University of Cincinnati

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I, Mary Kay Irwin, hereby submit this original work as part of the requirements for the degree of Doctor of Education in Special Education.

It is entitled: Educational Issues of Children who are Chronically Ill: A Qualitative Analysis of Patients', Caregivers', and Educators' Beliefs

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

A dissertation presented to the
Graduate School at the University of Cincinnati

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by

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Abstract

Advancements in medical treatments have led to increased survival and cure rates for children with cancer and other chronic illnesses (Sexson & Madan-Swain, 1993; Thies, 1999; Clay, Cortina, Harper, Cocco, & Drotar, 2004), thus more students with chronic medical conditions are being included in regular education settings (Nabors & Lehmkuhl, 2004). Several of the treatments credited with extending the lives of these pediatric patients can have long-term implications for survivors. As the lives of these children are extended and saved, the quality of their lives should be examined (Bessell, 2001). Identifying the perceptions of the patient, their caregivers, and their educators addresses a critical yet missed dimension of this research area; it is only by knowing and understanding the concerns of these stakeholders that educational and quality of life outcomes can truly be improved.

This qualitative analysis is a part of an ongoing longitudinal, mixed-methods study designed to capture the perceptions of stakeholders at significant phases in the treatment journey. For the qualitative portion of the research, participants are being interviewed at three time points to ensure understanding of evolving perceptions. For the purposes of this dissertation, I will report on the qualitative findings from the first time point (phase one), which occurs at the time the patient is diagnosed.

Ultimately, with the guidance of the results from this study, school intervention professionals can examine current standards of practice through the lens of the recipients of the services. Findings from all three phases of the research will be used to drive programmatic improvement, guide future methodological choices, and to ensure services offered by school intervention professionals align with the perceived educational issues of the stakeholders receiving services.
Acknowledgements

In my reflection of gratitude and in true qualitative form, themes of appreciation emerged. Many coincidental encounters and unexpected events transpired in my life that have culminated in a serendipitous theme which resulted in my pursuant of this doctoral degree and specifically my interest and study of educational issues for children with chronic illness. Numerous teachers in my college preparatory work as well as in my career as a teacher challenged me to explore unique prongs within the field of education. Multiple location moves early in my life and more recently forced me to pursue new opportunities and to appreciate the diversity of educational systems and approaches to teaching and learning. In the absence of these fortuitous experiences, I would not have the privilege of working on behalf of children with chronic illness.

In contrast, there have been many opportunities I purposefully sought and encounters with individuals that were quite deliberate. Collectively, these encounters make up another theme of appreciation best described as support with purpose. Dr. David Doleman, one of my undergraduate professors, inspired me to be a true professional; Dr. Annie Bauer provided encouragement and advice beginning with applying to the doctoral program all the way through my final hearing; Dr. John Perentesis guided my research design by narrowing my focus which resulted in an attainable yet impactful study; Dr. David Barnett and Dr. Stephen Kroeger provided very thoughtful recommendations that undoubtedly improved the quality of my work; and Dr. Pamela Williamson challenged my theoretical position relative to research with her approach to qualitative methodology by guiding me from reluctant exposure, toward criticism and ultimately appreciation. Dr. Megan Elam deserves significant acknowledgement as my research partner and my friend. To list the many ways she has supported me in this journey
would exceed reasonable space therefore the summation of my appreciation is best described as a research partner I hope to have for my entire career.

I am so very thankful to my family and friends for their love and support. They provided countless hours of child care allowing me time to work and encouragement when I felt I had taken on too much. Early in my life, as an aspiring teacher, my mother’s immeasurable dedication to my future success was demonstrated on countless occasions, thus allowing me to engage in opportunities that shaped the professional I eventually became. Additionally my father, Dr. Michael Grever, has provided me with a lifetime of inspiration as a devoted professional committed to spending a career improving the lives of others. Above all, I owe the deepest gratitude to my husband, Jason Irwin. He told me I could when others said I could not and has personally sacrificed the most to make my dream a reality. I am proud to be Dr. Irwin. While it is my accomplishment, it is fitting that is intertwined with his name. Thematically, this final group can be expressed as support driven by love.

