective on how the cancer treatment has impacted academic performance […] needs to be understood" (p. 87). These researchers studied the perceptions of fifty-nine parents of school age children with cancer to determine their beliefs about their child's educational issues pertaining to the impact of diagnosis. Findings suggest that "parents perceived that there were many barriers in the school related to their child's reentry to school" (p. 94), including teacher unhelpfulness, teacher unwillingness to make accommodations, inappropriate and lacking services, and lack of teacher knowledge related to the child's diagnosis. Parents also perceived limited peer contact to be problematic, and desired increased support services from school and hospital personnel to improve school-related outcomes for their child.

Educator perceptions. According to Chesler and Barbarin (1986), "even the best prepared and experienced teachers walk a thin line in deciding how to be truly helpful to students and their families" (p. 45). Teachers' feelings of fear and anxiety, ignoring issues or over-exaggerating problems can all lead to challenges in the educational setting for the child who is ill. Understanding teachers' perceptions can provide professionals and educational liaisons with an appreciation for teacher concerns and guide interventions appropriately.

Olson et al. (2004) emphasize that "little is known about what educators are concerned about if these children are in their classroom" (p. 53). In reaction to this vacancy, these authors studied perceptions of school professionals regarding chronic illness in the classroom. To understand the aspects of supporting a child with a chronic condition in the classroom that are most concerning to teachers, and to understand the impact teachers perceive that children who are ill may have in the classroom, 384 educators at twenty-three elementary schools each completed a survey composed of thirteen statements related to supporting children with chronic illness in the classroom. Survey responses were specific to six diagnoses: leukemia, epilepsy, diabetes, asthma, congenital heart disease, and AIDS; survey statements were categorized as follows: potential academic impact on the child, impact on peers, personal risk or liability, and additional time or demands for the teacher.

Regarding the perceived impact of a child with a chronic illness in the classroom across the six conditions studied, teacher responses suggested only a modest impact, with a mean score of 2.4 on a 5-point Likert scale (where a rating of 1 indicated low perceived impact and a rating of 5 indicated a high perceived impact). While the authors reported that overall perceptions of educators were positive, there were certainly educator perceptions that could negatively impact the school experience of a child with a chronic illness. Given the four areas of impact described above, teachers were least concerned about the academic impact on the child that may result from the illness, and most concerned about the direct impact on the educator. Teachers were concerned that a child with a chronic illness may require more time and attention, and may also pose a threat in terms of personal liability and risk in the classroom for the educator.

Paradoxically, the reality is to the contrary. While children who are ill rarely present an immediate risk in the classroom with respect to medical emergencies or personal liability for the educator, the child with a chronic condition will frequently experience sequelae related to learning and cognition in addition to other school difficulties. Yet, "few educators perceived their students' learning abilities as an issue" (Olson et al., 2004, p. 56). These results suggest that "educators may have unrealistic concerns about the potential classroom impact of different chronic health conditions and may benefit from educational instruction from primary health care professionals" (p. 57).

McCarthy, Williams, and Eidahl (1996) also studied the views of educators regarding children with chronic conditions. These authors contend that understanding the unique needs of students who are chronically ill may impact the school experience for these children. Consequently, the authors designed a descriptive, exploratory qualitative research study using semi-structured interviews to identify the concerns and needs of educators relative to serving children who are chronically ill in the educational setting. Semi-structured interview guides aligned questions with prominent topics identified in a review of existing literature. These four areas of focus included: school experiences of children with chronic health conditions, concerns regarding educating these children, resources to address these concerns, and recommendations for improving these resources. Twenty-nine school professionals participated in the

interview process, and categoric content analysis was used to analyze the data. Study outcomes revealed similar findings to the Olson et al. study. Educators expressed concerns related to emergency situations and medical emergencies related to the child's condition (62%), attendance and absenteeism (48%), behavioral issues (34%), educational impact (28%), parent communication (28%), and peer-related issues (21%). As with Olson et al. findings, the percentage of educators concerned with the academic impact resulting from a chronic condition was surprisingly low. Educators were also only minimally concerned with peer-related issues such as teasing, bullying, and peer acceptance.

In addition to their examination of parental perceptions, as part of the same research study, Kliebenstein and Broome (2000) examined the perceptions of twenty-four school professionals regarding school reentry for children who are chronically ill. Educators completed questionnaires which revealed that teacher concerns can be similarly classified in the same five categories as those of parental perceptions: sharing the news, making the transition, watching the child, teaching the teachers, and working with the child. Findings suggest that educators are most concerned about communication as it pertains to each of these categories, and desire clear communication between the parents, medical staff, and school regarding the child's diagnosis, transition plan, and how to appropriately meet the child's educational needs.

Moore et al. (2009) examined the views of school personnel as part of their perceptions study on school reentry for children with cancer. Consistent with findings expressed by parents in this research, school personnel reported that increased services from health care providers to support the child with an illness would be appreciated and contribute to improving outcomes for the child in the educational environment.

Clay, Cortina, Harper, Cocco, and Drotar (2004) report that educators are ill-prepared to serve children who are chronically ill in the classroom. Accordingly, the authors studied the perceptions of 480 school personnel using the 11-question School Health Questionnaire, developed for the purposes of the study. Educator participants reported feelings of responsibility pertaining to the child's education when a child is chronically ill. Despite this, they largely described a lack of training and academic preparation in

anticipation of supporting these children in the classroom. Overall, teachers' expressed concerns related to absenteeism, fatigue, academic performance, and school participation pertaining to the child's illness. Educators were less concerned about psychosocial and peer-related concerns for these children, despite the role these frequently play in impeding the child's school success for students who are ill.

Domains of concern. Beyond empirical research studies, additional literature has provided anecdotal commentary on the concerns of patients, parents, and educators with respect to educational issues for the child with cancer. Parents of children who are chronically ill have expressed reluctance to send their child to school for the following reasons: fears of infection, fears of medical emergency, fears of teasing by peers, and other fears that may or may not be realistic, misperceptions related to sending terminally ill child to school, guilt and overprotection, physical limitations, academic concerns, and psychological and behavioral concerns (Prevatt, Heffer, & Lowe, 2000). Likewise, teachers have reported fears related to responding in a medical emergency, the impact of the illness and/or treatment in the classroom and on academic performance, and demands on time and attention (Olson et al., 2004). Educator concerns regarding educational issues of children with cancer can be classified similarly to those of the patients and caregivers: school attendance issues, medical issues and concerns, classroom and teacher-related issues, academic performance concerns, and peer and social-related issues.

School attendance issues. For the student with cancer or another chronic illness, school attendance is of paramount importance. The degree of attendance may vary from one child to another based on his/her specific diagnosis, treatment plan, associated side effects, psychosocial and emotional well-being, and other factors. For the child experiencing devastating side effects, such as extreme fatigue, severe immunosuppression, pain, nausea, and/or others, school attendance may be infrequent or impossible. Inpatient hospital visits and frequent treatment may also impede regular attendance. Some children may develop school-related phobias and anxieties, preventing or delaying reentry (Chesler & Barbarin, 1986; Sexson & Madan-Swain, 1995). Furthermore, parents may experience feelings of fear and guilt, contributing to overprotection of the child and subsequent school refusal from the child (Sexson & Madan-Swain, 1993). Even as time passes, though the frequency of absences decline, for children who

experience a chronic illness, absence continues to be a challenge long after diagnosis (Vance & Eiser, 2002).

Caregiver and parental perceptions surrounding school attendance can inadvertently have a dramatic impact on the child's school attendance. Some parents perceive that their child is too ill or vulnerable to attend school, sending a message to the child that may result in hesitation and reluctance to attend school (Chesler & Barbarin, 1986). Some parents perceive efforts to reintegrate their child back into school as futile in the midst of frequent outpatient medical visits (Sexson & Madan-Swain, 1995). Overall, the emotional and physical effort of school reentry is often reportedly perceived as an excessive concern of parents. The process adds to an already overwhelming situation for parents in the midst of diagnosis, treatment, and even after (Sexson & Madan-Swain, 1995).

Classroom and teacher-related issues. Most teachers and educators have not been trained on how to meet the needs of children with medical conditions in the classroom (Olson et al., 2004). Despite the best of intentions, school personnel are often not familiar with the specific disease information when a student in their care is diagnosed with a chronic illness. In some cases, the teacher may not even be aware of the diagnosis. Not only does this put the educators at a disadvantage in caring for the child's disease, but this has serious implications for those illnesses that may require immediate attention at school. Limited knowledge about the child's disease may be detrimental in certain cases for a child with chronic illness in the classroom (Sexson & Madan-Swain, 1995).

Teachers express concerns regarding how to educate peers about the child's chronic illness, how the presence of the ill child may affect the other students, and how to facilitate acceptance of the child by peers. Additional classroom-specific concerns common for educators include balancing time and attention between the child who is ill and the other students (Sexson & Madan-Swain, 1995).

Some teachers have indicated reluctance having children who are ill in their classrooms. Teachers cite lack of knowledge about the disease, uncertainty regarding appropriate expectations to place on the student, and concern regarding how to manage peer concerns and reactions as reasons for reluctance. Educators express uncertainty of students' capabilities and how to discipline the student with chronic

illness. Teachers fear working with a child who might die, and over-solicit or avoid issues as a result (Prevatt et al., 2000).

Literature frequently suggests that teachers may react stereotypically and inappropriately when faced with educating a child who is ill (Chesler & Barbarin, 1986). This behavior may develop out of fear, uncertainty, confusion, and lack of understanding (Chesler & Barbarin, 1986). Lack of disease-related knowledge of teachers results in missed opportunities for psychological referrals when evaluations and interventions may be needed. Teachers attribute problems to the illness, thus allowing the impaired learning to continue without further intervention, and frustration and failure result from the student (Sexson & Madan-Swain, 1995). Teachers may place unrealistic expectations on the student as a result of an inability to recognize true limitations. Again, frustration and discouragement from the student may result (Sexson & Madan-Swain, 1995). In addition, teachers may lack an understanding on how to relate to the families, and may be overly sympathetic as a result. Teachers may be reluctant to challenge the student due to empathy or even pity (Sexson & Madan-Swain, 1995). Teachers may be overprotective of the child, may isolate the child unintentionally, and inadvertently hinder outcomes in the classroom as a result (Sexson & Madan-Swain, 1995).

Attitudes and preparation of school personnel are critical for successful school reintegration, and may affect school attendance and performance of the student with a chronic illness (Sexson & Madan-Swain, 1995). Prior negative experiences with a student with a chronic illness, fear related to changes in the child's appearance, particularly with any vulnerability conveyed by the child's appearance, and fear of the child's potential of dying are attitudes that may inadvertently impact the child's educational experience (Sexson & Madan-Swain, 1995).

In some cases, students have reported instances of teacher inflexibility (Henning & Fritz, 1983). In such instances, accommodations were not made, and teachers insisted on adhering to established district and classroom standards. Others describe the opposite: experiences with educators who refused to provide boundaries or minimal expectations due to exaggerated feelings of empathy and pity (Henning & Fritz, 1983). Parents have reported many barriers making school reintegration challenging after a child's

chronic diagnosis; of these, the most surprising may be perceived exclusion and ridicule on behalf of school personnel (Ashton, 2004).

Peer and social-related issues. Social isolation and lack of peer acceptance are issues frequently addressed in the literature for children who are ill (Chesler & Barbarin, 1986). Caregivers express concern related to stigmatization of their child by others (Chesler & Barbarin, 1986). Teachers express concern about helping children with cancer socially, as they perceive these students to be less prone to leadership and more withdrawn and socially isolated (Prevatt et al., 2000).

Concerns related to physical appearance often create anxiety with respect to the child's return to school and are often a cause for referrals to mental health services (Sexson & Madan-Swain, 1995). Peer interactions and fears of rejection are primary concerns related to school reentry (Prevatt et al., 2000). The child should be adequately prepared for what types of questions they may be asked by teachers and peers, and how to answer (Sexson & Madan-Swain, 1993); furthermore, fear of peer rejection due to physical changes can be circumvented through the education of peers about the child's disease (Sexson & Madan-Swain, 1995). The child needs a solid understanding of his/her own illness and how to discuss the disease with classmates and teachers (Prevatt et al., 2000).

Medical issues and concerns. The education of the child who is chronically ill may be impeded or made difficult by the child's illness and treatment sequelae. Fatigue, nausea, weakness, and general malaise may hinder attendance and classroom functioning (Sexson & Madan-Swain, 1995). Some children may even fear dying in the event of separation from the mother or primary caregiver, a fear specific to children who are chronically ill (Sexson & Madan-Swain, 1995). Conversely, Henning and Fritz (1983) report that some children who are chronically ill may have realistic concerns about their safety and medical issues with regard to school participation and attendance.

Parents and caregivers perceive school attendance hazards related to their child's immunosuppressed state, which can leave the child susceptible to contracting an infectious illness (Chesler & Barbarin, 1986). Some parents perceive their child to be too vulnerable to return to school despite recommendations from the medical team. Parents may feel overprotective and see a need for

constant surveillance of their child, thus preventing the child's return to school (Sexson & Madan-Swain, 1995).

Teachers may express concern related to the energy levels and physical health and endurance of children who have cancer (Chesler & Barbarin, 1986). Teachers feel that parents do not communicate enough about life expectancy, severity of disease, or possible complications that may arise during the school day (Prevatt et al., 2000). Teachers may fear approaching parents about the disease and fear approaching the student about the disease. Teachers also fear medical issues that may arise in the classroom (Sexson & Madan-Swain, 1995).

Academic performance concerns. Academic difficulties are common for the child with a chronic condition (Sexson & Madan-Swain, 1995). Frequent absences may be one cause of academic deficiency in children who are chronically ill (Nabors & Lehmkuhl, 2004). Associated weakness, fatigue, nausea, and pain may also contribute to diminished academic performance in the classroom (Nabors & Lehmkuhl, 2004). Anxieties related to having to "catch up" on missing work and to "catch up" with peers have been cited as barriers preventing children with chronic illness from wanting to return to school (Sexson & Madan-Swain, 1995). Many children with chronic illness have lower achievement test scores than their peers who are healthy, even without evidence of cognitive impairments (Sexson & Madan-Swain, 1995). Concerns regarding lowered academic performance are persistent for parents and caregivers (Chesler & Barbarin, 1986). Some educators have expressed concerns related to the child's difficulty concentrating (Chesler & Barbarin, 1986). As a reaction to the uncertainty educators may face when working with a child with cancer or chronic illness, one response is to frequently lower academic requirements for the child (Chesler & Barbarin, 1986).

Discussion

Despite literature that often cites the unexpected difficulties children, parents, and educators may encounter with respect to the education of children who are chronically ill (Henning & Fritz, 1983), perceptions studies have only examined the concerns of two of these three stakeholder groups.

Paradoxically, it is the perceptions of the child, the stakeholder most significantly and directly impacted, that have been consistently ignored.

The aforementioned areas of patient, caregiver, and educator concerns provide a strong case for defining five domains of educational issues for students who are chronically ill. A questionnaire to identify and evidence perceived educational issues from the view of each of the three stakeholder groups defined in this review (that is, patients, caregivers/parents, and educators) must address each of these domains to comprehensively understand these issues. "If we understand better what issues exist with different chronic health conditions, both primary health care providers and specialty care programs can provide appropriate information and develop appropriate interventions to address these issues in schools" (Olson et al., 2004, p. 54).

It is noteworthy that the perceptions described in this review "are most accurate in describing children who are in the midst of active and perhaps debilitating treatment. As treatment regimens ease, children who are in remission and doing well behave and often are seen more like all other children" (Chesler & Barbarin, 1986, p. 38). The majority of existing research and literature focuses on educational issues of children who are in active therapy and treatment for their illness. This highlights an additional need for future studies to examine educational issues of students with cancer or other chronic illnesses across various time-points to compare differences in perceived educational issues between initial time of diagnosis, midway through treatment, and post-treatment.

Additionally, much of the literature that exists to date was published in the 1980s and 1990s, when changes in medical advances began to make a dramatic impact on lifespans of children with chronic illnesses. Despite continued advances, literature on educational issues for children who are chronically ill has become stagnant. Moreover, most existing literature is based on anecdotal practitioner experience. Data is largely unavailable to truly define perceptions regarding educational issues for chronically ill patients from the perspectives of the student/patient, caregiver/parent, and educator.

A responsibility falls to health care professionals to support educators with appropriate interventions and provision for children who are ill in the educational setting. Up to "82% of the school

professionals agreed with the statement that health care providers would provide sufficient information regarding the chronic health condition and how to care for a child with that disease" (Olson et al., 2004, p. 56). More than half of the educators evaluated in the Olson et al. study reported that they needed additional training to support these students, but these types of training opportunities are rarely provided in formalized teacher education programs, including baccalaureate and post-graduate programs, to say nothing of other professional development opportunities. McCarthy, Williams, and Eidahl (1996) likewise report on the lack of teacher knowledge related to chronic conditions, and reiterate that teachers do not have the specific knowledge necessary for integrating these children into the classrooms or the educational opportunities to fill this vacancy. Ultimately, coordinated interventions must be designed that align with the perceived needs of all stakeholders in a child's education, including those of the patient/student, the parent/caregiver, and the educator.

Purpose

The purpose of this research was to study the perceptions of patients, caregivers, and educators regarding educational issues for patients who are chronically ill and use the knowledge gained to align the services offered by a school intervention program (SIP) at a large urban pediatric hospital with the perceived educational issues of the recipients of the services. Ultimately, with the guidance of the results from this study, school intervention professionals can examine current standard of practice through the lens of the recipients of the services. Additionally, school intervention professionals may be poised to disseminate these results across the country with the goal of illuminating the recipient's perceptions and their subsequent desired needs during and after a very difficult time in their lives.

The research questions and proposed hypotheses are outlined in Table 1. The primary aim of this research study was to identify the perceived educational issues of students who are chronically ill according to these patients, their caregivers, and their educators. The secondary aims of this research were as follows: to determine if perceptions of educational issues for students who are chronically ill varied from one stakeholder group to another and to determine if perceptions were impacted by the patient's diagnosis. It was hypothesized that perceptions will vary based on stakeholder role, and also that the

diagnosis of a patient may significantly impact the perceived educational issues for a child; with consideration of diagnosis, a child may experience a host of dramatically different outcomes that may impact school-related issues. A child with a brain tumor may experience markedly different impacts from treatments such as cranio-spinal radiation and tumor resection than a child who received treatment for another solid tumor such as osteosarcoma. Certain treatments are known to increase risk for cognitive late effects, while other treatments such as limb amputation for a solid tumor may result in concerns related to mobility at school and social/peer-related concerns.

Significance

School intervention professionals and other invested practitioners will be better equipped to meet the needs of patients, caregivers, and educators by understanding the perceptions of these stakeholders regarding educational issues. The results of this study will empower programs in other institutions to examine the alignment of the goals of their respective programs with stakeholder perceptions. The pediatric institution hosting this study serves patients from around the world, which allows for generalizability to encompass patients' needs not only locally, but for those across the country, as well. While this study focuses on patients with oncologic diagnoses, these results are generalizable to all chronically ill patients and their care providers (in an effort to increase such generalizability, a national expert panel review process was included to aid in the development and revisions of the questionnaires). Additionally, disseminating such results may provide rationale for expanding the sphere of influence to include chronically ill patients outside of oncology.

Table 1

Research Questions and Hypotheses

Research Questions	Related Hypotheses
What are the perceptions of school issues for children who are chronically ill according to patients, according to caregivers of patients, and according to educators of patients who are chronically ill?	Patients, their caregivers, and their educators are concerned about school issues across all 5 identified domains (academic performance, peer issues, medical issues, teacher knowledge, and school attendance)
Do perceptions vary from one stakeholder group to another?	Perceptions vary from one stakeholder group to another; specifically: Caregivers and Educators are more concerned than patients
Do perceptions vary based on the patient's diagnosis?	Perceptions vary based on the patient's diagnosis. For example, academic performance concerns for patients with brain tumors may be more significant than concerns for patients with other solid tumors. Concerns for student attendance may be more significant for patients with leukemia than for patients with other diagnoses.

Chapter Two: Methods

Study Design

This study utilized a quantitative survey design. The quantitative survey design was organized as follows: three different questionnaires were used to measure the perceptions of educational issues for children who are chronically ill, including a questionnaire to measure the perceptions of the patients, a questionnaire to measure the perceptions of the caregivers/parents of the patients, and a questionnaire to measure the perceptions of the educators of the patients. The study design is illustrated in Table 2.

Table 2

Study Design

	Patients	**Caregivers**	**Educators**
Perceptions at Diagnosis *(within 2 months of definitive diagnosis)*	PtPQ	CGPQ	EdPQ

Note: PtPQ = Patient Perceptions Questionnaire; CGPQ = Caregiver Perceptions Questionnaire; EdPQ = Educator Perceptions Questionnaire

These questionnaires were administered to each stakeholder group upon diagnosis of the patient to measure the perceptions of educational issues for the child who is chronically ill within two months of the patient's diagnosis. At this point of an oncologic diagnosis, there are no (or at the very least, few) cognitive effects of treatment and the stakeholders have no experience yet navigating the school process in the context of the illness. It was anticipated that concerns would be relatively high at this point due to "fear of the unknown." All data collection to measure the perceptions of educational issues of patients with chronic illnesses at diagnosis were completed within 2 months of the patient's definitive diagnosis date for all 3 stakeholders (patient, caregiver, and educator participants). Participants completed the appropriate educational perceptions questionnaire, Patient Perception Questionnaire (PtPQ), onsite at the pediatric institution. A member of the research team read the questionnaire aloud to patients ages 5-11. Caregiver participants completed the Caregiver Perception Questionnaire (CGPQ) onsite at the pediatric

institution. Educator participants completed the Educator Perception Questionnaire (EdPQ) at the patient's school or another desirable location at the preference of the educator.

Sample

Population and sample. The school intervention program at this study site is a referral-based program for patients with cancer and blood diseases. Annually, the program serves over 750 patients in the cancer and blood diseases division, including those with leukemia, lymphoma, solid tumors (including brain tumors), sickle cell disease, and long term survivors. While this specific population (with the exception of patients with sickle cell disease and long term survivors) within the institution was recruited for participation in the study, this accessible cohort is expected to be representative of the target population of this study (oncology patients across the country), as the institution attracts and serves oncology patients from the entire nation. Furthermore, the nature of the specific pediatric institution is such that it is the only pediatric oncology hospital in the region, thus serving all patients with pediatric cancer diagnoses in its Tri-State region. Consequently, the hospital population is very representative of the entire metropolitan area. Participant demographics for the specific study sample are described in Appendix H, Tables 12, 13, and 14.

To be eligible for participation in this study, patient participants were required to meet the following criteria: the patient was required to have an oncologic diagnosis or other benign tumor (leukemia, lymphoma, brain tumor, and other solid tumor, e.g., osteosarcoma, Ewing sarcoma, retinoblastoma, neuroblastoma, rhabdomyosarcoma); the patient was required to be school-aged – grades K-7 – at the time of study enrollment; and the patient and family were required to be receiving or willing to receive some level of school intervention support. Study enrollment occurred within two months of definitive diagnosis to ensure that data collected at the first time point successfully captured initial perceptions of educational issues at the time of diagnosis.

Patients known to have an extremely poor prognosis (less than 12-month life expectancy) at the time of study enrollment were not considered for this study. Specific diagnoses are known to have a poor prognosis, such as diffuse intrinsic pontine glioma (DIPG); therefore, these patients were not approached.

Due to variability in prognoses within diagnoses, a member of the research team confirmed prognosis for each patient approached for study enrollment with the patient's attending physician. The patient's attending physician confirmed the patient's enrollment by signing the Criteria Eligibility Form (Appendix C) for the patient participant. Additionally, patients not attending school were not considered for this study (i.e., those that are home schooled or refusing to participate in all school services were excluded; in contrast, those patients still engaged in traditional school through homebound instruction provided by the school were included). Participants were required to have the ability to speak English to participate. Any participant 11 years of age or older was required to have the ability to read English.

Sampling and recruitment. 49 participants were recruited and included in this analysis. A breakdown of the sample by the independent variable categories is outlined in Table 3. Power analysis information is provided in Appendix H, Table 16.

Table 3

Sample Size within Independent Variable Groups

	Leukemia	**Lymphoma**	**Brain Tumors**	**Other Solid Tumors**	**Total**
Patients	6	2	6	3	17
Caregivers	6	2	6	3	17
Educators	6	2	4	3	15
Total	18	6	16	9	49

Dual IRB approval was granted for this study, including permission from the governing IRB of the pediatric hospital, and also permission from the governing IRB of the related university (Appendix A). Subjects potentially eligible for enrollment were approached for participation after a member of the study staff obtained permission from the patient's attending physician (though to prevent coercion, the

patient and family were not informed that their physician granted approval; however, if specifically asked, the research staff did indicate that the physician granted medical permission to participate). The informed consent process for the patient and patient's caregiver took place onsite at the pediatric facility and included consultation with the patient and the patient's parents/guardians to discuss the objectives of the trial, the procedures involved, and the associated risks and discomforts.

Upon receiving consent from the patient and caregiver participants, the educator participant was recruited via telephone and/or email. The informed consent process for the educator participant then occurred at the patient's school (or via phone conference/secure email) and included consultation with the educator to discuss the objectives of the trial, the procedures involved and the associated risks and discomforts.

The order in which the educators were approached for participation was dependent upon a nomination system in which the caregiver and patient nominated their first choice for the educator participant, second choice, and so on. While a nomination system may result in a bias in the sample, this is simply reported as a study limitation. In cases in which the first educator approached declined to participate, the participation of another educator at the child's school was sought (i.e., if the child's first nominated teacher declines, the participation of the child's second nominated teacher was sought). Educators for consideration included the child's content area teachers, art, physical education, or other "special class" teacher, the child's nurse or counselor, the child's special education teacher, the child's physical or occupational therapist, the child's principal/assistant principal, etc.

Instrumentation

Prototype design. The instrumentation developed for this study (Appendix F) was designed to answer the research questions previously stated. The measures were designed to identify perceptions of educational issues for students who are chronically ill from the perspectives of chronically ill patients, their associated caregivers, and their associated educators, as well as to determine if perceptions vary from one stakeholder group to another, and to determine if perceptions were impacted by the patient's diagnosis.

To effectively measure the perceptions of each stakeholder group, five versions of the Perceptions Questionnaire were developed: Perceptions of Educational Issues for the Chronically Ill: Young Child Report (PtPQ, Young Child); Perceptions of Educational Issues for the Chronically Ill: Child Report (PtPQ, Child); Perceptions of Educational Issues for the Chronically Ill: Teen Report (PtPQ, Teen); Perceptions of Educational Issues for the Chronically Ill: Caregiver Report (CGPQ); and Perceptions of Educational Issues for the Chronically Ill: Educator Report (EdPQ). Each 22-item questionnaire was designed to promote comparability of content across instruments. To ensure comparability across groups, the content domains were operationalized in the same way across groups so that each instrument essentially measured the same content but differed in wording to reflect the perspective of the appropriate stakeholder group; examples of these variations are provided in Table 4.

The Perceptions Questionnaire format was adapted from the Varni, Seid, and Rhode (1999) PedsQL: Pediatric Quality of Life questionnaire modules. The questionnaire content was adapted from Olson et al. (2004) with permission granted from Ardis L. Olson, M.D. (A. Olson, personal communication, January 24, 2011). Additional content was adapted from published literature regarding school issues for chronically ill students and from anecdotal experiences of school intervention professionals.

Table 4

Sample Perceptions Questions across Versions

	Domain: Student Attendance	Domain: Teacher Knowledge	Domain: Peer Issues	Domain: Medical Issues	Domain: Academic Performance
PtPQ (Young Child)	I might have to miss some days of school because of my illness.	My teachers will need to learn more about my illness to help me at school.	My friends and classmates will treat me the same as before I was sick.	Because of my illness, I might have an emergency at school.	I may not get to go on to the next grade because I am sick.
PtPQ (Child)	I might have to miss some days of school because I am sick.	My teachers will need to learn more about my illness to help me at school.	My friends and classmates will treat me the same as before I was sick.	Because of my illness, I might have an emergency at school.	I may not pass to the next grade because of my illness.
PtPQ (Teen)	I might have to miss some days of school because of my illness.	My teachers will require extra training because of my illness.	My friends and classmates will treat me the same as before I was sick.	Because of my illness, I might have an emergency at school.	I may not pass to the next grade because of my illness.
CGPQ	My child might have to miss some days of school because of his/her illness.	My child's educators will require extra training because of my child's illness.	My child's friends and classmates will treat him/her the same as before he/she was sick.	Because of my child's illness, he/she might have an emergency at school.	My child may not pass to the next grade because of his/her illness.
EdPQ	This student might have to miss some days of school because of his/her illness.	I will require additional training because of this child's illness.	This child's friends and classmates will treat him/her the same as before he/she was sick.	Because of this student's illness, he/she might have an emergency at school.	This child may not pass to the next grade because of his/her illness.

Pilot testing and revision. A two-phase expert panel review process was used to measure initial inter-rater reliability (defined as total number of items achieving 75% agreement or better for each item divided by the total number of items) and content validity (defined as total number of mean ratings of 3 or 4 for each item divided by the total number of items) of the instrumentation (Davis, 1992). The expert panel review process, including the 4-point Likert relevance rating scale and analysis process, was modeled from the recommendations of Davis (1992). The first phase included experts based at the study site. In an effort to ensure generalizability across the country, a second expert panel phase sought the expertise of professionals nationwide, including professionals from various national associations dedicated to educational issues for children with chronic illnesses (and organizations specifically dedicated to children with hematologic and oncologic diagnoses), and other school reentry professionals.

Each panel member received a copy of each of the five instrument versions with directions for the review process (Appendix B), and each panel member worked independently to rate the relevance of each item on a 4-point scale (1 = not relevant, 2 = somewhat relevant, 3 = quite relevant, 4 = highly relevant, per the recommendations of Davis, 1992). Additional response items provided the opportunity to evaluate clarity, content, comprehensiveness, and appropriateness of the questions and instrument. The reviewers were also asked to provide suggestions for revisions as part of the review process.

Valuable revision suggestions were gleaned from the expert reviewer process. Qualitative feedback from the expert panel process combined with the quantitative ratings was considered in revisions made to the instruments. Results from the expert reviewers unanimously indicated that the measures were comprehensive and that directions were clear, though revisions were required to improve readability levels, particularly for the young child and child versions of the questionnaire because several questions for young child and child versions were not at a proper readability level for the age range. Final readability levels have been confirmed using Microsoft Word to ensure readability for final questionnaire versions, and are presented in Table 5. Specific questions identified by the expert panel reviewers as problematic were very consistent across reviewers. Problematic questions included questions related to concerns about the child dying at school, questions related to barriers in education, and risks posed by the

presence of the child at school. Appropriate revisions were made to these questions. Again, no concerns were identified with comprehensiveness or clarity of instruments or directions for completion.

Table 5

Flesch-Kincaid Reading Levels

Questionnaire Version	Initial Reading Level	Final Reading Level	Expected/Appropriate Reading Level
CGPQ	7.8	5.2	8
EdPQ	7.9	5.6	8
PtPQ* (Young Child)	5.8	3.9	1
PtPQ (Child)	6.3	4.2	3-6
PtPQ (Teen)	7.8	5.3	7-8

**Note: This version is read aloud to child*

Reliability and validity. Initial inter-rater reliability and content validity scores were obtained from the expert panel review process. Content underrepresentation and construct-irrelevant variance were prevented through this step by having experts rate the relevance of each item and comment on the comprehensiveness of the measures.

Instrument administration. Following the expert panel process, the pilot phase proceeded with subject recruitment, consenting, enrollment, and finally, administration of the instrument. After consent was obtained from all recruited participants for the pilot phase, participants completed the appropriate educational perceptions questionnaire and accompanying demographic information (when applicable). Patient participants completed the Patient Perception Questionnaire onsite at the pediatric hospital. A member of the research team read the questionnaire aloud to patients ages 5-11. Caregiver participants completed the Caregiver Perception Questionnaire and Data Capture onsite at the pediatric hospital. Educator participants completed the Educator Perception Questionnaire at the patient's school. Upon analysis of the pilot data and completion of post-pilot study revisions, the study ensued, following the same steps described above for subject recruitment, consenting, enrollment, and instrument administration.

Exploratory Factor Analysis. The pilot phase/internal validation process was designed to pilot the instrumentation with the goal of obtaining validity and reliability data beyond that obtained in the expert panel review process. For the pilot phase of this study, 10 patient participants and their associated caregivers and educators were recruited, for a combined total of 30 participants, resulting in a balanced design. This pilot study included an evaluation of the five questionnaire domains for inconsistent items. Exploratory Factor Analysis (EFA) was used to examine initial questionnaire data. Data was analyzed separately for each of the three groups. The EFA utilized the Principal Components Analysis (PCA) extraction method and the Varimax rotation method. Five components were extracted and retained (these five factors were pre-specified based on questionnaire design); total cumulative variance for retaining five factors was considered acceptable based on the 90% variance explained in the analysis. Revisions to questionnaires were based on factor loadings within the rotated component matrix. In instances in which an item loaded more heavily on a factor other than that which it was originally intended, the item was moved to the factor with the stronger loading. Ultimately, 22 of the original 37 items were retained (Appendix H, Table 17). Four items were moved to domains deemed more appropriate based on analysis and final review for suitability.

Data Creation

Data creation procedures, including data file structures, data coding and entry, and data evaluation occurred as outlined below for both the pilot study and the subsequent study (perceptions at diagnosis).

Data file structure. Participants recorded their questionnaire responses directly onto the appropriate questionnaire instrument, which utilized a paper/pencil format. Responses were manually entered by a school intervention research assistant into Oncore (Forte Research Systems, Inc., 2003), a study management system frequently used at the pediatric institution (and others nationwide) which provides a system for managing study schedules, documents, and data. The data file was subsequently exported into an excel file then uploaded into SPSS for analysis. The data file structure utilized a common Participant ID to link stakeholder triads. This Participant ID was simply coded based on enrollment

number (that is, patient one, the associated caregiver, and the associated educator were each linked with the common Participant ID: P01). Each individual subject then received a unique Subject ID, which was coded as follows: #-M/F-##-#-##-##, or Diagnosis - Gender – Enrollment - Triad Role – Patient Age-Patient State of Residence, where the first single number indicated the patient's diagnosis (Diagnosis of patient: 1 – Leukemia, 2 – Lymphoma, 3 - Brain Tumor, 4 - Other Solid Tumor), then a letter denoting the patient's gender (Gender of patient: M – male, F – female), then a two digit number that indicated the patient's enrollment number (Participant ID) (2 spaces to denote PATIENT enrollment number, 01, 02, 03…45…60…75), followed by another dash with a single number indicating the participant's triad role (Triad Role: 1 – Patient, 2 – Caregiver, 3 – Educator), another dash followed by two numbers to denote the patient's age, and the final two numbers which indicated the patient's state of permanent residence (1 – Ohio, 2 – Kentucky, 3 – Indiana, 4 – Other).

The data file was structured by domain according to the five domains that were analyzed. The five domains analyzed include: Domain 1 – Student Attendance (SA), Domain 2 – Medical Issues (MI), Domain 3 – Classroom-Related Issues and Teacher Knowledge (TK), Domain 4 – Peer and Social-Related Issues (PI), and Domain 5 – Academic Performance (AP).

Data Scaling for domain-related questions was as follows: Strongly Disagree = 1, Disagree = 2, Neutral = 3, Agree = 4, Strongly Agree = 5. Inverse/reverse coding was required for several questions. In the case of these questions, scaling occurred as follows: Strongly Disagree = 5, Disagree = 4, Neutral = 3, Agree = 2, Strongly Agree = 1. Domain scores were then created using the sum score of each domain divided by the number of items within each domain.

Data coding and entry. As previously indicated, participants directly recorded their responses onto the paper instruments. Data was then manually entered into Oncore, the data management system. A Code Sheet (Appendix G) was created to designate codes for entry into the data spreadsheet. Codes were designated for participant ID numbers, demographic information, and questionnaire responses, including codes for item-level responses and domain-levels.

Data Evaluation

Data cleaning. Evaluability for participant inclusion in data analysis required that the following criteria be met: each subject was considered evaluable if he/she completed at least 75% of the individual survey components.

The data checking procedure for outliers started with a built-in data-monitoring procedure in Oncore. After the research assistant entered data from each questionnaire, the assigned study Data Monitor was required to review the inputted data and accept the data entry or query the research assistant if errors were detected. As a built-in safeguard, additional actions could not occur for a study participant until the Data Monitor signed off to approve the data entry. Next, visual inspection of the data occurred to locate potential outliers, including both visual inspection of the coded data and visual inspection of the data in scatterplot format. Root cause analysis was then used to attempt to identify the cause of any potential outliers. For data entry errors, the errors were corrected when possible by returning to the original form for accurate response data. However, if the data entry error could not be corrected, the data was to be eliminated (this did not occur in any cases in the pilot or subsequent study). For outliers resulting from unintentional error by the participant, a master list of coded data was maintained, and in several instances, discrepancies were identified and noted in the master list, however, these discrepancies only occurred in collection of demographic data, and were corrected. “Obvious” intentional outliers that could not be corrected were to be eliminated. Overall, the goal was to eliminate any illegitimate outliers.

Chapter Three: Results

To answer research questions about the perceived educational issues for children who are chronically ill at the time of diagnosis, descriptive statistics were explored and a MANOVA analysis was employed. The independent variables (triad role/stakeholder group and patient's diagnosis) were analyzed for effect on the dependent variables (student attendance, medical issues, teacher knowledge, peer issues, and academic performance). Effect of independent variables on dependent variables was explored at the domain level. Descriptive statistics were analyzed at the domain level and individual item level for dependent variables.