While my circle of support is rooted in three themes: serendipitous encounters, support with purpose, and support driven by love; I believe the individuals, the encounters, and the interplay between themes has been crafted by a higher power. My journey is far too seamless for me to take credit for its crafting. I am eternally grateful to God for choosing me to fulfill His desire to help children with chronic illness. I pray that I never forget to center my work around His purpose.
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Introduction

Advancements in medical treatments have led to increased survival and cure rates for children with cancer and other chronic illnesses (Sexson & Madan-Swain, 1993; Thies, 1999; Clay, Cortina, Harper, Cocco, & Drotar, 2004), thus more students with chronic medical conditions are being included in regular education settings (Nabors & Lehmkuhl, 2004). Several of the treatments credited with extending the lives of these pediatric patients can have long-term implications for survivors. For example, many treatments for cancer, including high-dose and intrathecal chemotherapies, as well as cranial and cranio-spinal radiation, may cause cognitive late effects (Harila, Winqvist, Lanning, Bloigu, & Harila-Saari, 2009; Nortz, Hemme-Phillips, & Ris, 2007;). Cognitive late effects resulting from treatments impact the quality of life of childhood cancer survivors, particularly in education (Nortz et al., 2007). The impact of childhood cancer on educational quality of life is evidenced in a large scale retrospective study contrived from the infamous Childhood Cancer Survivor Study. Using results from this large-scale longitudinal data set, Mitby et al. (2003) discovered that childhood cancer survivors were more likely to utilize special education services compared to siblings without an oncologic diagnosis. While impacts on cognition and academic performance may seem to be a “small price to pay” in exchange for extended life spans, researchers and practitioners would be remiss to overlook the opportunities to make advancements in these areas for the children surviving illnesses once categorized as terminal. As the lives of these children are extended and saved, the quality of their lives should be examined (Bessell, 2001).

While the number of children with chronic medical conditions in the classroom is increasing and many of their educational needs are well documented (Henning & Fritz, 1983; Nabors & Lehmkuhl, 2004; Harila et al., 2009), school settings often present barriers for children
with chronic illnesses and educational systems and school personnel remain ill prepared to cope with the multiple demands of these students (Kliebenstein & Broome, 2000; Clay et al., 2004). The need for a successful school reentry plan post initial diagnosis is a salient theme in the literature (Sexson & Madan-Swain, 1995; McCarthy, Williams, & Eidahl, 1996; Vance & Eiser, 2002). Critical components for a comprehensive approach to achieve success upon reentry have been outlined (Henning & Fritz, 1983; Chesler & Barbarin, 1986; Kliebenstein & Broome, 2000; Ashton, 2004), yet the availability of such services is limited. Less prominent in the literature, however equally significant, is the need for long-term educational supports for children with chronic medical conditions. Sexson and Madan-Swain (1995) suggest that school psychologists should proactively monitor the educational functioning of children with chronic illness given:

Successful school functioning is a dynamic, ongoing process which requires continuous cooperation and commitment among the home, medical team, and school. Failure to prioritize the school experience compromises both the educational and social development of these chronically ill students as they enter adulthood. (p. 367)

Nabors and Lehmkuhl (2004) echo this sentiment and suggest that school mental health professionals may be in an optimal position to facilitate the ongoing coordinated effort between medical providers, educators, and parents in their support of children with chronic medical conditions. While Nabors and Lehmkuhl recognize the importance of “assessing the child’s progress in meeting academic and social milestones” (p. 13), they do not emphasize investigating the needs of the children in the same way they recommend examining the needs of parents. They insist understanding the needs of the parents and family lifestyle is essential in developing care plans for children with chronic medical conditions, however do not outline provisions for exploring the needs from the perspectives of the actual children.
Several studies have examined perceptions of various stakeholders, including perceptions of school professionals regarding classroom issues for students with chronic illness (Olson, Seidler, Goodman, Gaelic, & Nordgren, 2004) and perceptions of school reentry issues for children with cancer from the perspective of school nurses, educators, and parents (Moore, Kaffenberger, Goldberg, Oh, & Hudspeth, 2009). Olson et al. (2004) revealed while school professionals have positive attitudes about students with chronic illnesses being in the classroom, they do have concerns about the amount of extra time they have to spend with these students, the liability their presence imposes, and concerns associated with an emergency taking place in the classroom due to the student’s illness. Results generated by Moore et al. (2009) highlight a recommendation that a liaison position may avert the identified problems in their study including nurses feeling ill-equipped to advise parents with respect to navigating the school system, school personnel feeling as though they did not have enough information about the disease/patient, and parents feeling like their child did not receive adequate school reentry services. While these contributions are related to this study, none have examined the perceptions of the patient, particularly in a direct comparison with the perceptions of the caregivers and educators of the patient.

The literature supports the need to examine quality of life as it relates to educational outcomes for patients with chronic medical conditions; educators and researchers have a professional obligation to respond to this concern (Irwin & Elam, 2011). The few studies that exist focus primarily on initial school reentry and neglect an analysis of interventions that may aid long-term deficits. Further, the absence of studies that examine the evolving needs of various stakeholders over time makes it difficult to identify educational interventions that may result in positive outcomes for students with a chronic illness at different time points in their treatment.
Bessell (2001) and Shaw and McCabe (2008) reinforce the importance of intervening and assessing educational interventions as interventions may positively influence educational outcomes related to cognitive late effects of treatment, but also quality of life concerns related to absenteeism, socio-emotional health, and other issues.

Frequently, hospital-based school intervention programs and programs of the like, such as the School Intervention Program (SIP) at Cincinnati Children’s Hospital Medical Center (CCHMC), are resurrected out of an emergent need without much regard for establishing a data-driven methodology (Prevatt, Heffer, & Lowe, 2000). These programs are actively engaged in supporting patients, caregivers, and educators, and seem to play a significant role in improving educational outcomes and quality of life for children with chronic illness, but currently do so in the absence of a strong methodological platform. The SIP at CCHMC was established in 1979 to serve patients with cancer and blood diseases. As one of the first and largest of its kind, the program is well positioned to facilitate studies to address the aforementioned vacancies in the literature.

**Purpose**

The paucity of research evaluating the effectiveness of school intervention and school reentry programs with respect to meeting the perceived educational needs of the recipients is the overarching motivation for this study. This study is novel in its aim to capture perceptions of educational issues of students with chronic illness according to three key stakeholders in a patient’s education: the patient, associated caregiver, and associated educator. Although the primary purpose of this research is to identify the perceived educational issues according to patients with chronic medical conditions, their caregivers, and their educators, secondarily we are investigating if beliefs vary from one group of stakeholders to another, from one time point...
in treatment to another, and determining if perceptions are impacted by various factors, including the age of the patient, the gender of the patient, the diagnosis of the patient, and/or the state of permanent residence of the patient. While the rationale to consider the age, gender, and diagnosis of the patient may seem obvious, the relevance of the state of residence is a bit obscure. State of residence is an important component to consider as state laws and resources vary relative to allocation and type of support available to students with chronic illnesses (e.g. delivery and amount of home instruction varies from state to state).

Table 1

*Study Aims*

<table>
<thead>
<tr>
<th>Primary Aims</th>
<th>Secondary Aims</th>
</tr>
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<tbody>
<tr>
<td>• To identify the perceived educational issues according to patients with a chronic medical condition.</td>
<td>• To determine if beliefs vary from one group of stakeholders to another.</td>
</tr>
<tr>
<td>• To identify the perceived educational issues, according to the caregivers, of patients with a chronic medical condition.</td>
<td>• To determine if beliefs vary from one time-point in treatment to another.</td>
</tr>
<tr>
<td>• To identify the perceived educational issues, according to the educators, of patients with a chronic medical condition.</td>
<td>• To determine if beliefs are impacted by various factors, including the age of the patient, the gender of the patient, the diagnosis of the patient, and/or the state of permanent residence of the patient.</td>
</tr>
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</table>

Including children in this study assists in the interpretations of the patient participants’ beliefs rather than solely relying on the adults in their lives to correctly interpret their perceptions (Eder & Fingerson, 2003). Identifying the perceptions of the patient addresses a critical yet missed dimension of this research area; it is only by knowing and understanding the concerns of these students that educational and quality of life outcomes can truly be improved.