Assumption checks. The following assumptions were reviewed using IBM SPSS Statistics, version 21.0, and were met prior to proceeding with the MANOVA analysis:

- Multivariate normality
    - Dependent variables were distributed normally, per visual scan of histograms
    - Skewness and kurtosis were also reviewed, and were largely within acceptable limits of ± 1 for most dependent variables, with one exception – kurtosis of the Medical Issues domain (Appendix H, Table 18)
    - The Shapiro-Wilk test also revealed normality of data for all dependent variables when split for the two independent variables
        - The Shapiro-Wilk test is effective for assessing normality for small sample sizes (< 50 participants)
        - Because the values in the Significance column were greater than .05 for all five domains/dependent variables for the Shapiro-Wilk test, normal distribution is assumed (Appendix H, Table 19)

- Homogeneity of variance
    - Using Levene's Test of Equality of Error Variances, all p-values were greater than .05, thus the assumption of homogeneity of variances was met (Appendix H, Table 20)
    - Using Box's Test of Equality of Covariance Matrices, the assumption of homogeneity of variances was met (P = .017) (Appendix H, Table 21)

Reliability. Reliability is a measure of an instrument's consistency; a measure that repeatedly produces the same results under the same conditions would be considered highly reliable. To measure the internal consistency of the time point one data, Cronbach's alpha was calculated for the 22 perceptions questionnaire items. The resulting Cronbach's alpha was .854 (Appendix H, Table 22), which indicates a high level of internal consistency for the 22 item questionnaire with this specific sample. A review of Item-Total Statistics reported in this reliability analysis, specifically *Values for Cronbach's Alpha if Item Deleted* (Appendix H, Table 23), represent the value that Cronbach's alpha would be if any particular item were to be deleted from the scale. These were all relatively high (.841-.861), and removal of any single item would not significantly increase or decrease the Cronbach's alpha. These results are suggestive that all items within the questionnaire are relatively reliable, which affirms that there are no single items that should be removed from the measure.

Data Analysis

Primary research aim. To answer the primary research aims (to identify the perceptions of school issues for children who are chronically ill from the perspective of patients, of their caregivers, and of their educators), descriptive statistics were analyzed. The perceptions relative to each dependent variable at the domain level and at the individual item level were explored. At the domain level, items with a mean greater than 3.000 were coded as areas of concern per the 5-point Likert scale. Likewise, at the individual item level, items with a mean greater than 3.000 were coded as areas of concern per the 5-point Likert scale. Table 6 and Table 7 highlight the descriptive statistics at the domain and item levels for each dependent variable with respect to both independent variables: stakeholder role/triad role and

patient's diagnosis. Significant mean scores (that is, those greater than 3.000) are highlighted to denote areas of concern within each domain and across items.

Table 6

Perceived Educational Issues: Domain Level Descriptive Statistics

	Domain									
	Student Attendance Domain		**Teacher Knowledge Domain**		**Medical Issues Domain**		**Peer Issues Domain**		**Academic Performance Domain**	
	Triad Role	Mean	Triad Role	Mean	Triad Role	Mean	Triad Role	Mean	Triad Role	Mean
Leukemia			1	3.167	1	2.500	1	2.800	1	2.766
			2	3.833	2	2.833	2	2.667	2	3.267
			3	3.500	3	2.167	3	4.167	3	2.967
Lymphoma	1	2.600	1	3.667	1	2.500	1	2.800	1	2.600
	2	3.200	2	3.333	2	3.167	2	3.100	2	3.100
	3	2.900	3	2.833	3	2.000	3	2.200	3	2.600
Brain Tumors	1	2.467	1	1.778	1	1.667	1	1.967	1	2.900
	2	2.767	2	3.222	2	2.222	2	2.467	2	2.933
	3	3.500	3	4.167	3	2.417	3	2.100	3	3.350
Other Solid Tumors	1	2.733	1	3.222	1	2.333	1	2.933	1	1.800
	2	3.133	2	4.444	2	2.667	2	3.400	2	2.933
	3	2.800	3	3.444	3	1.889	3	1.933	3	2.133

Notes: Triad role 1 denotes patient participant, Triad role 2 denotes caregiver participant, Triad role 3 denotes educator participant; Mean items > 3 retained as perceived concern per 5-point Likert scale

Table 7

Perceived Educational Issues: Item Level Descriptive Statistics

	Student Attendance									
	Student Attendance Item 1		**Student Attendance Item 2**		**Student Attendance Item 3**		**Student Attendance Item 4**		**Student Attendance Item 5**	
	Triad Role	Mean	Triad Role	Mean	Triad Role	Mean	Triad Role	Mean	Triad Role	Mean
Leukemia	1	2.833	1	3.833	1	3.667	1	3.000	1	2.167
	2	4.833	2	2.833	2	4.833	2	4.833	2	1.000
	3	4.833	3	1.833	3	4.833	3	4.833	3	1.667
Lymphoma	1	1.500	1	3.000	1	4.000	1	2.500	1	2.000
	2	2.000	2	3.500	2	4.500	2	4.500	2	1.500
	3	3.000	3	1.500	3	5.000	3	4.000	3	1.000
Brain Tumors	1	2.333	1	2.833	1	3.500	1	2.333	1	1.333
	2	2.333	2	2.167	2	4.500	2	3.167	2	1.667
	3	3.750	3	3.500	3	4.500	3	4.250	3	1.500
Other Solid Tumors	1	2.333	1	3.333	1	3.333	1	3.000	1	1.667
	2	3.667	2	1.333	2	4.667	2	4.000	2	2.000
	3	2.333	3	1.667	3	5.000	3	4.000	3	1.000

Notes: Triad role 1 denotes patient participant, Triad role 2 denotes caregiver participant, Triad role 3 denotes educator participant; Mean items > 3 retained as perceived concern per 5-point Likert scale

	Teacher Knowledge					
	Teacher Knowledge Item 1		**Teacher Knowledge Item 2**		**Teacher Knowledge Item 3**	
	Triad Role	Mean	Triad Role	Mean	Triad Role	Mean
Leukemia	1	2.667	1	3.333	1	3.500
	2	3.167	2	4.667	2	3.667
	3	3.167	3	4.333	3	3.000
Lymphoma	1	3.500	1	3.500	1	4.000
	2	2.000	2	4.500	2	3.500
	3	2.000	3	4.500	3	2.000
Brain Tumors	1	2.333	1	1.167	1	1.833
	2	3.167	2	4.000	2	2.500
	3	4.000	3	4.250	3	4.250
Other Solid Tumors	1	3.333	1	2.000	1	4.333
	2	4.333	2	5.000	2	4.000
	3	3.000	3	4.667	3	2.667

Notes: Triad role 1 denotes patient participant, Triad role 2 denotes caregiver participant, Triad role 3 denotes educator participant; Mean items > 3 retained as perceived concern per 5-point Likert scale

	Peer Issues									
	Peer Issues Item 1		**Peer Issues Item 2**		**Peer Issues Item 3**		**Peer Issues Item 4**		**Peer Issues Item 5**	
	Triad Role	Mean	Triad Role	Mean	Triad Role	Mean	Triad Role	Mean	Triad Role	Mean
Leukemia	1	3.000	1	2.667	1	2.000	1	3.833	1	2.500
	2	2.500	2	3.500	2	2.667	2	2.500	2	2.167
	3	2.667	3	3.667	3	2.000	3	2.333	3	1.833
Lymphoma	1	3.000	1	3.000	1	2.500	1	3.000	1	2.500
	2	3.500	2	3.500	2	3.000	2	2.500	2	3.000
	3	1.500	3	2.500	3	1.500	3	3.000	3	2.500
Brain Tumors	1	2.500	1	1.667	1	1.500	1	2.500	1	1.667
	2	2.500	2	2.500	2	2.167	2	2.667	2	2.500
	3	1.750	3	3.750	3	2.000	3	1.500	3	1.500
Other Solid Tumors	1	1.667	1	4.000	1	3.667	1	2.667	1	2.667
	2	3.000	2	4.667	2	2.667	2	3.667	2	3.000
	3	1.667	3	3.667	3	1.333	3	2.000	3	1.000

Notes: Triad role 1 denotes patient participant, Triad role 2 denotes caregiver participant, Triad role 3 denotes educator participant; Mean items > 3 retained as perceived concern per 5-point Likert scale

	Medical Issues					
	Medical Issues Item 1		**Medical Issues Item 2**		**Medical Issues Item 3**	
	Triad Role	Mean	Triad Role	Mean	Triad Role	Mean
Leukemia	1	2.333	1	2.000	1	3.167
	2	4.000	2	1.833	2	2.667
	3	3.833	3	1.333	3	1.333
Lymphoma	1	2.500	1	2.000	1	3.000
	2	4.500	2	2.500	2	2.500
	3	4.000	3	1.000	3	1.000
Brain Tumors	1	2.333	1	1.167	1	1.500
	2	3.333	2	1.667	2	1.667
	3	4.000	3	1.000	3	2.250
Other Solid Tumors	1	3.333	1	2.000	1	1.667
	2	3.667	2	2.000	2	2.333
	3	3.667	3	1.000	3	1.000

Notes: Triad role 1 denotes patient participant, Triad role 2 denotes caregiver participant, Triad role 3 denotes educator participant; Mean items > 3 retained as perceived concern per 5-point Likert scale

	Academic Performance					
	Academic Performance Item 1		Academic Performance Item 2		Academic Performance Item 3	
	Triad Role	Mean	Triad Role	Mean	Triad Role	Mean
Leukemia	1	2.667	1	2.667	1	2.333
	2	2.667	2	3.167	2	2.833
	3	3.333	3	2.667	3	3.167
Lymphoma	1	2.500	1	2.500	1	2.500
	2	3.000	2	4.000	2	3.500
	3	3.000	3	3.000	3	2.000
Brain Tumors	1	2.833	1	1.667	1	2.500
	2	2.667	2	3.167	2	2.833
	3	3.500	3	3.500	3	3.750
Other Solid Tumors	1	1.333	1	2.000	1	1.000
	2	2.667	2	4.000	2	2.667
	3	2.000	3	2.667	3	1.667

Notes: Triad role 1 denotes patient participant, Triad role 2 denotes caregiver participant, Triad role 3 denotes educator participant; Mean items > 3 retained as perceived concern per 5-point Likert scale

	Academic Performance					
	Academic Performance Item 4		Academic Performance Item 5		Academic Performance Item 6	
	Triad Role	Mean	Triad Role	Mean	Triad Role	Mean
Leukemia	1	2.000	1	2.000	1	2.167
	2	2.833	2	3.167	2	1.667
	3	2.667	3	2.000	3	1.000
Lymphoma	1	2.500	1	1.000	1	2.000
	2	2.000	2	1.500	2	1.500
	3	2.500	3	1.500	3	1.000
Brain Tumors	1	2.667	1	1.833	1	3.000
	2	2.333	2	2.167	2	1.500
	3	3.000	3	2.000	3	1.000
Other Solid Tumors	1	1.333	1	2.000	1	1.333
	2	2.333	2	1.667	2	1.333
	3	2.333	3	1.000	3	1.000

Notes: Triad role 1 denotes patient participant, Triad role 2 denotes caregiver participant, Triad role 3 denotes educator participant; Mean items > 3 retained as perceived concern per 5-point Likert scale

Secondary research aims. A MANOVA, or multivariate analysis of variance, is used to compare differences among groups when more than one dependent variable is present. A MANOVA was employed, treating triad role and patient's diagnosis each as independent variables. Results were significant for both independent variables (patient's diagnosis and triad role) at the .05 level. Results were

not significant for an interaction effect between diagnosis and triad role. Thus, while perceptions vary based on triad role without consideration for specific diagnoses, and perceptions vary based on specific diagnoses without consideration for stakeholder role, perceptions do not vary to a statistically significant degree when considering specific diagnoses within each stakeholder group.

Table 8

Multivariate Test: Wilks' Lambda

Effect	Value	F	Significance	Partial Eta Squared	Observed Power
Diagnosis	.424	2.227	.011	.249	.939
Triad Role	.540	2.386	.018	.265	.906
Diagnosis*Triad Role	.445	1.001	.474	.149	.689

Note: Computed using alpha = .05

The significance column reveals values of .011 and .018 for diagnosis and triad role, respectively; thus, in the cases of the independent variables (diagnosis and triad role), $P < .05$. Practical significance was also detected for both diagnosis and triad role, as respective values for partial eta squared revealed a large effect size for each ($\eta_p^2 > .14$). Therefore, there was a statistically significant difference among different stakeholder roles on perceptions of school issues (F (9, 66) = 2.39, $P < .05$ ($P = .018$); Wilk's λ = .540, partial $\eta_p^2 = .265$), and among different patient's diagnoses on perceptions of school issues (F (14, 91.5) = 2.23, $P < .05$ ($P = .011$); Wilk's $\lambda = .424$, partial $\eta_p^2 = .249$) at the .05 level. Power to detect these effects was .906 and .939, respectively; thus, power to detect these effects was relatively high. There was not a significant difference given the interaction effect between triad role and patient's diagnosis, though this is expected to change with the increased sample size as participant recruitment continues, as power to detect this effect was only .689 given the small sample size at the time of analysis.

Given the significance of the overall multivariate test, the univariate main effects were examined to determine how the dependent variables differ for the independent variables. Significant univariate main effects for the dependent variables were only obtained for teacher knowledge for triad role ($F(2, 37) = 3.546$, $p < .05$, partial eta squared = .161, power = .623) and for teacher knowledge for triad role*diagnosis ($F(6, 37) = 3.167$, $p < .05$, partial eta squared = .339, power = .871) (Table 9). Results at the univariate level are not compelling, particularly with the very low observed power results illustrated in Table 9; though, again, these are expected to increase when a full sample is achieved.

Table 9

Test of Between-Subjects Effects

Effect	Dependent Variable	F	Significance	Partial Eta Squared	Observed Power
Diagnosis	Student Attendance	1.757	.172	.125	.420
	Teacher Knowledge	1.678	.188	.120	.403
	Peer Issues	1.724	.179	.123	.413
	Medical Issues	1.205	.321	.089	.296
	Academic Performance	1.300	.289	.095	.318
Triad Role	Student Attendance	1.524	.231	.076	.303
	Teacher Knowledge	3.546	.039	.161	.623
	Peer Issues	3.219	.051	.148	.579
	Medical Issues	3.005	.062	.140	.548
	Academic Performance	.992	.380	.051	.209
Diagnosis * Triad Role	Student Attendance	.425	.857	.065	.156
	Teacher Knowledge	3.167	.013	.339	.871
	Peer Issues	.783	.589	.113	.269
	Medical Issues	.983	.451	.137	.337
	Academic Performance	.326	.919	.050	.128

Note: Computed using alpha = .05

Table 10 reveals the results of Tukey's HSD post-hoc tests, which indicate that there is a significant difference for mean scores for concerns within the Teacher Knowledge domain between triad role 1 and triad role 2 ($p < .05$) and between triad role 1 and triad role 3 ($p < .05$), but not between triad role 2 and triad role 3 ($p = .941$). That is, perceptions vary relative to teacher knowledge between patients and caregivers, and between patients and educators, but not between caregivers and educators. This is consistent with pilot findings.

Table 10

Multiple Comparisons Table: Tukey's HSD Post-Hoc

Dependent Variable	Triad Role	Triad Role	Mean Difference	Standard Error	Significance	95% Confidence Interval	95% Confidence Interval
						Lower Bound	Upper Bound
Teacher Knowledge Domain	1	2	-2.765	.7786	.003	-4.666	-.864
		3	-2.498	.8042	.010	-4.461	-.535
	2	1	2.765	.7786	.003	.864	4.666
		3	.267	.8042	.941	-1.697	2.230
	3	1	2.498	.8042	.010	.535	4.461
		2	-.267	.8042	.941	-2.230	1.697

Note: Computed using alpha = .05

Chapter Four: Discussion

The purpose of this research was to identify the perceptions of educational issues for children who are chronically ill from the perspective of patients, their caregivers, and their educators, to determine if these perceptions varied based on stakeholder role, and to determine if these perceptions varied based on a patient's specific oncologic diagnosis. It was hypothesized that patients, their caregivers, and their educators are concerned about school issues across all 5 identified domains (academic performance, peer issues, medical issues, teacher knowledge, and school attendance), that perceptions vary from one stakeholder group to another (specifically, that caregivers and educators are more concerned than patients) and that perceptions vary based on the patient's specific oncologic diagnosis.

Main Findings

Domain level dependent analysis. Table 11 reveals the results of the domain level dependent analysis. Discussion is provided for domain-level results according to stakeholder role and according to specific diagnoses.

Stakeholder role. Caregivers expressed perceived concerns across 5 domains: student attendance, teacher knowledge, medical issues, peer issues, and academic performance, each with respect to the education of their children who are chronically ill. Within these domains, there were specific items of perceived concern (discussed below). Educators expressed perceived concerns across 3 of the 5 identified domains: student attendance, teacher knowledge, and academic performance. Educators did not express perceived concerns with respect to medical issues or peer issues for their students with chronic illness at school; however, within these domains, there were specific items of notable concern (discussed below). Patients expressed perceived concerns across 2 of the 5 identified domains: student attendance and teacher knowledge. Patients did not express perceived concerns with respect to peer issues, medical issues, or academic performance at school; however, within these domains, there were specific items of notable concern (discussed below).

Leukemia. At the domain level, student attendance and teacher knowledge are unanimous concerns across stakeholder role for patients with leukemia. Caregivers are uniquely concerned about the

academic performance of their children with leukemia. Student attendance is likely a pervasive concern within this diagnosis due to the treatment length associated with leukemia, inclusive of significant (frequent and sometimes long) inpatient stays and severe neutropenia which inhibit school attendance. Likewise, the length of treatment coupled with the ongoing risk for immunosuppression and increased need for infection control precautions to be taken at school, and long term risk for cognitive late effects associated with certain treatments may increase concerns around teacher knowledge (though the child may be aware of these risks to a lesser extent). Caregivers may express academic performance concerns associated with short-term attendance implications but also due to an awareness of the child's risk for long term cognitive effects that may emerge as a result of treatment. These stakeholders may understand the complex and multidimensional implications of student attendance over time, and how cognitive effects may further complicate those implications. Educators of patients with leukemia did not specifically promote concerns about academic performance despite these implications. This may be reflective of a tendency for teachers to minimize the impact of illness, to underestimate the impact of missed instructional opportunities in the immediate and long-term sense, and reflective of a lack of awareness of the implications of risks for cognitive late effects associated with treatments for leukemia. Neither the medical issues domain nor the peer issues domain were cited as collective areas of concern for patients with leukemia from the perspective of any stakeholder group. It is assuring that stakeholders are not particularly concerned about perceived risks for medical issues in the classroom for children with leukemia, as these are not often likely in the school setting for children receiving treatment for this specific diagnosis, though it is of interest that no collective concerns were expressed relative to the domain of peer issues. The absence of concern in this domain may be associated with the surge of initial peer support that accompanies a cancer diagnosis. Unfortunately, it is not unrealistic to anticipate that a child's peer relationships may change with a leukemia diagnosis. Treatment for leukemia is long; the child will likely miss out on important socialization opportunities and experiences with peers, and regrettably, the initial surge of support and outreach often tapers over time as peers return to their own routines and normalcy. Specific treatments associated with leukemia may also impact the child's

appearance, including changes such as hair loss, weight gain, facial puffiness, and others. It may be naïve to think that these effects would not result in potential consequences relative to peer interactions. Fortunately, concerted efforts to educate peers on the impact of illness and proactive attempts to maintain outreach and positive support over time can justify a lack of concern related to peer issues.