The longitudinal, mixed-methods study was designed to capture the beliefs of
stakeholders at significant time points in the treatment journey and will span approximately seven years. All participants are completing a questionnaire at three time points, and purposefully selected participants are being interviewed to ensure understanding of perceptions in their totality. Quantitative data will be analyzed using MANOVA and linear mixed effects methods; qualitative data will be analyzed using inductive analyses. Parallels will be drawn between qualitative and quantitative findings. For the purposes of this dissertation, I will report on the qualitative findings from the first time point (phase one), which occurs at the time the patient is diagnosed. Of note, phase one is ongoing as recruitment for time point one remains open.

Ultimately, with the guidance of the results from this study, school intervention professionals can examine current standards of practice through the lens of the recipients of the services. Findings from all three phases of the study will be used to drive programmatic improvement, guide future methodological choices and to ensure services offered by the SIP at CCHMC align with the perceived educational issues of the stakeholders receiving services. At the conclusion of this study, school intervention professionals will be poised to disseminate findings across the country with the goal of illuminating the recipient’s beliefs and their subsequent desired needs during and after a very difficult time in their lives.

**Method**

In the methodological continuum spanning qualitative and quantitative research, positivist researchers consider subjectivity as a challenge that must be overcome. These researchers seek to control and prevent bias in the data collection and analyses processes, whereas traditional qualitative researchers welcome the penetration of subjectivity and prefer transparency in their perspectives and dispositions (Brantlinger, Jimenez, Klingner, Pugach, &
Richardson, 2005). The method employed by researchers in this study acknowledges the need for equilibrium by minimizing opportunities where bias may exist while recognizing that a level of subjectivity is certain and useful, thereby expressing that an explicit appreciation of these preferences and melding of perspectives serves as structure for reliability. As previously stated, this research is part of a larger, longitudinal study. Therefore a balance will be achieved as findings are merged through a mixed-methods design which will incorporate quantitative data to support the rich, detailed findings obtained in the qualitative interviews.

The researchers’ experience as school intervention professionals informs the need for this study, provides a basis for question formulation and facilitates the recognition that as professionals we are unable to design exemplary service-orientated programs in the absence of input from the very population the services are envisioned to support. Therefore, we lean on Crotty’s (1998) articulation of constructivism intending to reap benefit from the “epistemological considerations focusing exclusively on ‘the meaning-making activity of the individual mind’ (p. 58). As researchers, we will profit from understanding the way in which our participants make sense of their situation related to educational issues for patients with a chronic medical condition and we believe that the perspectives of each individual will adjust the focus of our lens enabling us to improve upon the services provided to the populations in which the stakeholders in our study represent.

Mertens (2010) reminds us that the ontology of constructivism presents researchers with the challenge of making sense of evolving perceptions of reality throughout the study. Consequently, we designed a longitudinal study to increase the probability of capturing the ever changing perceptions of individuals spanning cycles of
treatment and healing. Involving the various stakeholders will allow us to describe the perspectives and meaning-making processes (Koro-Ljungberg, Yendol-Hoppey, Smith, & Hayes, 2009) of complex experiences directly from the individuals who live those experiences.

According to Seidman (1998), when researchers are truly interested in understanding the experiences of their participants and the meaning they make of their experiences, in-depth interviewing is a valuable method. Furthermore, using multiple methods is particularly critical in researching children’s experiences as Darbyshire, MacDougall, and Schiller (2005) contend that multiple methods offers complementary insights and considerations that may be challenging to identify when depending on a single method of data collection. Consequently, the aforementioned literature coupled with our experience resulted in the design of a robust longitudinal, mixed-methods study intended to yield rich data to guide future directions for those interested in supporting the educational needs of children with a chronic illness. Ultimately, we hope to use the outcomes of our research to positively influence the delivery of service and interventions for individuals living with a chronic illness or those caring for an individual with a chronic medical condition by disseminating results and improving programs aiming to support the educational needs of patients.