Lymphoma. At the domain level, caregivers of patients with lymphoma expressed concern across 5 domains: student attendance, teacher knowledge, medical issues, academic performance, and peer issues. Teacher knowledge was of notable concern for both patients with lymphoma and their caregivers. Similarly to treatment for leukemia, treatment for lymphoma, particularly for non-Hodgkin's lymphoma, can be particularly long. Caregivers' pervasive concern across all 5 domains for their children with lymphoma is certainly reflective of the proposed hypothesis, which suggests that concerns may be elevated at the time of an initial cancer diagnosis due to the "fear of the unknown." Because parents and caregivers are not certain as to what to expect with respect to school issues, their concerns relative to school and education for their child are widespread. This reinforces the need for support from school liaisons and health care professionals, who may educate caregivers on the potential effects of treatment for lymphoma on their child's school needs, and then pair this education with assurance of the interventions that will help to circumvent negative consequences of these effects to the greatest extent possible. Both patients with lymphoma and their caregivers expressed concerns about teacher knowledge with respect to school concerns. This again affirms the need for school liaison support, which is often inclusive of school staff education, and thus may alleviate concerns that are suggestive of teacher unpreparedness. Educators of children with lymphoma did not express concerns across any of the 5 domains. While it is encouraging that these educators are not concerned for the child with lymphoma in regards to school, this may be reflective of the dynamic described for educators of patients with leukemia – it may be theorized that educators either minimize or underestimate the effects of this serious illness and its lengthy and often invasive treatments on the child's education, or that teachers simply do not know what they do not know. This may actually validate perceived concerns of patients with lymphoma and their caregivers, who express concern about teacher knowledge. Again, education of school personnel is

of particular importance to ensure that educators are appropriately informed about the impact of lymphoma on the various domains of a child's school experience.

Brain tumors. At the domain level, educators of children with brain tumors expressed notable concern about the child's attendance, the child's academic performance, and about their own knowledge with respect to supporting the child. Caregivers of patients with brain tumors only expressed concern about teacher knowledge; patients with brain tumors did not express concerns at the domain level. Educators of patients with brain tumors may be appropriately concerned about areas of impact relative to school for a child with a brain tumor. Certainly a brain tumor may impact a child's attendance at school and the child's academic performance. Cognizance of teacher knowledge shortcomings suggests that these educators are aware of the significance of this disease, and that they may be open to education on the appropriate care and interventions for these children. Coordinated teacher education on the effects of the child's tumor can ensure that educators are informed with accurate information about the child's illness as well as how to provide appropriate care for the child; this, in turn, may alleviate the expressed concerns. Caregivers of patients with brain tumors may be assured in knowing that their child's teacher is appropriately educated on the effects of the child's tumor and how to care for the child, but may also benefit from targeted education on the short-term and long-term effects of a brain tumor diagnosis on school attendance, cognition, and peer relationships. This information should only be provided in the context of aligning potential consequences with proactive solutions and targeted interventions (e.g., peer education, academic monitoring, evaluations, and provision of accommodations). If caregivers do not anticipate potential effects, opportunities for support may be missed and long term outcomes may be compromised. A school liaison or other health care professional plays an essential role in providing this information to the caregivers of patients with brain tumors. It is not surprising that patients with brain tumors did not express concerns across the domains of school issues. It is likely that the impact of the tumor itself hinders these children from understanding the implications of their own disease.

Other solid tumors. At the domain level, teacher knowledge was a pervasive concern across stakeholder groups for patients with solid tumors. Caregivers of patients with solid tumors were also

concerned about student attendance and peer issues for their child. Solid tumors can often be complex, and the implications of these tumors and related treatments in the school setting may not be immediately apparent to an educator. All stakeholders seemingly acknowledge the need for teacher education about the child's potentially rare tumor and its effects on the child's education. While some children with solid tumors may experience little impact on attendance, peer relationships, and academic performance, others may experience significant effects. Due to the variation in treatments, length of treatment, and possible educational impact of different solid tumors, education in these cases should be very specific to the child and his/her unique diagnosis.

All diagnoses. Collectively speaking for all diagnoses, at the domain level, student attendance and teacher knowledge are areas of concern for stakeholders in the educational process of children with cancer. Caregivers of children with cancer are also concerned about their child's academic performance. Because it can be expected that school attendance will be impacted with a cancer diagnosis, regardless of the severity of the illness (which may determine the extent and significance of related absences), it is apparent that all stakeholders across all oncologic diagnoses can benefit from specific education on the impacts of absences and the interventions that may minimize the effects of these absences. Stakeholders across all diagnoses may also benefit from knowing that teacher education will occur that is specific to the child in which they are caring for; this education should be provided by health care professionals/hospital-school liaisons who can speak to the child's health and educational needs. This may alleviate concerns relative to teacher knowledge. Caregivers may be comforted in knowing that interventions may reduce the negative impact on academic performance, while educators must be taught about the potential effects on academic performance and appropriate supports that are required.

Table 11

Perceived Educational Issues: Domain Level Dependent Variable Analysis

		Student Attendance	Teacher Knowledge	Medical Issues	Academic Performance	Peer Issues	Notes
Leukemia	***Patient***	Concern	Concern				Student attendance and teacher knowledge are unanimous concerns across stakeholder role for patients with leukemia. Caregivers are uniquely concerned about the academic performance of their children with leukemia.
	Caregiver	Concern	Concern		Concern		
	Educator	Concern	Concern				
	Total	Concern	Concern		Concern		
Lymphoma	***Patient***		Concern				Caregivers of patients with lymphoma expressed concern across 5 domains: student attendance, teacher knowledge, medical issues, academic performance, and peer issues. Teacher knowledge was of notable concern for both patients with lymphoma and their caregivers.
	Caregiver	Concern	Concern	Concern	Concern	Concern	
	Educator						
	Total		Concern				

		Student Attendance	Teacher Knowledge	Medical Issues	Academic Performance	Peer Issues	Notes
Brain Tumors	*Patient*						Educators of children with brain tumors expressed notable concern about the child's attendance, the child's academic performance, and about their own knowledge with respect to supporting the child. Caregivers of patients with brain tumors only expressed concern about teacher knowledge; patients with brain tumors did not express concerns at the domain level.
	Caregiver		Concern				
	Educator	Concern	Concern		Concern		
	Total						
Other Solid Tumors	***Patient***		Concern				Teacher knowledge was a pervasive concern across stakeholder groups for patients with solid tumors. Caregivers of patients with solid tumors were also concerned about student attendance and peer issues for their child.
	Caregiver	Concern	Concern			Concern	
	Educator		Concern				
Total (All Diagnoses)	***Patient***		Concern				Collectively speaking for all diagnoses, student attendance and teacher knowledge are areas of concern for stakeholders in the educational process of children with cancer. Caregivers of children with cancer are also concerned about their child's academic performance.
	Caregiver	Concern	Concern		Concern		
	Educator	Concern	Concern				
	Total	Concern	Concern				

Item level dependent analysis. Table 12 reveals the results of the item level dependent analysis. Discussion is provided for item-level results according to stakeholder role for items of concern.

Student attendance item 1. *[This] child is too sick to go to school right now.* Caregivers perceive that their child is too sick to attend school. Notably, patients and educators do not share this perceived concern. This may echo the trends in literature which suggest that parents may become overprotective and shelter their children to a more significant degree than necessary during phases of treatment for cancer. Conversely, it may also reflect a lack of understanding of educators and patients regarding immunosuppression and school attendance with respect to safety of the child. In both scenarios described, this discrepancy reinforces the need for health care professionals and school intervention professionals to educate all stakeholders on the specific child's needs with respect to appropriate school attendance.

Student attendance item 3. *[This] child might have to miss some days of school because of his/her illness.* Patients, caregivers, and educators unanimously agreed across all diagnosis groups that the child will miss school as a result of the oncologic diagnosis. This is certainly reflective of the reality of school attendance for children with cancer. Disease and treatment related side effects such as fatigue, immunosuppression, nausea, headaches, and others may inhibit school attendance; treatments and frequent hospital visits may also directly impact school attendance. While this may vary based on a child's specific diagnosis, a child's specific course of treatment, and a child's unique response to treatment, it is certain that the child with cancer will miss an insurmountable amount of school in comparison to their peers who are not ill.

Student attendance item 4. *[This] child may catch a contagious illness like a cold or the flu if he/she goes to school right now.* Caregivers and educators were unanimously concerned across diagnosis groups that the child may be at risk for catching a contagious illness if present at school. While this certainly represents a valid concern due to the risk of immunosuppression due to chemotherapy and other treatments, educators and caregivers may benefit from education on precautions that may be taken at school to reduce this risk. Conversely, patients, who do not express concerns about this valid risk, may

benefit from education on the significance of these risks to ensure that they understand the importance of infection control.

Teacher knowledge item 1. *[This] child will require more attention than his/her peers from the classroom teacher(s) because of his/her illness.* Caregivers perceive that their child with cancer will require additional attention from the teacher as a result of the chronic condition. This is certainly an area where significant variability can be expected, depending on the child's specific diagnosis, treatments, academic ability, classroom behavior, and even age. This can also vary significantly depending on the specific teacher's style and overall classroom management. Regardless of these factors, it should be anticipated that the student with cancer may involve some degree of additional attention from the teachers, whether that be monitoring for emergence of academic difficulty, providing accommodations and supports to alleviate the impact of side effects in the classroom, or supporting the child academically and/or socially during periods of absence. It is noteworthy that neither teachers nor the patients themselves perceive that the child will require extra attention from the teacher.

Teacher knowledge item 2. *More time will be required communicating with [this] child's teachers because of the child's illness.* Caregivers alone perceive additional communication demands between parent and teacher given their child's illness. While it can be expected that the child may not understand the importance or the complexities regarding communication between the parent and teacher, it is of notable surprise that educators did not perceive a need for increased time spent communicating with the parents of a child with cancer. Existing literature has emphasized the role of clear and constant communication between school and family in achieving positive outcomes for the child who is ill with respect to education; educators tend to appreciate the role of effective communication in supporting any child academically, to say nothing of the child who is ill. Thus, this discrepancy is not only concerning, but also surprising.

Teacher knowledge item 3. *[This] child's educator will require extra training because of the child's illness.* Caregivers and patients share the perception that teachers would benefit from additional training to effectively support the child who is ill. Paradoxically, those stakeholders serving in the

capacity as these children's educators did not share this perception. Caregivers and patients seem aware of the complexities of cancer and its potential impact in the classroom; they perceive that an educator may not be aware of these complexities. Furthermore, in practice, school personnel often express significant gratitude for in-services on a child's diagnosis and unique needs when provided school intervention services. It is certainly of interest that across the three items pertaining to teacher knowledge, teachers did not collectively express any perceived concerns.

Peer issues item 2. *[This] child feels shy about going to school because he/she might look different.* Caregivers and educators agree that the child's changes in appearance due to disease/treatment sequelae may result in reluctance and shyness on behalf of the child when facing his/her peers upon reentry to school. Ironically, the children themselves were not particularly concerned about feelings of shyness related to changes in appearance. Additionally, neither patients, nor caregivers, nor educators perceived that the child's peers may treat him/her differently, that the child's peers may not want to be friends anymore, or that the child may be a distraction to others because of the oncologic diagnosis. While it is optimistic to hope that changes in peer relationships may not occur when a child is diagnosed with cancer, it is often an unfortunate reality. Peer relationships are often impacted by the student's inability to be present during school and other social activities, by changes in the child's appearance and behavior, and by other implications over time. However, with appropriate peer education, these effects can often be minimized. Making educators and caregivers aware of these potential effects and providing them with strategies to support the child's peer relationships can increase the likelihood of successful social outcomes over time.

Medical issues item 1. *Because of [this] child's illness, he/she might have an emergency at school.* Caregivers and educators across all diagnosis groups expressed concern that the child with cancer may have a medical emergency at school. While this is always a possibility, it is typically not likely. Specific and accurate information about the child's needs in the school setting may decrease unnecessary worry by caregivers and educators while ensuring appropriate care for the child. Unwarranted concern may have undesirable impacts on the child's school attendance, may result in unneeded and restrictive

limitations on the child's participation in school, and may cause superfluous worry by the child. Furthermore, teachers' perceived liability of the child who is ill may also result in unintentional restrictions on the child in the classroom as teachers inadvertently attempt to be self-protective.

Academic performance item 2. *[This] child might act differently at school because of his/her illness.* Caregivers across all four diagnosis groups shared in the concern that their child's diagnosis may impact his/her behavior at school. Changes in classroom behavior can occur as a result of steroids and medications which can specifically impact behavior, but can also occur due to treatment-related effects on cognition or due to social/emotional effects of the diagnosis itself. It is again concerning that educators have not anticipated the effects of cancer on the child's behavior or academic performance at school. Caregivers, educators, and patients collectively expressed no concerns about the child not doing as well in school, about the child having increased difficulty in school, or about the child experiencing long term challenges as a result of the illness. Considering the risk for short-term and long-term learning difficulties, the inevitable missed instruction and missed opportunities for school participation, this may be optimistic, but may also be neglectful of the true implications of cancer on academic performance. All stakeholders may benefit from increased education on the risk for cognitive late effects and other short and long-term academic implications, coupled with specific interventions that may help to overcome these unfortunate consequences.

Table 12

Perceived Educational Issues: Item Level Dependent Variable Analysis

	Patients				Caregivers				Educators			
Questionnaire Item	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*
Student Attendance 1					Concern		Concern	Concern	Concern		Concern	
Question	**I am too sick to go to school right now.*				*My child is too sick to go to school right now.*				*I believe this student is too sick to attend school right now.*			
Student Attendance 2	Concern			Concern		Concern					Concern	
Question	**My parents are worried about sending me to school.*				*I feel guilty about sending my child to school.*				*I feel guilty about requiring this child to attend school.*			
Student Attendance 3	Concern	Concern	Concern	Concern	Concern	Concern	Concern	Concern	Concern	Concern	Concern	Concern
Question	**I might have to miss some days of school because I am sick.*				*My child might have to miss some days of school because of his/her illness.*				*This student might have to miss some days of school because of his/her illness.*			
Student Attendance 4					Concern	Concern	Concern	Concern	Concern	Concern	Concern	Concern
Question	**I am worried I might get a contagious illness like a cold if I go to school right now.*				*I am concerned that my child may catch a contagious illness like a cold or the flu if he/she goes to school right now.*				*I am concerned about the risk that school attendance presents for this child with respect to catching a contagious illness such as a cold.*			
Student Attendance 5												
Question	**I am afraid to go to school.*				*I am afraid my child may die at school.*				*I am afraid this child may die at school.*			

*Denotes Patient Report-Child (ages 8-12)

	Patients				Caregivers				Educators			
Questionnaire Item	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*
Teacher Knowledge 1	Concern			Concern	Concern		Concern	Concern		Concern	Concern	
Question	**I will require more attention than my classmates from the teacher(s) because of my illness*				*My child will require more attention than his/her peers from the classroom teacher(s) because of his/her illness.*				*This child will require more attention than his/her peers in the classroom because of his/her illness.*			
Teacher Knowledge 2	Concern	Concern			Concern	Concern	Concern	Concern	Concern	Concern		
Question	**My parents will have to spend more time with my teachers because of my illness.*				*I will have to spend more time communicating with my child's teachers because of his/her illness.*				*I will have to spend more time communicating with this child's parent because of his/her illness.*			
Teacher Knowledge 3	Concern	Concern		Concern	Concern	Concern		Concern			Concern	
Question	**My teacher will need to learn more about my illness to help me at school.*				*My child's educator will require extra training because of my child's illness.*				*I will require additional training because of this child's illness*			

*Denotes Patient Report-Child (ages 8-12)

	Patients				Caregivers				Educators			
Questionnaire Item	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*
Peer Issues 1						Concern						
Question	**My friends and classmates will treat me the same as before I was sick.*				*My child's friends and classmates will treat him/her the same as before he/she was sick.*				*This child's friends and classmates will treat him/her the same as before he/she was sick.*			
Peer Issues 2				Concern	Concern	Concern		Concern	Concern		Concern	Concern
Question	**I feel shy about going to school because I might look different.*				*My child feels shy about going to school because he/she might look different.*				*This child may feel shy about going to school because he/she might look different.*			
Peer Issues 3				Concern								
Question	**My classmates might not want be my friend because of my illness.*				*My child's classmates might not want to be friends with him/her because of his/her illness.*				*This child's classmates might not want to play with him/her because of his/her illness.*			
Peer Issues 4	Concern							Concern				
Question	**My classmates may pay too much attention to me because of my illness.*				*My child may be a distraction to his/her peers due to his/her illness.*				*This child may be a distraction to his/her peers due to his/her illness.*			
Peer Issue 5												
Question	**My illness may lead to problems in the classroom.*				*My child's illness may lead to disruptions in the classroom learning environment.*				*This child's illness may lead to disruptions in the classroom learning environment.*			

*Denotes Patient Report-Child (ages 8-12)

	Patients				Caregivers				Educators			
Questionnaire Item	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*
Medical Issues 1				Concern	Concern	Concern	Concern	Concern	Concern	Concern	Concern	Concern
Question	**Because of my illness, I might have an emergency at school.*				*Because of my child's illness, he/she might have an emergency at school.*				*Because of this student's illness, he/she might have an emergency at school.*			
Medical Issues 1	Concern											
Question	**My teacher would rather not have me in class because of my illness.*				*My child's teachers would rather not have my child in class because of my child's illness.*				*I would rather not have this child in class because of the child's illness.*			
Medical Issues 3												
Question	**My teachers worry that if I have an emergency at school, it will be their fault.*				*My child's teachers may feel at risk by having my child with an illness in class.*				*I feel at risk by having this child with an illness in class.*			

*Denotes Patient Report-Child (ages 8-12)

	Patients				Caregivers				Educators			
Questionnaire Item	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*	*Leukemia*	*Lymphoma*	*Brain Tumors*	*Other Solid Tumors*
Academic Performance 1											Concern	
Question	**I might not do as well in school because of my illness.*				*My child might not do as well in school because of his/her illness.*				*This child might not do as well in school because of his/her illness.*			
Academic Performance 2					Concern	Concern	Concern	Concern			Concern	
Question	**I might act differently at school because of my illness.*				*My child might act differently at school because of his/her illness.*				*This child might act differently at school because of his/her illness.*			
Academic Performance 3						Concern			Concern		Concern	
Question	**I will have a hard time with my school work because of my illness.*				*My child will have more difficulty in school because of his/her illness.*				*This child will have more difficulty in school because of his/her illness.*			
Academic Performance 4												
Question	**School and learning will be hard for a long time because of my illness.*				*My child will experience long-term challenges with school and learning because of his/her illness.*				*This child will experience long-term challenges with school and learning because of his/her illness.*			
Academic Performance 5					Concern							
Question	**I may not pass to the next grade because of my illness.*				*My child may not pass to the next grade because of his/her illness.*				*This child may not pass to the next grade because of his/her illness.*			
Academic Performance 6												
Question	**My teachers will be able to help me at school regardless of my illness.*				*My child's teachers will be able to help him/her at school despite his/her illness.*				*I will be able to help this child at school despite his/her illness.*			

*Denotes Patient Report-Child (ages 8-12)

Conclusions

The results of this quantitative analysis were, at times, surprising, and frequently contradictory to what may have been anticipated. For example, teacher knowledge is an area of concern for caregivers and patients, though not necessarily for educators themselves; likewise, peer issues were a concern for caregivers and educators, though not for the patients.

Caregivers tended to represent the stakeholder group with the most widespread and significant concerns. Caregivers expressed perceived concerns across all 5 domains: student attendance, teacher knowledge, medical issues, peer issues, and academic performance. This supports the hypothesis that concerns are heightened at the time of a child's cancer diagnosis, likely due to "fear of the unknown." It is clear from these results that caregivers will benefit from targeted interventions to alleviate these concerns. Specifically, education from health care professionals (and specifically school liaisons/school intervention specialists) about realistic school-related concerns paired with specific solutions and interventions to address these concerns and real issues is warranted, and may empower caregivers to more effectively support the child in the context of school.

Educators and patients were concerned to a lesser degree across the 5 areas of concern; these stakeholders did not express concern across all 5 domains, and thus this did not support the proposed hypotheses for these groups. While it is encouraging that patients and educators do not express significant worry about school issues, there are certainly areas where a small degree of concern may be appropriate. An overall lack of concern may be suggestive of a lack of awareness of the true impact of cancer on a child's academic and social well-being. Unfortunately, the reality of childhood cancer is that it can have adverse effects on a child's academic performance, school attendance, and peer relationships. Understanding these risks is essential for interventions and proactive measures to be implemented; these may in turn serve to circumvent possible negative outcomes that can occur as a result of these effects. Teachers may benefit from training on the very real educational implications of childhood cancer, as well as interventions, supports, and accommodations that will minimize and even prevent these effects. Of

note, these results are representative of preliminary data, and may be expected to change as recruitment continues.

Limitations

The limited sample size of this study was a significant limitation of this preliminary data assessment. A longitudinal component of this study will ultimately achieve large sample sizes, with participant maximums set at 375, which will rectify this issue. The increased sample size will also allow for analysis of additional independent variables, including the impact of a patient's state of permanent residence and a patient's age on perceived school issues. Ongoing validity and reliability testing will occur to ensure effective use of the instrumentation through the course of the longitudinal study.

Additionally, though unlikely to significantly impact generalizability of results, subjects were representative of only a single institution in a single region. This limitation may be corrected future study opportunities, which may include multi-site study expansion.

During the pilot phase of the study, it became apparent that the election of the participating teacher may be an area with potential for bias. When approached to provide a potential educator participant, families frequently provided the name and contact information for the child's favorite teacher, which may impact the way that educators respond (or even willingness to participate). After exploring several methods to attempt to control this dynamic, the best approach appeared to be the use of a ranking or nomination system. This nomination system was used to designate the order educator participants were approached. Patient and caregiver participants nominated teachers to approach for the study using a ranking system (i.e., approach my math teacher first, social studies teacher second, etc.). If the first educator nominated declined to participate, then the second teacher nominated was approached. This nomination system was developed to control the inherent limitations that may occur in approaching educators (i.e., if all science teachers are recruited, it is possible that all science teachers are inherently less concerned about school issues, which would limit results). Without a nomination system, there is no clear way to control this dynamic. Though the nomination system inherently created a bias in results, this simply remained a known limitation of the study.

Implications for Future Research

This research will extend beyond these preliminary results to encompass a 5-year longitudinal study examining perceptions of educational issues for children who are chronically ill. Initial time point one data of this longitudinal study (within two months of a new diagnosis) was analyzed for the purpose of this dissertation study. Additional time point one data, as well as time point two data and time point three data (to measure perceptions over time) are yet to be collected, and will certainly inform future practice. Results of the longitudinal study will be used to determine if perceptions of school issues for children who are chronically ill change over time. The questionnaires will be administered to each stakeholder group at three different time points: upon diagnosis of the patient, when the patient is mid-treatment, and when the patient is post-treatment. The purpose of the initial time point is to measure the perceptions of educational issues for the child who is chronically ill within two months of the patient's diagnosis, which serves as a baseline measure. At this point of an oncologic diagnosis, there are no (or at the very least, few) cognitive effects of treatment and the stakeholders have no experience yet navigating the school process in the context of the illness. It is anticipated that concerns will be relatively high at this point due to "fear of the unknown." During the second time point, when the patient is mid-treatment (defined as 1-3 years into treatment), cognitive effects may begin to emerge for the patient, and school attendance may be challenging, thus perceptions of educational issues may begin to change. It may be expected that some, however, begin to experience feelings of "a new normal" as they settle into the routines of the child's treatment and related effects; thus, concerns may subside or be lesser during this middle time point. Finally, the purpose of the final time point, the post-treatment measure, will be to determine if educational perceptions change following treatment, because though attendance may stabilize and peer concerns may be of less concern for stakeholders, cognitive (and other) late effects may be present, and academic performance concerns may increase. It is expected that concerns may again surge due to new issues that may emerge following treatment.

The longitudinal study will also will also allow for analysis of additional independent variables, including the impact of a patient's state of permanent residence and a patient's age on perceived school

issues. These additional independent variables were chosen carefully based on anecdotal evidence and the experiences of school intervention professionals and hospital teachers in various capacities. It is suspected that the age of a patient may significantly impact the perceived educational issues for that child; that is, concerns related to academic performance and school attendance may be more significant for a high school senior when compared to those for a child in kindergarten. The state of a child's residence may also impact the perceived educational concerns for a child due to differences in educational law and entitlement from one state to another. A child in one state may be eligible for 5 hours of home instruction per week when unable to attend school due to medical concerns, while a child in another state is only entitled to 2 hours of home instruction per week. Furthermore, some states differ in eligibility criteria for special education services, which may impact the perceptions of the educator and/or caregiver of the child.

As this study is specific to children with oncologic diagnoses, future studies may examine the use of these perceptions questionnaires for other patient populations, including but not limited to pediatric patients with cardiac conditions, gastroenterology disorders, endocrinology diseases, immunological disorders, and others.

Future research must also begin to examine alignment of interventions with results of this study. With a better understanding of the perceived educational issues for chronically ill students from the perspective of the patient, caregiver, and educator, practitioners must begin to align services with these perceived needs and evaluate those services using empirical methods. Through developing the research base with respect to educational issues for children who are chronically ill, long term outcomes for these children will ultimately be improved.

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Appendix A: Institutional Review Board Approval Letters

Institutional Review Board - Federalwide Assurance #00002988
Cincinnati Childrens Hospital Med Ctr

Date: 5/17/2012 9:56 AM

From: IRB Committee

To: Principal Investigator: Mary Kay Irwin
Cancer and Blood Diseases Institute

Re: Study ID: 2011-0125
Study Title: Perceptions of Educational Issues for the Chronically Ill

This study expires on: 4/5/2013.

An amendment to the above referenced protocol was reviewed and **APPROVED** using an **EXPEDITED** review procedure as set forth in 45 CFR 46.110(b) on **5/17/2012** .

The following items were reviewed:

Addition of Ashley Distler and Angela Sefcik to the study team

Removal of Kyle Brown from the study team

Please note the following requirements:

OTHER APPROVALS: Principal investigators are responsible for maintaining approval from other applicable review committees and performance sites. This includes, but is not limited to, Divisional Scientific Review committee, General Clinical Research Center (GCRC), Radiation Safety, Institutional Biosafety Committee (IBC), Conflict of Interest (COI) Committee, and any sites (i.e. schools, hospitals) where the research may be conducted. Principal investigators are also responsible for maintaining approval from the FDA and a valid contract between the sponsor and this institution, as applicable. If any of these entities require changes to the IRB-approved protocol and/or informed consent/assent document(s), the changes must be submitted to and approved by the IRB prior to implementation.

AMENDMENTS: The principal investigator is responsible for notifying the IRB of any changes in the protocol, participating investigators, procedures, recruitment, consent forms, FDA status, or conflicts of interest. Approval is based on the information as submitted. New procedures cannot be initiated until IRB approval has been given. If you wish to change any aspect of this study, please submit an Amendment via ePAS to the IRB, providing a justification for each requested change.

CONTINUING REVIEW: The investigator is responsible for submitting a Continuing Review via ePAS to the IRB at least 30 days prior to the expiration date listed above. Please note that

study procedures may only continue into the next cycle if the IRB has reviewed and granted re-approval prior to the expiration date.

UNANTICIPATED PROBLEMS: The investigator is responsible for reporting **unanticipated problems** promptly to the IRB via ePAS according to current CCHMC reporting policy found on CenterLink.

STUDY COMPLETION: The investigator is responsible for notifying the IRB by submitting a Request to Close via ePAS when the research, including data analysis, has completed.

Statement regarding International conference on Harmonization and Good Clinical Practices: The Institutional Review Board is duly constituted (fulfilling FDA requirements for diversity), has written procedures for initial and continuing review of clinical trials; prepares written minutes of convened meetings, and retains records pertaining to the review and approval process; all in compliance with requirements defined in 21 CFR Parts 50, 56 and 312 Code of Federal Regulations. This institution is in compliance with the ICH GCP as adopted by FDA/DHHS.

Thank you for your cooperation during the review process.

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§46.110. Expedited review procedures for certain kinds of research involving no more than minimal risk, and for minor changes in approved research.

§46.108(b) An IRB may use the expedited review procedure to review either or both of the following:

1. some or all of the research appearing on the list and found by the reviewer(s) to involve no more than minimal risk,
2. minor changes in previously approved research during the period (of one year or less) for which approval is authorized.

Under an expedited review procedure, the review may be carried out by the IRB chairperson or by one or more experienced reviewers designated by the chairperson from among members of the IRB. In reviewing the research, the reviewers may exercise all of the authorities of the IRB except that the reviewers may not disapprove the research. A research activity may be disapproved only after review in accordance with the non-expedited procedure set forth in §46.108(b).

Cincinnati Children's

change the outcome®

Division of
Hematology/Oncology

May 3, 2011

Dear University of Cincinnati Institutional Review Board:

The following research protocol has been accepted by the Cincinnati Children's Hospital Medical Center Institutional Review Board. The following materials include all materials approved by the CCHMC IRB, the CCHMC IRB approval notice, and the signed Authorization Agreement forms.

While the Principal Investigator and Co-Investigator of this study are University of Cincinnati doctoral students in the College of Education, Cincinnati Children's Hospital IRB will remain the IRB of record for this research study. Both the Principal Investigator and Co-Investigator of this study are employed by CCHMC, and the research study uses only CCHMC patients (including their caregivers and educators). Additionally, this study will extend beyond the investigators' course of study at UC.

Regards,

Mary Kay Irwin, Principal Investigator

(513) 636-8604

MaryKay.Irwin@cchmc.org

Megan Elam, Co-Investigator

(513) 803-3272

Megan.Elam1@cchmc.org

Appendix B: Expert Panel Directions

Perceptions of Educational Issues for the Chronically Ill

Expert Review Panel

The attached instruments have been developed to measure the perceptions of educational issues for students who are chronically ill. Each instrument has been specially tailored to measure the perceptions of a specific stakeholder group: patients who are chronically ill, caregivers of patients who are chronically ill, and educators of patients who are chronically ill.

Frequently, when a new data collection instrument is designed, an expert panel is utilized to evaluate the instrument. The use of a panel of experts "maximize[s] the likelihood of content-valid, well-constructed data collection instruments" (Davis, 1992, p. 197). You have been asked to participate in this expert panel review process due to your professional experience related to educational issues for chronically ill patients and/or instrument development.

Please consider the following steps as a participant in this process:

1. Review the **Study Goals and Objectives** (attached) to familiarize yourself with the purpose of the research study and instruments.
2. Review the attached instrument items. Please note the intended audience for each instrument as described on the title page of each instrument (i.e., Patient – Young Child, Ages 5-7; Patient – Child – Ages 8-12; Patient – Teen, Ages 13-17; Caregiver; Educator), and consider this audience when reviewing the respective instrument.
3. Begin the review process, as follows:
    a. Please read each item and score it for its relevance representing the concept (that is, its relevance representing a perceived educational issue for a chronically ill child). Please use the following scale:
        - 1 = not relevant
        - 2 = somewhat relevant
        - 3 = quite relevant
        - 4 = highly relevant
    b. To indicate your response rating the relevance of each item, please circle the number associated with each item using the 4-point Likert scale provided. Disregard the ranking categories provided on the instrument for the purpose of rating relevance.
    c. After you have ranked each item according to relevance, please respond to the attached **Expert Panel Review Questions**.

Expert Panel Review Questions

1. Based on your understanding of the purpose of the instruments and proposed research, are the established instrument rating scales (1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree) appropriate for measuring the perceptions of educational issues for the chronically ill for each respective stakeholder group? Please explain your response in the space below:

2. How well are possible perceptions of educational issues for patients who are chronically ill represented in the instruments? Are there any questions that you would add?

3. Are there any questions that you would expand or refine? If so, please make proposed changes directly on the instrument item that you would like to expand/refine. You may consider providing a brief explanation to justify your decision.

4. Are there any questions that you would delete? If so, please place an “X” over the questions that you would delete. You may consider providing a brief explanation to justify your decision.

5. Were the directions clear for each instrument? Please consider the intended audience of the measure in responding to this question. Explain your response in the space below:

6. Were there any ambiguous questions in the instruments? Please list the item number of any unclear questions in the space below. You may consider providing a brief explanation to justify your decision. Please refer to version titles to refer to specific question/items.

7. Were the categories used to identify the various domains of perceptions understandable (i.e., Beliefs about School Attendance; Beliefs about Academic Performance, etc.)? Would you consider changing the titles of these categories, or re-categorizing any specific items? If so, please explain below:

8. Did you find any questions that may be perceived as offensive to questionnaire participants? Please list the item number of any offensive questions in the space below. You may consider providing a brief explanation to justify your decision. Please refer to version titles to refer to specific question/items.

9. Please consider providing a brief explanation about what you understand about these instruments:

10. Please consider providing a brief explanation about what you did NOT understand about these instruments:

Study Goals and Objectives

The purpose of this research is to study the perceptions of patients, caregivers, and educators regarding educational issues for chronically ill patients and use the knowledge gained to align the services offered by the School Intervention Program (SIP) at Cincinnati Children's Hospital Medical Center (CCHMC) with the perceived educational issues of the recipients of the services. Ultimately, with the guidance of the results from this study, school intervention professionals can examine current standard of practice through the lens of the recipients of the services. As a result of this study, school intervention professionals will be poised to disseminate results across the country with the goal of illuminating the recipient's perceptions and their subsequent desired needs during and after a very difficult time in their lives.

2.1 Primary Aims:
- 2.1.1 To identify the perceived educational issues according to chronically ill patients.
- 2.1.2 To identify the perceived educational issues, according to the caregivers, of chronically ill patients.
- 2.1.3 To identify the perceived educational issues, according to the educators, of chronically ill patients.

2.2 Secondary Aims:
- 2.2.1 To determine if perceptions vary from one group of stakeholders to another.
- 2.2.2 To determine if perceptions vary from one time-point in treatment to another.
- 2.2.3 To determine if perceptions are impacted by various factors, including the age of the patient, the degree or severity of the patient's illness, the socioeconomic status (SES) of the patient/patient's family, and/or the state of permanent residence of the patient.

Appendix C: Recruitment Materials

Criteria Eligibility Form

Study Identification Number: Patient's Initials:	Answer:	Researcher's Initials:
Does the patient have an oncologic diagnosis or other benign tumor (leukemia, lymphoma, brain tumor, and other solid tumors, i.e., osteosarcoma, Ewing sarcoma, retinoblastoma, neuroblastoma, rhabdomyosarcoma, etc.)?	Yes/No	
Date of diagnosis (confirmed by histiological pathology or radiological)	____ / ____/ _____	
Is patient actively receiving treatment?	Yes/No	
Is the patient a school-age student within grades K-12 at the time of enrollment?	Yes/No	
Has the patient/patient's family accepted, or willing to accept, school intervention services?	Yes/No	
Does the patient have an extremely poor prognosis?	Yes/No	
Is the patient attending school or receiving home instruction?	Yes/No	

Signature of Researcher: _____

Signature of Attending Physician: _____

Date of study enrollment: _____

Recruiting and Data Collection Checklist

Critical: At the end of each day, researcher must return any completed research documents to cabinet

Recruiting and Data Collection Checklist	**Researcher's Initials/Date**
1. Complete the Criteria Eligibility Checklist (Including obtaining attending physician's signature)	
2. Determine if participants will be asked to complete interview using interview eligibility form a. Pleases circle (YES or NO)	
3. Use the Recruitment Script to recruit caregiver and patient participants a. If individual agrees proceed to step 4 b. If individual declines note declination in Oncore	
4. Ask Parent what they are calling diagnosis a. RA should have SIP brochure to give to parent if they inquire about SIP services b. RA should not share medical information with school or family	
5. Obtain consent for the caregiver participant a. Parent will complete the HIPPA authorization consent (ONLY if child is under the age of 18) b. Parent will complete the Informed Consent form c. Parent will complete the Parental Permission form (ONLY if child is under the age of 18) d. Parent will complete SIP Disclosure Consent forms (ONLY if child is under the age of 18)	
6. Obtain consent for the patient participant a. Patient will complete the ASSENT form (ONLY if child is age 11 or older) b. Patient will complete the HIPPA authorization consent (ONLY if patient is age 18 or older) c. Patient will complete the Informed Consent form (ONLY if patient is age 18 or older) d. Patient will complete SIP Disclosure Consent forms	

(ONLY if patient is age 18 or older)	
7. Assign the patient and caregiver Participant Identification Numbers and a Subject Identification Number a. Refer to SIN codes and master list to assign SIN b. Note SIN and PIN on master list immediately following consent	
8. Caregiver will complete the CGPQ a. Note date and time of completion b. Ensure SIN# is identified on questionnaire	
9. Caregiver will complete the interview (if eligible) a. State on audio recording: date, name of interviewer, name of participant being interviewed, and if others are present b. Before interview, researcher should secure location for interview c. Researcher should request that interview be conducted with only caregiver and researcher present	
10. Patient will complete the PtPQ a. Provide patient with the appropriate questionnaire i. Young Child version for ages 5-7 ii. Child version for ages 8-12 iii. Teen version for ages 13-18 b. Note date and time of completion c. Ensure SIN# is identified on questionnaire d. Explain to patient that the questionnaire can be completed independently or researcher can read questions aloud and patients can respond orally EXCEPT patient s ages 5-11 who must have questionnaire read aloud e. If questionnaire is being read aloud, request that caregiver leave the room during the administration of the questionnaire -Be prepared to provide caregiver copy of questionnaire to increase comfort in leaving the room	
11. Patient will complete the interview (if eligible)	

a. State on audio recording date, name of interviewer, name of participant being interviewed, and if others are present b. Researcher should request that interview be conducted with only patient and researcher present	
12. Request patient/caregiver to nominate educators for study a. Ask caregiver if school is aware of diagnoses (YES/NO) If caregiver answers NO, a School Intervention Coordinator (SIC) MUST make the initial contact; this SIC must also be a member of the research team b. Ask who they would like contacted 1st, 2nd, 3rd	
13. Obtain Site Support from patient's school a. Call school for site support and initial recruitment of educator b. Use SITE SUPPORT LETTER Template (via secure fax, in person, or secure email) c. Put site support letter in blue research folder	
14. Obtain consent from educator a. Can occur at patient's school, via phone conference, or secure email b. Educator will complete the Informed Consent form; can be returned via secure email or secure fax c. Kept in locked office of research team d. Obtain attendance record, GPA, and test scores from educator and input into School Data Record spreadsheet	
15. Assign the educator a Participant Identification Number and a Subject Identification Number a. Complete this information in Master List b. Refer to SIN codes and master list to assign SIN#	
16. Educator will complete the EdPQ a. Note date and time of completion b. Ensure SIN# is identified on questionnaire c. Can be completed at school or other location, electronically, via secure email or secure fax line d. Kept in locked office of research team	

17. Educator will complete the interview (if eligible) a. State on audio recording date, name of interviewer, name of participant being interviewed, and if others are present b. Researcher should request that interview be conducted with only the educator and researcher present	

After completion of consent process and data collection, proceed to data entry process.