**Study Design**

A pilot study was conducted for the purposes of validating the measurement tools, including questionnaires and interview questions. The utilization of national and local expert panels, statistical analysis and triangulation of quantitative and qualitative results guided the revisions of our data collection tools as we eliminated and reallocated questions on the questionnaires and embraced a more thorough interview structure by adopting the “Waking Day Interview” framework described by Barnett, Bell, and Carey (1998) in their book *Designing*
The subsequent three phases of this study adhere to a longitudinal, mixed-methods design, incorporating both quantitative methods (survey/questionnaire) and qualitative methods (interview) using repeated measures. Each stakeholder group will complete the same measure (survey/questionnaire and interview for specified participants) at multiple time points: at diagnosis, mid-treatment, and one year post-treatment. The timing of this dissertation is midway through phase one, therefore interpretations are preliminary and are inclusive of pilot considerations and the data captured in phase one, thus far.

Select participants are engaged in interviews at the aforementioned time points. In the interviews, patients are asked to describe daily routines from awakening until bedtime. Parallel interviews are being conducted with the caregivers and educators. Caregivers are asked to describe daily routines from awakening until school departure and then to describe the events that take place from the time the child arrives home until bedtime. Educators are asked to describe routines from school drop off until school departure. Provisions have been made for patients not attending school at all due to treatment or illness.

The waking day interview generally yields detailed descriptions of behaviors within settings, allows for rapport-building between the researcher and participant and results in participants revealing their greatest concerns about behaviors and settings (Barnett et al., 1998). Thus, this interview approach is providing rich descriptions of perceived educational issues in and outside of the classroom allowing us to fully appreciate quantitative results generated by the questionnaires.
Data collection begins within the two months after definitive diagnosis and each patient will be followed up to one year post the end of treatment (+/− 30) days unless this timeframe cannot be achieved within the 5 year timespan of data collection. Patients who experience their one year post treatment visit after the study has closed will not be included in the final time point.

Table 2

*Instruments to Collect Perceptions of Educational Issues for Patients with Chronic Illnesses*

<table>
<thead>
<tr>
<th>Study Phase</th>
<th>Patients</th>
<th>Caregivers</th>
<th>Educators</th>
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<tbody>
<tr>
<td><strong>Pilot Phase</strong></td>
<td>PtPQ</td>
<td>DemoInfo</td>
<td>EdPQ</td>
</tr>
<tr>
<td></td>
<td>PtPI⁴</td>
<td>CGPQ</td>
<td>EdPI⁴</td>
</tr>
<tr>
<td>1: New Diagnosis</td>
<td>PtPQ</td>
<td>DemoInfo</td>
<td>DemoInfo</td>
</tr>
<tr>
<td></td>
<td>PtPI⁴</td>
<td>CGPQ</td>
<td>EdPQ</td>
</tr>
<tr>
<td>2: Active Treatment</td>
<td>PtPQ</td>
<td>DemoInfo</td>
<td>DemoInfo</td>
</tr>
<tr>
<td></td>
<td>PtPI⁴</td>
<td>CGPQ</td>
<td>EdPQ</td>
</tr>
<tr>
<td>3: Post-Treatment</td>
<td>PtPQ</td>
<td>DemoInfo</td>
<td>DemoInfo</td>
</tr>
<tr>
<td></td>
<td>PtPI⁴</td>
<td>CGPQ</td>
<td>EdPQ</td>
</tr>
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</table>

**Measurement Key:**

DemoInfo – Demographic Information
PtPQ – Patient Perception Questionnaire
CGPQ – Caregiver Perception Questionnaire
EdPQ – Educator Perception Questionnaire
PtPI – Patient Perception Interview
CGPI – Caregiver Perception Interview
EdPI – Educator Perception Interview

⁴ Indicates this assessment is only being administered to the selected subgroup of participants.