Recruitment Script

Recruitment Announcement Script

I would like to discuss an opportunity for you to participate in a research study related to educational issues of patients with chronic illness.

This study is called Perceptions of Educational Issues for the Chronically Ill: Identifying Perceptions of Patients, Caregivers, and Educators. The purpose of the research is to study what children, their caregivers, and their teachers think about education for children who are chronically ill.

The research will study beliefs about school issues and will answer the following questions:

- Do views and opinions vary from one group of stakeholders to another?
- Do views and opinions vary from one time-point in treatment to another?
- Are views and opinions impacted by the age of the patient, by the degree or severity of the child's illness, by the socioeconomic status (SES) or state of residence of the patient/patient's family?

This is a longitudinal study, meaning the study will last for 5 years. Data will be collected at three different time points during treatment. Your participation will require several things:

1. Completion of a questionnaire about educational issues within two months of definitive diagnosis; completion of the same questionnaire midway through treatment, and completion of the same questionnaire within the first year after treatment is finished.

2. Participation in a series of interviews at the same time points (at diagnosis, midway through treatment, and after treatment) IF you are selected for the interview portion of the study. Not all participants will be selected for the interview process.

3. Participation of a patient will also require participation of a caregiver of that patient. An educator of that patient will also be recruited.

While appreciated, your participation in the study is not in any way required. The services provided to you at CCHMC will not and cannot in any way be impacted by your decision to participate or not participate.

Questionnaires will take approximately 30 minutes to complete. Interview sessions will last approximately 1 hour. We will do our best to conduct research activities during your scheduled appointments at CCHMC.

I will need signed consent from each person who is interested in participating. If you are under the age of 18, I will need your parent's permission in addition to your own assent. Again, I want to stress that there is no pressure to participate – that choosing to participate or to not participate will not and cannot in any way impact your CCHMC-related services. You will not be treated differently if you do not participate.

I am now going to provide you with a copy of the Adult Consent Form for Research or Youth Assent Form for Research and Parent Permission for Child's Participation in Research form, as appropriate.

Do you have any questions about the study, your participation in the study, or anything else related to the study or research activities?

(Recruiter will pause for questions, and answer any questions at this time.)

Please remember that that there is no pressure to participate – that choosing to participate or to not participate will not and cannot in any way impact the services provided to you through CCHMC. You will not be treated differently if you do not participate.

Also, please remember that if you choose to participate, you may stop at any time. You may approach any member of the research team with questions at any time. If you feel uncomfortable at any time during the course of the research, you may speak to the research team, or access any member of your care team at CCHMC as needed.

The following steps are very important steps for interested participants.

If you are interested in participating in the study, you will need to do the following:

1. If you are over the age of 18, you will need to read the Adult Consent Form for Research, sign and date the bottom, and return the signed and completed form to a member of the care team.

3. If you are under the age of 18, you will need to include your parents in the consent process. If they are willing to allow you to participate, you will have two steps to complete in regards to the signed consent forms: You will read the Youth Assent Form for Research, sign and date the bottom, and return the signed and completed form to a member of the care team. You will also need your parents to read the Parent Permission for Child's Participation in Research form, sign and date the bottom, and return the signed and completed form to a member of the care team.

I would like to take a final moment to ask if there are any additional questions.

Again, please return the signed consent forms to a member of the care team if you are interested in participating: the Adult Consent Form for Research if you are 18 years old or older, and the Youth Assent form for Research and the Parent Permission for Child's Participation in Research forms if you are under the age of 18.

Thank you for your time, and again, please contact a member of the research team at any time if you have any questions.

Thank you!

Appendix D: Consent Forms

IRB #: 2011-0125

Approved: 4/6/2012
Do Not Use After: 4/5/2013

CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER

INFORMED CONSENT
FOR PARTICIPATION IN A RESEARCH STUDY

STUDY TITLE: PERCEPTIONS OF EDUCATIONAL ISSUES FOR THE CHRONICALLY ILL

INVESTIGATOR INFORMATION:

Mary Kay Irwin — (513) 218-6033
Principal Investigator Name — Telephone Number 24 hr Emergency Contact

INTRODUCTION:

You have been asked to participate in a research study. Before agreeing to participate in this study, it is important that you read and understand the following explanation. It describes the purpose, procedures, benefits, risks and discomforts of the study and the precautions that will be taken. It also describes the alternatives available and your right to withdraw from the study at any time. No guarantee or assurance can be made as to the results of the study. Participation in this research study is completely **voluntary**. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may **withdraw** from the study at any time without penalty.

WHO IS CONDUCTING THE RESEARCH STUDY?

The people in charge of this research study are Megan P. Elam, M.Ed. and Mary Kay Irwin, M.Ed., of Cincinnati Children's Hospital Medical Center (CCHMC) Cancer and Blood Diseases Institute in the School Intervention Program (SIP).

They are being guided in this research by Anne Bauer, EdD from the University of Cincinnati and John Perentesis, MD, FAAP from CCHMC.

There may be other people on the research team helping at different times during the study.

WHY IS THIS RESEARCH BEING DONE?

The purpose of this research is to study the views and opinions patients, caregivers, and educators have about school and education for those who are diagnosed with cancer or a benign tumor. The knowledge gained will help the School Intervention Program at CCHMC make sure the services provided to patients and their families address their true educational needs.

WHY HAVE YOU BEEN ASKED TO TAKE PART IN THIS RESEARCH STUDY?

You are being asked to take part in this research study because you are the caregiver or educator of a school-age patient (K-7) diagnosed with a cancer or benign tumor who has agreed to accept some level of school intervention support.

WHO SHOULD NOT BE IN THE RESEARCH STUDY?

You should not be in this study if the child you care for is not likely to survive for at least 12 months.

HOW LONG WILL YOU BE IN THE RESEARCH STUDY?

If you are the patient's caregiver:

- You will be in this research study for 3-5 years, depending on the length of the patient's treatment
- Participation in this research study will involve approximately 3 study visits (in conjunction with the patient's scheduled clinical visits) (approximately 30 minutes each to complete a questionnaire)

If you are the patient's educator:

- You will be in this study for less than one year
- Participation in this study will involve approximately one study visit (approximately 30 minutes to complete a questionnaire)

The research will take place onsite at CCHMC if you are a patient or caregiver, and at the child's school (or at another desirable location at the preference of the educator) if you are an educator.

You may also be asked to participate in an interview process but that is not a required part of the study and you may decline to participate. The interview will take about 60 minutes to complete. The interview will take place onsite at CCHMC if you are a patient or caregiver, and at the child's school (or another desirable location at the preference of the educator) if you are an educator. Interviews will be recorded using audio equipment.

The researcher may decide to end your participation in this research study at any time, without your permission, for any of the following reasons: your child's doctor determines that it is in your child's medical best interest, the study is ended early for any reason or new information becomes available.

HOW MANY PEOPLE WILL TAKE PART IN THE RESEARCH STUDY?

About 180-400 people will take part in this study (60-80) patient participants, plus associated caregivers and educators). For each patient participant, one caregiver participant and at least one educator participant will be recruited.

WHAT IS INVOLVED IN THE RESEARCH STUDY?

You will be asked to complete a questionnaire at various time points and may be asked to also undergo an interview process at various time points (as described above).

WHAT ARE THE RISKS AND DISCOMFORTS OF THE RESEARCH STUDY?

- It is not expected that you will be exposed to any risk by being in this research study.
- Some questions may make you uncomfortable. You can refuse to answer any questions that you don't want to answer.
- If you want to talk to someone because this research made you feel upset, the researchers can give you information about people who may be able to help you.
- There may be unknown or unforeseen risks associated with study participation.

ARE THERE DIRECT BENEFITS TO TAKING PART IN THE RESEARCH STUDY?

You will probably not get any benefit because of being in this study. But, being in this study may help school intervention professionals and educators understand educational issues concerning patients with cancer and benign tumors, their caregivers and educators.

WHAT OTHER CHOICES ARE THERE?

If you do not want to take part in this research study, you may simply choose not participate. Your child will receive the same services all patients receive, and they will not be treated any differently.

You have a choice whether or not to take part in the interview portion of this study. If you choose to participate in the interview process, the interview will be audio recorded. If you do not want to be audio recorded, you may still participate in the research study by completing the questionnaires only.

HOW WILL INFORMATION ABOUT YOU BE KEPT PRIVATE AND CONFIDENTIAL?

Cincinnati Children's Hospital Medical Center and/or the Investigator will take precautionary measures to protect your privacy and confidentiality of your research and/or medical records. Information about you will be kept private by:

- using a study ID number instead of the participant's name on the research forms
- keeping the master list of names and study ID numbers in a separate location from the research forms
- limiting access to research data to the research team
- not including the participant's name on the typed transcript of the interview
- keeping research data on a password-protected computer

Your information will be kept in a locked cabinet located in the locked School Intervention Program office until all analyses are complete. After that it will be destroyed by shredding all papers and deleting all data files.

Consent forms will be kept in the locked cabinet with the master list. Personal identifiers will be removed as soon as data is entered into the database or spreadsheet. Survey responses will be identifiable using the participants' identification numbers only. Audio recordings and transcriptions of the interviews will be stored in a database linked to participants only through their identification number. Data stored in a database/spreadsheet will be password protected.

Agents of Cincinnati Children's Hospital Medical Center may inspect study records for audit or quality assurance purposes.

The researcher cannot promise that information sent by the internet or email will be private.

WHAT IF NEW INFORMATION BECOMES AVAILABLE DURING THE RESEARCH?

The investigator will tell you about new information from this or other studies that may affect your health, welfare, or willingness to stay in this study. The information from the research study may be published; however, you will not be identified in such publication. The publication will not contain information about you that would enable someone to determine your identity as a research participant without your authorization.

WHAT ARE YOUR COSTS TO BE IN THIS STUDY?

You will not have to pay anything to take part in this study.

WILL YOU BE PAID TO PARTICIPATE IN THIS RESEARCH STUDY?

You will not be paid (or given anything) to take part in this study.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Your participation in this study is completely **voluntary**. You may choose either to take part or not to take part in this research study. Your decision whether or not to participate will not result in any penalty or loss of benefits to you and the standard medical care for your condition will remain available to you.

If you decide to take part in the research study, you are **free to withdraw** your consent and discontinue your participation in this research study at any time. Leaving the study will not result in any penalty or loss of benefits to you.

If you have questions about the study, you will have a chance to talk to one of the study staff or your regular doctor. Do not sign this form unless you have had the chance to ask questions and have received satisfactory answers.

Nothing in this consent form waives any legal rights you may have nor does it release the investigator, the sponsor, the institution, or its agents from liability for negligence.

ABILITY TO CONDITION TREATMENT ON PARTICIPATION IN THIS STUDY

You have a right to refuse to sign this consent form and Authorization to use/disclose your Protected Health Information for research purposes.

If you refuse to sign this consent, your rights concerning treatment, payment for services, enrollment in a health plan or eligibility for benefits will not be affected.

WHO DO YOU CALL IF YOU HAVE QUESTIONS OR PROBLEMS?

For questions, concerns, or complaints about this research study or to report a research-related injury, you can contact the researcher Megan Elam at (513) 460-7054 or (513) 803-3272 or Mary Kay Irwin at (513) 218-6033 or (513) 636-8604. Researchers are available to answer any questions you may have about the research at any time.

If you have general questions about your rights as a research participant in this research study, or questions, concerns, or complaints about the research, you can call the Cincinnati Children's Hospital Medical Center Institutional Review Board at 513-636-8039. You can also call this number if the research staff could not be reached, or if you wish to talk to someone other than the research staff.

SIGNATURES:

I have read the information given above. The investigator or his/her designee have personally discussed with me the research study and have answered my questions. I am aware that, like in any research, the investigators cannot always predict what may happen or possibly go wrong. I have been given sufficient time to consider if I should participate in this study. I hereby give my consent to take part in this study as a research study subject. I will receive a copy of this signed form for my records.

_____ _____

Signature of Subject Date

_____ _____

Signature of individual obtaining consent Date

IRB #: 2011-0125

Approved: 4/6/2012
Do Not Use After: 4/5/2013

CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER

PARENTAL PERMISSION
FOR PARTICIPATION IN A RESEARCH STUDY

STUDY TITLE: Perceptions of Educational Issues for the Chronically Ill

INVESTIGATOR INFORMATION:

Mary Kay Irwin	(513) 218-6033
Principal Investigator Name	Telephone Number 24 hr Emergency Contact

INTRODUCTION:

You are being asked to give permission for your child to participate in a research study. Before agreeing to give permission for your child to participate in this study, it is important that you read and understand the following explanation. It describes the purpose, procedures, benefits, risks and discomforts of the study and the precautions that will be taken. It also describes the alternatives available and your right to withdraw your child from the study at any time. No guarantee or assurance can be made as to the results of the study. Participation in this research study is completely voluntary. Refusal to participate will involve no penalty or loss of benefits to which you or your child are otherwise entitled. You may withdraw your child from the study at any time without penalty.

WHO IS CONDUCTING THE RESEARCH STUDY?

The people in charge of this research study are Megan P. Elam, M.Ed. and Mary Kay Irwin, M.Ed., of Cincinnati Children's Hospital Medical Center (CCHMC) Cancer and Blood Diseases Institute in the School Intervention Program (SIP).

They are being guided in this research by Anne Bauer, EdD from the University of Cincinnati and John Perentesis, MD, FAAP from CCHMC.

WHY IS THIS RESEARCH BEING DONE?

The purpose of this research study is to study the views and opinions patients, caregivers, and educators have about school and education for those who are diagnosed with cancer or a benign tumor. The knowledge gained will help the School Intervention Program at CCHMC make sure the services provided to patients and their families address their true educational needs.

WHY HAS YOUR CHILD BEEN ASKED TO TAKE PART IN THIS RESEARCH STUDY?

Your child is being asked to take part in this research study because your child is a school-age patient (K-7) diagnosed with a cancer or benign tumor who has agreed to accept some level of school intervention support.

WHO SHOULD NOT BE IN THE RESEARCH STUDY?

Your child should not be in this study if he/she is not likely to survive for at least 12 months.

HOW LONG WILL YOUR CHILD BE IN THE RESEARCH STUDY?

Your child will be in this research study for 3-5 years, depending on the length of his/her treatment. Your child will be asked to complete a questionnaire at 3 different times throughout the patient's treatment (within one month of diagnosis, midway through treatment, and after treatment). Your child will complete research activities in approximately 3 study visits.

Questionnaires will take about 30 minutes to complete. The research will take place onsite at CCHMC.

Your child may also be asked to participate in an interview process. You may decline participation in the interview but still participate in the research by completing the questionnaires only. Each interview will take about 60 minutes to complete. The interview will take place onsite at CCHMC. Interviews will be recorded using audio equipment.

The researcher may decide to end your child's participation in this research study at any time, without your permission, for any of the following reasons: your child's doctor determines that it is in your child's medical best interest, the study is ended early for any reason or new information becomes available.

HOW MANY PEOPLE WILL TAKE PART IN THE RESEARCH STUDY?

About 180-375 people will take part in this study (60-75 patient participants, plus associated caregivers and educators). For each patient participant, one caregiver participant and at least one educator participant will be recruited.

WHAT IS INVOLVED IN THE RESEARCH STUDY?

You will be asked to complete questionnaires and you may also be asked to be interviewed.

WHAT ARE THE RISKS AND DISCOMFORTS OF THE RESEARCH STUDY?

Some questions may make your child uncomfortable. Your child can refuse to answer any questions that he/she does not want to answer.
If your child wants to talk to someone because this research made him/her feel upset, the researchers can give you information about people who may be able to help.
There may be unknown or unforeseen risks associated with study participation.

ARE THERE DIRECT BENEFITS TO TAKING PART IN THE RESEARCH STUDY?

Your child will probably not get any benefit because of being in this study. But, being in this study may help school intervention professionals and educators understand educational issues concerning patients with cancer and benign tumors, their caregivers and educators.

WHAT OTHER CHOICES ARE THERE?

If you do not want your child to take part in this research study, you may simply choose not to have your child participate.

HOW WILL INFORMATION ABOUT YOUR CHILD BE KEPT PRIVATE AND CONFIDENTIAL?

Cincinnati Children's Hospital Medical Center and/or the Investigator will take precautionary measures to protect your child's privacy and confidentiality of your child's research and/or medical records. Information about your child will be kept private by:

using a study ID number instead of the participant's name on the research forms
keeping the master list of names and study ID numbers in a separate location from the research forms
limiting access to research data to the research team
not including the participant's name on the typed transcript of the interview
keeping research data on a password-protected computer

Your child's information will be kept in a locked cabinet located in the locked School Intervention Program office until all analyses are complete. After that it will be destroyed by shredding all papers and deleting all data files.

Consent forms will be kept in the locked cabinet with the master list. Personal identifiers will be removed as soon as data is entered into the database or spreadsheet. Survey responses will be identifiable using the participants' identification numbers only. Audio recordings and transcriptions of the interviews will be stored in a database linked to participants only through their identification number. Data stored in a database/spreadsheet will be password protected.

Agents of Cincinnati Children's Hospital Medical Center may inspect study records for audit or quality assurance purposes.

The researcher cannot promise that information sent by the internet or email will be private.

WHAT IF NEW INFORMATION BECOMES AVAILABLE DURING THE RESEARCH?

The investigator will tell you about new information from this or other studies that may affect your child's health, welfare, or willingness to stay in this study. The information from the research study may be published; however, your child will not be identified in such publication. The publication will not contain information about your child that would enable someone to determine your child's identity as a research participant without your authorization.

WHAT ARE YOUR COSTS TO BE IN THIS STUDY?

You will not have to pay anything in order for your child to take part in this study.

WILL YOU/YOUR CHILD BE PAID TO PARTICIPATE IN THIS RESEARCH STUDY?

You and your child will not be paid (or given anything) to take part in this study.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Your child's participation in this study is completely voluntary. You or your child may choose either to take part or not to take part in this research study. Your decision whether or not to participate will not result in any penalty or loss of benefits to you or your child and the standard medical care for your child's condition will remain available to him/her.

If you decide to allow your child to take part in the research study, you are free to withdraw your permission and discontinue your child's participation in this research study at any time. Leaving the study will not result in any penalty or loss of benefits to your child.

If you or your child has questions about the study, you will have a chance to talk to one of the study staff or your child's regular doctor. Do not sign this form unless you have had the chance to ask questions and have received satisfactory answers.

Nothing in this parental permission form waives any legal rights you or your child may have nor does it release the investigator, the sponsor, the institution, or its agents from liability for negligence.

ABILITY TO CONDITION TREATMENT ON PARTICIPATION IN THIS STUDY

You have a right to refuse to sign this parental permission form and Authorization to use/disclose your child's Protected Health Information for research purposes.

If you refuse to sign this consent, your and your child's rights concerning treatment, payment for services, enrollment in a health plan or eligibility for benefits will not be affected.

WHO DO YOU CALL IF YOU HAVE QUESTIONS OR PROBLEMS?

For questions, concerns, or complaints about this research study or to report a research-related injury, you can contact the researcher Megan Elam at (513) 460-7054 or (513) 803-3272 or Mary Kay Irwin at (513) 218-6033 or (513) 636-8604. Researchers are available to answer any questions you may have about the research at any time.

If you have general questions about your rights as a research participant in this research study, or questions, concerns, or complaints about the research, you can call the Cincinnati Children's Hospital Medical Center Institutional Review Board at 513-636-8039. You can also call this number if the research staff could not be reached, or if you wish to talk to someone other than the research staff.

SIGNATURES:

I have read the information given above. The investigator or his/her designee have personally discussed with me the research study and have answered my questions. I am aware that, like in any research, the investigators cannot always predict what may happen or possibly go wrong. I have been given sufficient time to consider if my child should participate in this study. I hereby give my permission for my child to take part in this study as a research study subject. I will receive a copy of this signed form for my records.

_____ _____

Signature of Participant's Parent or Legally Authorized Representative* Date

_____

* If signed by a legally authorized representative, a description of such representative's authority must be provided

_____ _____

Signature of individual obtaining permission Date

CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER

HIPAA AUTHORIZATION FOR USE/DISCLOSURE OF

PROTECTED HEALTH INFORMATION

FOR A RESEARCH STUDY

STUDY TITLE: PERCEPTIONS OF EDUCATIONAL ISSUES FOR THE CHRONICALLY ILL

We understand that information about you and your health is personal and we are committed to protecting the privacy of that information. Because of our commitment to protect your privacy, we must obtain your written authorization (permission) before we may use or disclose (release) your "protected health information" (sometimes referred to as "PHI") related to the study described to you. This form provides that authorization and helps us make sure that you are properly informed of how this information will be used or disclosed. Please read the information below carefully before signing this form either for you, as the participant, or as the personal representative (parent, legal guardian, etc.) for the participant. Note that when we refer to "you" or "your" throughout this document, we are referring to the participant, even when this form is signed by the participant's personal representative.

USE AND DISCLOSURE COVERED BY THIS AUTHORIZATION

If you sign this document, you give permission to Cincinnati Children's Hospital Medical Center ("Cincinnati Children's") to use or disclose your medical and research information for the purpose of this study. Your PHI that will be used and disclosed in connection with this study consists of:

- Your Cincinnati Children's medical records
- Your research record for this study
- Results of your laboratory tests
- Clinical and research observations made during your participation in the study
- In the event that your medical record contains such information, information concerning HIV testing or the treatment of AIDS or AIDS-related conditions, drug or alcohol abuse, drug-related conditions, alcoholism, and/or psychiatric/psychological conditions (but not psychotherapy notes).

WHO WILL DISCLOSE, RECEIVE AND/OR USE THE INFORMATION?

This form authorizes the following to disclose, use and receive your PHI:

- Every research site of the study (including Cincinnati Children's and each site's research staff and medical staff)
- Every health care provider who provides services to you in connection with the study
- Any laboratories and other individuals and organizations that analyze your PHI in connection with the study

- The Sponsor and the people and companies they use to oversee, administer and/or conduct the study
- Federal regulatory agencies, other foreign regulatory agencies, and others as required by law
- The members of the Cincinnati Children's Institutional Review Board and staff of the Office of Research Compliance and Regulatory Affairs
- The Principal Investigator and members of the study's research team
- Data Safety Monitoring Board (if applicable)

By signing this document, you are authorizing Cincinnati Children's to use and/or disclose your PHI for this study. The purpose for the uses and disclosures is to conduct the study explained to you during the informed consent process and to ensure that information relating to the study is available to all parties who may need it for research purposes.

Those persons who receive your information may not be required by Federal privacy laws (such as the Health Insurance Portability and Accountability Act, also known as "HIPAA") to protect it and may share the information with others without your permission, if permitted by laws governing them.

You may revoke (choose to withdraw) this authorization at any time after you have signed it by providing the Principal Investigator (listed on the first page of the informed consent document) with a written statement that you wish to revoke it. Your revocation will be effective immediately and your PHI can no longer be used or disclosed for this study by Cincinnati Children's and the other persons or organizations that are identified above, except to the extent that Cincinnati Children's and/or the other persons or organizations identified above have already acted in reliance on the Authorization. In addition, the information may continue to be used and/or disclosed to preserve the integrity of the study.

Unless you notify us in writing of your decision to withdraw this authorization to use and disclose your PHI, it will expire at the end of the study. If the study involves the creation or maintenance of a research database repository, this authorization will not expire.

If you refuse to sign this authorization, you may not be able to receive research-related procedures and may not be able to continue in this study. However, your rights concerning treatment not related to this study, payment for services, enrollment in a health plan or eligibility of benefits will not be affected.

For further information about your rights, please see the Cincinnati Children's Notice of Privacy Practices on our website at http://www.cincinnatichildrens.org/about/corporate/hipaa.

You will receive a copy of this signed authorization.

SIGNATURES:

_____ _____

Signature of Participant (or Participant's Personal Representative*) Date

*Complete below if signed by a Personal Representative

(parent, legal guardian, etc.)

_____

Description of Personal Representative's Authority to Sign for Participant

_____

Printed Name of Personal Representative

_____ _____

Signature of Person Obtaining Authorization Date

IRB #: 2011-0125

Approved: 4/6/2012
Do Not Use After: 4/5/2013

ASSENT FORM

STUDY TITLE: PERCEPTIONS OF EDUCATIONAL ISSUES FOR THE CHRONICALLY ILL

INVESTIGATOR INFORMATION:

Mary Kay Irwin (513) 218-6033

Principal Investigator Name Telephone Number 24 hr Emergency Contact

WHAT IS RESEARCH?

We are asking you to be in a research study. Research is a way to test new ideas. Research helps us learn new things.

Being in research is your choice. You can say Yes or No. Whatever you decide is OK. We will still take good care of you.

WHY ARE WE DOING THIS RESEARCH?

We want to know people think about school issues for kids who are sick.

We are asking you and other children who have cancer or a benign tumor to be in this study.

WHAT WILL HAPPEN IN THE RESEARCH?

- If you agree, you will be asked to complete a survey 3 times.
    - The first time will be soon after you agree to be in this study.
    - The second time will be in the middle of your treatment.
    - The last time will be after you are done with treatment.
- It will take about 30 minutes to complete the survey each time.
- You will take the survey at CCHMC during a visit to see your doctor.
- Some children may be asked to participate in an interview.
- If you are interviewed, you will interview at 3 different times.
    - The first time will be soon after you agree to be in this study.
    - The second time will be in the middle of your treatment.
    - The last time will be after you are done with treatment.

- It will take about 60 minutes to complete the interview each time.
- For the interview, you will sit in a room at CCHMC with an adult who will ask you several questions.
- Your answers will be recorded on a tape so that the people in charge of this study can listen to your answers later.

WHAT ARE THE GOOD THINGS THAT CAN HAPPEN FROM THIS RESEARCH?

Being in this research may not help you right now. When we finish the research, we hope that we will know more about what people think school for children who are sick. This may help other children with cancer later on.

WHAT ARE THE BAD THINGS THAT CAN HAPPEN FROM THIS RESEARCH?

You probably won't have anything bad happen from this study.

If any questions on the survey or in the interview make you feel upset or sad, you can skip those questions.

If you want to talk to someone because this research made you feel upset, the researchers can help you.

WHAT ELSE SHOULD YOU KNOW ABOUT THE RESEARCH?

Being in the research is your choice. You can say Yes or No. It is OK to say No. No matter what you decide, we will still take good care of you.

If you say Yes now and change your mind later that is also OK. You can stop being in the research at any time.

If you want to stop being in the research, all you have to do is tell one of the doctors or nurses here at the hospital.

Take all the time you need to make your choice. Ask us any questions you have.

It is also okay to ask more questions after you decide to be in the research. You can ask questions at any time.

CHILD'S ASSENT

After you have read this form and talked about this research with your parents and the doctors or nurses you need to decide if you want to be in this research.

If you want to be in this research you should sign or write your name below.

_____	_____
Child's Assent	Date
_____	_____
Signature of Person Obtaining Assent	Date

Appendix E: Sample Site Support Letter

_____ (Name)

_____ (Title)

_____ (Address)

_____(Address Line 2)

Dear CCHMC IRB:

I grant permission for research-related activities for the following study: *Perceptions of Educational Issues for the Chronically Ill* to be conducted onsite at _____. (School)

Sincerely,

_____(Date)

Appendix F: Instrumentation

ID # :

Date:

Perceptions of Educational Issues for the Chronically Ill

Version 2.0

Caregiver Report

PtPQ

Directions

Children who have a serious illness sometimes have special challenges at school. Please tell us how much you believe each of the following statements to be true regarding your child with a chronic illness by circling:

1 if you STRONGLY DISAGREE with the statement
2 if you DISAGREE with the statement
3 if you are NEUTRAL regarding the statement (neither agree nor disagree)
4 if you AGREE with the statement
5 if you STRONGLY AGREE with the statement

There are no right or wrong answers.
If you do not understand a question, please ask for help.

Beliefs about School Attendance					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My child is too sick to go to school right now.	1	2	3	4	5
I feel guilty about sending my child to school.	1	2	3	4	5
My child might have to miss some days of school because of his/her illness.	1	2	3	4	5
I am concerned that my child may catch a contagious illness like a cold or the flu if he/she goes to school right now.	1	2	3	4	5
I am afraid my child may die at school.	1	2	3	4	5

Beliefs about Classroom-Related Issues and Teacher Knowledge					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My child will require more attention than his/her peers from the classroom teacher(s) because of his/her illness.	1	2	3	4	5
I will have to spend more time communicating with my child's teachers because of his/her illness.	1	2	3	4	5
My child's educators will require extra training because of my child's illness.	1	2	3	4	5

Beliefs about Peer and Social-Related Issues					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My child's friends and classmates will treat him/her the same as before he/she was sick.	1	2	3	4	5
My child feels shy about going to school because he/she might look different.	1	2	3	4	5
My child's classmates might not want to be friends with him/her because of his/her illness.	1	2	3	4	5
My child may be a distraction to his/her peers due to his/her illness.	1	2	3	4	5
My child's illness may lead to disruptions in the classroom learning environment.	1	2	3	4	5

Beliefs about Medical Issues					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Because of my child's illness, he/she might have an emergency at school.	1	2	3	4	5
My child's teachers would rather not have my child in class because of my child's illness.	1	2	3	4	5
My child's teachers may feel at risk by having my child with an illness in class.	1	2	3	4	5

Beliefs about Academic Performance					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My child might not do as well in school because of his/her illness.	1	2	3	4	5
My child might act differently at school because of his/her illness.	1	2	3	4	5
My child will have more difficulty in school because of his/her illness.	1	2	3	4	5
My child will experience long-term challenges with school and learning because of his/her illness.	1	2	3	4	5
My child may not pass to the next grade because of his/her illness.	1	2	3	4	5
My child's teachers will be able to help him/her at school despite his/her illness.	1	2	3	4	5

Demographic Information

Please respond to the following questions by circling your response or filling in the blank.

Describe your gender:

Male

Female

The number of individuals that live in my house is:

1 2 3 4 5 6 7 8 9

My role as this child's caregiver is:

Biological Mother
Biological Father
Stepmother
Stepfather
Grandmother
Grandfather
Other _____

The family dynamic in our home is best explained as:

Biological parents living together
Single parent (father)
Single parent (mother)
Biological parent and stepparent
Legal guardian (please explain): _____

The patient lives with me:

All of the time

1-3 days per week

4-6 days per week

Weekends only

Summers only

Other (please explain): _____

The highest level of education that I have completed is:

8th grade

High school

Vocational or professional training

Some college

Bachelor's Degree

Graduate Degree

My annual household income is between:

$0 - $25,000

$26,000 - $50,000

$51,000 - $75,000

$76,000 - $100,000

$100,000+

RESEARCH STUDY INFORMATION

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ID # :

Date:

Perceptions of Educational Issues for the Chronically Ill

Version 2.0

Educator Report

PtPQ

Directions

Children who have a serious illness sometimes have special challenges at school. Please tell us how much you believe each of the following statements to be true regarding your student with a chronic illness by circling:

1 if you STRONGLY DISAGREE with the statement
2 if you DISAGREE with the statement
3 if you are NEUTRAL regarding the statement (neither agree nor disagree)
4 if you AGREE with the statement
5 if you STRONGLY AGREE with the statement

There are no right or wrong answers.
If you do not understand a question, please ask for help.

Beliefs about School Attendance					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I believe this student is too sick to attend school right now.	1	2	3	4	5
I feel guilty about requiring this child to attend school.	1	2	3	4	5
This student might have to miss some days of school because of his/her illness.	1	2	3	4	5
I am concerned about the risk that school attendance presents for this child with respect to catching a contagious illness such as a cold.	1	2	3	4	5
I am afraid this child may die at school.	1	2	3	4	5

Beliefs about Classroom-Related Issues and Teacher Knowledge					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
This child will require more attention than his/her peers in the classroom because of his/her illness.	1	2	3	4	5
I will have to spend more time communicating with this child's parents because of his/her illness.	1	2	3	4	5
I will require additional training because of this child's illness.	1	2	3	4	5

Beliefs about Peer and Social-Related Issues					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
This child's friends and classmates will treat him/her the same as before he/she was sick.	1	2	3	4	5
This child may feel shy about going to school because he/she might look different.	1	2	3	4	5
This child's classmates might not want to play with him/her because of his/her illness.	1	2	3	4	5
This child may be a distraction to his/her peers due to his/her illness.	1	2	3	4	5
This child's illness may lead to disruptions in the classroom learning environment.	1	2	3	4	5

Beliefs about Medical Issues					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Because of this student's illness, he/she might have an emergency at school.	1	2	3	4	5
I would rather not have this child in class because of the child's illness.	1	2	3	4	5
I feel at risk by having this child with an illness in class.	1	2	3	4	5

Beliefs about Academic Performance

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
This child might not do as well in school because of his/her illness	1	2	3	4	5
This child might act differently at school because of his/her illness.	1	2	3	4	5
This child will have more difficulty in school because of his/her illness.	1	2	3	4	5
This child will experience long-term challenges with school and learning because of his/her illness.	1	2	3	4	5
This child may not pass to the next grade because of his/her illness.	1	2	3	4	5
I will be able to help this child at school despite his/her illness	1	2	3	4	5

Demographic Information

Please respond to the following questions by circling your response or filling in the blank.

Describe your gender:

Male

Female

Please continue with the questions continued on the following page.

I have been teaching for:

1-5 years

6-10 years

11-15 years

16-20 years

More than 20 years

Describe your relationship with this student prior to the current academic year:

No relationship

I saw this student in the hallways

I worked with this student in an extra-curricular type setting (i.e. coach)

I had this student in class

I have a personal relationship with this student's family

Other: _____

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Date:

Perceptions of Educational Issues for the Chronically Ill

Version 2.0

Patient Report – Young Child (ages 5-7)

PtPQ

Instructions for the interviewer:

"I am going to ask you some questions about things that some children might believe. I want to know how much you believe any of these things might be true for you."

Show the child the template and point to the responses as you read.

"If you do not believe it is true for you, point to the small word no.

If you DEFINITELY do not believe it is true for you, point to the big word NO!! with exclamation marks.

If you do believe it is true for you, point to the small word yes.

If you DEFINITELY believe it is true for you, point to the big word YES!! with exclamation marks.

If you are NEUTRAL, which means you do not agree or disagree, point to the question mark.

I will read each question. Point to the word to show me how much you believe it might be true for you. Let's try a practice one first."

	Strongly Disagree	Disagree	Neutral (I do not agree or disagree)	Agree	Strongly Agree
My doctors at Children's Hospital help me get well.	NO!!	no	?	yes	YES!!

Ask the child to point to the correct answer. Repeat the question if the child demonstrates a response that is different from what is expected.

Beliefs about going to school

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I am too sick to go to school right now.	1	2	3	4	5
My parents are worried about sending me to school.	1	2	3	4	5
I might have to miss some days of school because of my illness.	1	2	3	4	5
I am worried I might catch a cold or the flu if I go to school right now.	1	2	3	4	5
I am afraid to go to school.	1	2	3	4	5

Beliefs about my teacher

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I will need more help than my classmates from the teacher(s) because of my illness.	1	2	3	4	5
My parents will have to spend more time with my teachers because of my illness.	1	2	3	4	5
My teachers will need to learn more about my illness to help me at school.	1	2	3	4	5

Beliefs about my friends and classmates					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My friends and classmates will treat me the same as before I was sick.	1	2	3	4	5
I feel shy about going to school because I might look different.	1	2	3	4	5
My classmates might not want to play with me because of my illness.	1	2	3	4	5
My classmates may pay too much attention to me because of my illness.	1	2	3	4	5
My illness may lead to problems in the classroom.	1	2	3	4	5

Beliefs about my illness					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Because of my illness, I might have an emergency at school.	1	2	3	4	5
My teacher would rather not have me in class becauseof my illness.	1	2	3	4	5
My teachers worry that if I have an emergency at school, it will be their fault.	1	2	3	4	5

Beliefs about school work and grades					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I might not do as well in school because I am sick.	1	2	3	4	5
I might act differently at school because I am sick.	1	2	3	4	5
I will have a hard time with my school work because I am sick.	1	2	3	4	5
School and learning will be hard for a long time because I am sick.	1	2	3	4	5
I may not get to go on to the next grade because I am sick.	1	2	3	4	5
My teachers will be able to help me at school even though I have an illness.	1	2	3	4	5

How much do you believe this is true for you?

Strongly Disagree	Disagree	Neutral (I do not agree or disagree)	Agree	Strongly Agree
NO!!	no	?	yes	**YES!!**

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Date:

Perceptions of Educational Issues for the Chronically Ill

Version 2.0

Patient Report – Child (ages 8-12)

Cincinnati Children's Hospital Medical Center

Instructions for the interviewer:

"I am going to ask you some questions about things that some children might believe. I want to know how much you believe any of these things might be true for you."

Show the child the template and point to the responses as you read.

"If you do not believe it is true for you, point to the small word no.

If you DEFINITELY do not believe it is true for you, point to the big word NO!! with exclamation marks.

If you do believe it is true for you, point to the small word yes.

If you DEFINITELY believe it is true for you, point to the big word YES!! with exclamation marks.

If you are NEUTRAL, which means you do not agree or disagree, point to the question mark.

I will read each question. Point to the word to show me how much you believe it might be true for you. Let's try a practice one first."

	Strongly Disagree	Disagree	Neutral (I do not agree or disagree)	Agree	Strongly Agree
My doctors at Children's Hospital help me get well.	NO!!	no	?	yes	YES!!

Ask the child to point to his/her answer. Repeat the question if the child demonstrates a response that is different from what is expected.

Beliefs about going to school					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I am too sick to go to school right now.	1	2	3	4	5
My parents are worried about sending me to school.	1	2	3	4	5
I might have to miss some days of school because I am sick.	1	2	3	4	5
I am worried I might get a contagious illness like a cold if I go to school right now.	1	2	3	4	5
I am afraid to go to school.	1	2	3	4	5

Beliefs about my teacher					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I will require more attention than my classmates from the teacher(s) because of my illness.	1	2	3	4	5
My parents will have to spend more time with my teachers because of my illness.	1	2	3	4	5
My teachers will need to learn more about my illness to help me at school.	1	2	3	4	5

Beliefs about my friends and classmates					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My friends and classmates will treat me the same as before I was sick.	1	2	3	4	5
I feel shy about going to school because I might look different.	1	2	3	4	5
My classmates might not want to be my friend because of my illness.	1	2	3	4	5
My classmates may pay too much attention to me because of my illness.	1	2	3	4	5
My illness may lead to problems in the classroom.	1	2	3	4	5

Beliefs about my illness					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Because of my illness, I might have an emergency at school.	1	2	3	4	5
My teacher would rather not have me in class because of my illness.	1	2	3	4	5
My teachers worry that if I have an emergency at school, it will be their fault.	1	2	3	4	5

Beliefs about school work and grades					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I might not do as well in school because of my illness.	1	2	3	4	5
I might act differently at school because of my illness.	1	2	3	4	5
I will have a hard time with my school work because of my illness.	1	2	3	4	5
School and learning will be hard for a long time because of my illness.	1	2	3	4	5
I may not pass to the next grade because of my illness.	1	2	3	4	5
My teachers will be able to help me at school regardless of my illness.	1	2	3	4	5

How much do you believe this is true for you?

Strongly Disagree	Disagree	Neutral (I do not agree or disagree)	Agree	Strongly Agree
NO!!	no	?	yes	**YES!!**

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Perceptions of Educational Issues for the Chronically Ill

Version 2.0

Patient Report – Teen (ages 13-18)

Cincinnati Children's Hospital Medical Center

Directions

Children who have a serious illness sometimes have special challenges at school. Please tell us how much you believe each of the following statements to be true by circling:

1 if you STONGLY think this is NOT true for you
2 if you simply do NOT believe it is true for you
3 if you do not AGREE or DISAGREE (neutral)
4 if you simply DO believe it is TRUE for you
5 if you STRONGLY DO believe it is true for you

There are no right or wrong answers.
If you do not understand a question, please ask for help.

Beliefs about going to school					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I am too sick to go to school right now.	1	2	3	4	5
My parents feel guilty about sending me to school.	1	2	3	4	5
I might have to miss some days of school because of my illness.	1	2	3	4	5
I am worried I might catch a contagious illness or cold if I go to school right now.	1	2	3	4	5
I am afraid to go to school.	1	2	3	4	5

Beliefs about my teacher					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I will require more attention than my classmates from the teacher(s) because of my illness.	1	2	3	4	5
My parents will have to communicate more with my teachers because of my illness.	1	2	3	4	5
My teachers will require extra training because of my illness.	1	2	3	4	5

Beliefs about my friends and classmates					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My friends and classmates will treat me the same as before I was sick.	1	2	3	4	5
I feel shy about going to school because I might look different.	1	2	3	4	5
My classmates might not want to socialize with me because of my illness.	1	2	3	4	5
I may be a distraction to my classmates due to my illness.	1	2	3	4	5
My illness may lead to disruptions in the classroom learning environment.	1	2	3	4	5

Beliefs about my illness					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Because of my illness, I might have an emergency at school.	1	2	3	4	5
My teacher would rather not have me in class because of my illness.	1	2	3	4	5
My teachers worry that if I have an emergency at school, they will be responsible if something bad happens.	1	2	3	4	5

Beliefs about school work and grades					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I might not do as well in school because of my illness.	1	2	3	4	5
I might act differently at school because of my illness.	1	2	3	4	5
I will have more difficulty in school because of my illness.	1	2	3	4	5
I will experience long-term challenges with school and learning because of my illness.	1	2	3	4	5
I may not pass to the next grade because of my illness.	1	2	3	4	5
My teachers will be able to help me at school despite my illness.	1	2	3	4	5

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Appendix G: Quantitative Questionnaire Code Sheet

Column	Col. Heading (row1)	Data	Scale Code
1 (A)	Participant ID	Participant Number	Number assigned in order of recruitment
2 (B)	Time Point	Time Point Number	Time point 1 = 1, Time point 2=2, Time point 3=3
3 (C)	Subject Identification Number	Subject Identification Number	Diagnosis – Gender - Enrollment # - Triad Role – Age-State of Pt. Residence (where the following applies: Diagnosis of patient: 1 – Leukemia, 2 – Lymphoma, 3 - Brain Tumor, 4 - Other Solid Tumor; Gender of patient: M – male, F – female; Enrollment #: 2 spaces to denote PATIENT enrollment number, 01, 02, 03…45…60…75; Triad Role: 1 – Patient, 2 – Caregiver, 3 – Educator 1, 4 – Educator 2, 5 – Educator 3; State of Pt. Residence: OH-1, KY-2, IN-3, Other -4)
4 (D)	Triad Role	Triad Role	Patient = 1, Caregiver = 2, Educator = 3
5 (E)	Diagnosis	Diagnosis	Leukemia = 1, Lymphoma = 2, Brain Tumor = 3, Other Solid Tumor = 4
5 (F)	Age	Age	Age of patient. Not required for Caregiver or Educator
6 (G)	State of Residence	State of Residence	State of Pt. Residence: OH-1, KY-2, IN-3, Other -4
7 (H)	D1	Demographic Information: Gender Description	1 = Male, 2 = Female
8 (I)	D2	Demographic Information: Household Size	1 = 1, 2 = 2, 3 = 3, 4 = 4, 5 = 5, 6 = 6 , 7 = 7, 8 = 8, 9 = 9
9 (J)	D3	Demographic Information: Caregiver Role	1 = Biological Mother, 2 = Biological Father, 3 = Stepmother, 4 = Stepfather, 5 = Grandmother, 6 = Grandfather, 7 = Other
10 (K)	D4	Demographic Information: Family Dynamic	1 = Biological Parents Living Together, 2 = Single Parent (Father), 3 = Single Parent (Mother), 4 = Biological Parent + Stepparent, 5 = Legal guardian
11 (L)	D5	Demographic Information: Time Patient Lives with Caregiver	1 = All the time, 2 = 1 – 3 days per week, 3 = 4 – 6 days per week, 4 = Weekends only, 5 = Summers only, 6 = Other
12 (M)	D6	Demographic Information: Caregiver Level of Education	1 = 8th grade, 2 = High School, 3 = Vocational or Professional Training, 4 = Some College, 5 = Bachelor's Degree, 6 = Graduate Degree
13 (N)	D7	Demographic Information: Annual Household Income	1 = 0-25K, 2= 26-50K, 3 = 51K-75K, 4 = 76K-100K, 5 = 100K+
14 - 18 (O – S)	SA1 – SA5	Beliefs about Student Attendance	1 = Strongly Disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, 5 = Strongly Agree

19 (T)	SA Domain	Beliefs about Student Attendance Domain	∑/5* ≤ 3 = Not a concern; ∑/5* > 3 = Perceived Concern *Denotes number of questions
20 – 22 (U-W)	TK1 – TK3	Beliefs about Classroom – Related and Teacher Related Knowledge	1 = Strongly Disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, 5 = Strongly Agree
23 (X)	TK Domain	Beliefs about Classroom – Related Issues and Teacher Knowledge Domain	∑/3* ≤ 3 = Not a concern; ∑/3* > 3 = Perceived Concern *Denotes number of questions
24 (Y)	PI1	Beliefs about Peer and Social – Related Issues (Inverse Coding)	**5 = Strongly Disagree, 4 = Disagree, 3 = Neutral, 2 = Agree, 1 = Strongly Agree**
25 – 28 (Z-AC)	PI2 – PI5	Beliefs about Peer and Social – Related Issues	1 = Strongly Disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, 5 = Strongly Agree
29 (AD)	PI Domain	Beliefs about Peer and Social – Related Issues Domain	∑/5* ≤ 3 = Not a concern; ∑/5* > 3 = Perceived Concern *Denotes number of questions
30-32 (AE-AG)	MI1 – MI3	Beliefs about Medical Issues	1 = Strongly Disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, 5 = Strongly Agree
33 (AH)	MI Domain	Beliefs about Medical Issues Domain	∑/3* ≤ 3 = Not a concern; ∑/3* > 3 = Perceived Concern *Denotes number of questions
34 – 38 (AI-AM)	AP1 – AP5	Beliefs about Academic Performance	1 = Strongly Disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, 5 = Strongly Agree
39 (AN)	AP6	Beliefs about Academic Performance (Inverse Coding)	**5 = Strongly Disagree, 4 = Disagree, 3 = Neutral, 2 = Agree, 1 = Strongly Agree**
40 (AO)	AP Domain	Beliefs about Academic Performance Domain	∑/5* ≤ 3 = Not a concern; ∑/5* > 3 = Perceived Concern *Denotes number of questions
41 (AP)	EdD1	Demographic Information: Gender Description	1 = Male, 2 = Female
42 (AQ)	EdD2	Demographic Information: Teaching Experience	1 = 1 – 5 years, 2 = 6 – 10 years, 3 = 11 – 15 years, 4 = 16 – 20 years, 5 = More than 20 years
43 (AR)	EdD3	Demographic	1 = No Relationship, 2 = I saw this student in the

		Information: Prior Relationship with Student	hallways, 3 = I worked with this student in an extra – curricular type setting, 4 = I had this student in class, 5 = I have a personal relationship with this student's family, 6 = Other
44 (AS)	Misc.	"Error" Flagged Data	Description of Error
45 (AT)		Marked "Other"	Participant's Description of "Other"
Other		Unanswered Questions	0

Appendix H: Tables

Table H13

Patient Demographic Information

Participant Number	Patient's Diagnosis	Patient's Age	Patient's State of Residence	Patient's Grade	Patient's Gender	Patient's Race (ethnicity)
P15-1	Leukemia	10	Ohio	4	M	African American
P17-1	Brain tumor	10	Ohio	4	F	Caucasian
P18-1	Brain tumor	6	Ohio	1	F	African American
P19-1	Leukemia	9	Ohio	3	M	Caucasian
P20-1	Other solid tumor	6	Ohio		F	Caucasian
P21-1	Other solid tumor	7	Ohio	2	F	Caucasian
P22-1	Lymphoma	8	Ohio	3	M	Caucasian
P23-1	Brain tumor	9	Ohio	4	F	American Indian/Alaskan Native
P24-1	Brain tumor	6	Ohio	KG	M	Caucasian
P25-1	Leukemia	11	Ohio	5	M	Other (Hispanic)
P26-1	Other solid tumor	6	Ohio	KG	F	Caucasian
P27-1	Leukemia	6	Kentucky	1	M	African American
P28-1	Lymphoma	11	Ohio	5	F	Caucasian
P29-1	Brain tumor	12	Ohio	6	M	Caucasian
P30-1	Leukemia	8	Ohio	3	M	Caucasian
P31-1	Leukemia	7	Kentucky	2	F	Caucasian
P33-1	Lymphoma	11	Ohio	5	M	Caucasian

Table H14

Caregiver Demographic Information

Participant Number	Gender	Caregiver Role	Family Dynamic	# of Days Child Resides with Caregiver	Household Size	Household Income	Education Level
P15-2	F	Biological Mother	Biological parent and stepparent	All of the time	4	$100,000+	Bachelor's Degree
P17-2	M	Biological Father	Biological parents living together	All of the time	3	$76,000-$100,000	Vocational or professional training
P18-2	F	Biological Mother	Single parent (mother)	All of the time	4	$0-$25,000	High school
P19-2	F	Biological Mother	Biological parents living together	All of the time	5	$76,000-$100,000	High school
P20-2	F	Biological Mother	Legal guardian: Grandmother-Step grandfather	All of the time	4	$26,000-$50,000	High school
P21-2	F	Biological Mother	Single parent (mother)	4-6 days per week	3	$26,000-$50,000	Some college
P22-2	F	Biological Mother	Biological parents living together	All of the time	5	$100,000+	Bachelor's degree
P23-2	F	Biological Mother	Biological parent and stepparent	All of the time	7	$0-$25,000	High School

P24-2	M	Stepfather	Biological parent and stepparent	Other: All the time except every other weekend and every other Monday evening	5	$100,000+	Bachelor's degree
P25-2	F	Biological Mother	Biological parents living together	All of the time	5	$76,000-$100,000	Some college
P26-2	F	Biological Mother	Biological parents living together	All of the time	5	$100,000+	Graduate Degree
P27-2	F	Biological Mother	Single parent (mother)	All of the time	2	$26,000-$50,000	Some college
P28-2	F	Biological Mother	Biological parents living together	All of the time	4	$76,000-$100,000	Vocational or professional training
P29-2	F	Biological Mother	Biological parents living together	All of the time	6	$76,000-$100,000	Some college
P30-2	M	Biological Father	Biological parents living together	All of the time	4	$100,000+	Bachelor's degree
P31-2	F	Biological Mother	Single parent (mother)	NA	4	NA	NA
P33-2	F	Biological Mother	Biological parents living together	All of the time	4	$51,000-$75,000	Vocational or professional training

Table H15

Educator Demographic Information

Participant Number	Gender	Professional Role	Relationship with Student	Years of Experience
P15-3	F	Teacher	Personal relationship with student's family/I taught the student's sibling	11-15 years
P17-3	F	Teacher	I saw this student in the hallways	1-5 years
P18-3	F	Principal	I saw this student in the hallways/also had the student in class for a period of time	6-10 years
P19-3	F	Teacher	I saw this student in the hallways	More than 20 years
P20-3	F	Teacher	I had this student in class	More than 20 years
P21-3	F	Teacher	I have this student in class	More than 20 years
P22-3	F	Teacher	I had this student in class/I have a personal relationship with this student's family (had 2 older children in my class as well)	11-15 years
P23-3	F	Teacher	No relationship	6-10 years
P24-3	F	Teacher	No relationship	11-15 years
P25-3	Waiting	Teacher		
P26-6	F	Teacher	I saw this student in the hallways	More than 20 years
P27-3	F	Teacher	I saw this student in the hallways	More than 20 years
P28-3	Declined			
P29-3				
P30-3	F	Teacher	Other: I taught his older brother. I have not yet taught student	11-15 years
P31-3	F	Teacher	I saw this student in the hallways/She was in my	16-20 years

Participant Number	Gender	Professional Role	Relationship with Student	Years of Experience
			classroom at the end of last year on Transition Day. Visited child at CCHMC in summer	
P33-3	F	Teacher	I had this student in class.	More than 20 years

Table H16

Power Analysis: Sample Size Needed in Three Group Manova for Power = .70, .80, and .90 for α = .05 and α = .01 (Guilford & Frunchter, 1978)

		α = .05			**α = .01**		
Power		**.70**	**.80**	**.90**	**.70**	**.80**	**.90**
Sample Size	*(Small effect)*	110	135	170	155	185	220
Sample Size	*(Moderate effect)*	50	60	76	72	82	100

Note: Computed for 5 variables

Table H17

Questionnaire Revision Results

Original Item		Final Decision
SA1	I am too sick to go to school right now.	Retained
SA2	My parents are worried about sending me to school.	Retained
SA3	I might have to miss some days of school because I am sick.	Retained
SA4	*The number of days that I miss school will keep me from passing to the next grade.*	*Moved to AP5*
SA5	I will not be impacted by the number of days that I attend school.	Discarded

Original Item		Final Decision
MI1	*I am worried I might get a contagious illness like a cold if I go to school right now.*	*Moved to SA4*
MI2	Because of my illness, I might have an emergency at school.	Retained
MI3	I may need emergency care at school.	Discarded
MI4	My teacher would rather not have me in class because of my illness.	Retained
MI5	My teachers worry that if I have an emergency at school, they will be responsible if something bad happens.	Retained
MI6	*I am afraid to go to school.*	*Moved to SA5*

Original Item		Final Decision
TK1	My teachers know a lot about my sickness.	Discarded
TK2	*My teachers will be able to help me at school regardless of my illness.*	*Moved to AP6*
TK3	My teachers know what I can do at school.	Discarded
TK4	I will require more attention than my classmates from the teacher(s) because of my illness.	Retained
TK5	My parents will have to spend more time with my teachers because of my illness.	Retained
TK6	My teachers will need extra training because of my illness.	Retained
TK7	I should be in a special learning classroom because of my illness.	Discarded

Original Item		Final Decision
PI1	My friends and classmates will treat me the same as before I was sick.	Retained
PI2	My friends and classmates know about my sickness.	Discarded
PI3	I feel shy about going to school because I might look different.	Retained
PI4	My classmates might not want to be my friend because of my illness.	Retained
PI5	I do not know what to say to my classmates about my sickness.	Discarded
PI6	I may be a distraction to my classmates due to my illness.	Retained (reworded)
PI7	My illness may put my classmates in danger in the classroom.	Discarded
PI8	My illness may lead to disruptions in the classroom.	Retained (reworded)

Original Item		Final Decision
AP1	I will be able to do my schoolwork.	Retained (reworded)
AP2	I might not do as well in school because of my illness.	Retained
AP3	I might not act the same at school because of my illness.	Discarded
AP4	I might miss a lot of school work because of my illness.	Discarded
AP5	I will have more difficulty in school because of my illness.	Retained
AP6	I will have a harder time doing well at school because of my illness.	Discarded
AP7	I will not learn as quickly as I would have learned before I got sick.	Discarded
AP8	I will experience long-term challenges with school and learning because of my illness.	Discarded
AP9	I may not pass to the next grade because of my illness.	Retained
AP10	I will not have learning problems because of my illness.	Discarded
AP11	I will get good things at school not otherwise available because of my illness.	Discarded

Table H18

Skewness and Kurtosis

Domain	***Skewness***	***Kurtosis***
Student Attendance	-.438	-.442
Teacher Knowledge	-.593	.305
Peer Issues	.356	-.272
Medical Issues	.042	1.788
Academic Performance	.451	.509

a. Standard error for skewness was .340
b. Standard error for kurtosis was .668

Table H19

Shapiro-Wilk Test for Multivariate Normality

Domain	***Statistic***	***Significance***
Student Attendance	.824	.096
Teacher Knowledge	.942	.677
Peer Issues	.888	.308
Medical Issues	.960	.820
Academic Performance	.913	.459

Table H20

Levene's Test of Equality of Error Variances

	F	Sig.
		.
Student Attendance Domain	2.033	053
Teacher Knowledge Domain	1.163	.345
Peer Issues Domain	1.941	.065
Medical Issues Domain	1.467	.186
Academic Performance Domain	1.025	.445

a. df 1 = 11
b. df 2 = 37

Table H21

Box's Test of Equality of Covariance

Box's Test of Equality of Covariance Matrices	
Box's M	149.813
F	1.312
df1	60
df2	1254.496
Sig.	.058

Table H22

Reliability (Cronbach's Alpha)

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.854	.854	22

Table H23

Cronbach's Alpha if Item Deleted

Questionnaire Item	Cronbach's Alpha if Item Deleted
SA1	.848
SA2	.849
SA3	.853
SA4	.842
SA5	.851
TK1	.844
TK2	.851
TK3	.849
PI1	.854
PI2	.849
PI3	.853
PI4	.845
PI5	.845
MI1	.855
MI2	.848
MI3	.850
AP1	.847
AP2	.842
AP3	.841
AP4	.843
AP5	.844
AP6	.861