At each time point, patient and caregiver participants complete the questionnaire onsite at CCHMC, unless they specifically request to complete the questionnaire elsewhere (at which
point researchers provide participants with online access or the appropriate paper forms and return envelopes). Select patient and caregiver participants engage in the interview process onsite at CCHMC. Educator participants complete their questionnaire and interview (if applicable) at the patient’s school or another desirable location at the preference of the educator. Options for online survey completion and phone (recorded) interviews are available for participants.

Quantitative data are uploaded into Oncore (Forte Research Systems, Inc., 2003) a study management database. Interview data are transcribed, then cross-transcribed by a different member of the research team and subsequently uploaded into QSR International’s NVivo 9 qualitative data analysis software. A list of transcription rules (e.g. how to handle inaudibles) was created during the pilot phase of this study and all rules are applied to study transcriptions.

Sample

The minimum number of patient participants that we will enroll for phases 1-3 is 60, for a total of 300 participants. This total participant number includes the potential for up to 3 educators per participant. The maximum number of patient participants that we plan to enroll is 80, for a total of 400 participants. Recruitment is ongoing and will continue for 24 months from study startup or when a maximum of 80 patient participants is enrolled, whichever occurs first.

Patient participants must have an oncologic diagnosis or other benign tumor (leukemia, lymphoma, brain tumor, and other solid tumors, i.e., osteosarcoma, Ewing sarcoma, retinoblastoma, neuroblastoma, rhabdomyosarcoma) and must be patients of CCHMC. Enrollment must occur within two months of definitive diagnosis (diagnosis
must be confirmed by histological pathology or radiologically). CCHMC is the sole provider of care for pediatric oncologic diagnoses in the Cincinnati metropolitan area (inclusive of counties in Ohio, Kentucky and Indiana). Thus, the sample in this study is considered representative of the population in the Cincinnati metropolitan area.

The patient must be school age, in grades K-7 (to ensure that 5 years of follow-up are limited to grade 12 or under) at the time of study enrollment. The patient and family must be willing to receive or currently receiving some level of school intervention support. The patient cannot participate if he/she is known to have an extremely poor prognosis (less than 12 month life expectancy) at the time of initial diagnosis. Specific diagnoses are known to have a poor prognosis, such as diffuse intrinsic pontine glioma (DIPG); therefore, these patients will not be approached. Due to variability in prognoses within diagnoses, a member of the research team will confirm prognosis with the attending physician. The physician will confirm prognosis by signing the Criteria Eligibility Form or by responding to the specific question via email. Regardless of the method of transaction, the documentation from the physician will be kept in the office of the School Intervention Program in a locked cabinet with other study materials.

Patients not attending school (i.e., those that are home schooled or refusing to participate in all school services will be excluded; in contrast, those patients still engaged in traditional school through homebound instruction provided by the school district will be included) cannot participate in this study. Participants must have the ability to speak English. Any participant 11 years of age or older must have the ability to read English.

Purposeful sampling directs the selection of participants in each group for interviews. Those selected for interviews during the initial data collection time point will be followed for subsequent interviews at the remaining two data collection time points. Criteria for selecting the
participants for interviews are intended to ensure diversity in diagnosis of patient. The first male and first female patients diagnosed in the following categories are approached to participate in the interview portion of the study: leukemia, lymphoma, brain tumor, and other solid tumor. Recruitment and participation is tracked using an interview guide chart.

Patients and caregivers who agree to be interviewed provide consent for the research team to approach the patient’s educator and suggest which educator should be recruited. Patients and caregivers sequentially list educators they feel know the patient best. Educators must be those currently assigned (by the school) to work with the patient. The research team recruits the educators in the order recommended by the patients and caregivers. In the event that none of the associated educators agree to participate in the interview, the patient and caregiver participants are notified that they can continue in the questionnaire portion of the study only. In this situation, the next patient with that diagnosis is approached for interview participation. This process continues until a consenting triad has agreed to participate in the interview process. The nature of this longitudinal study requires that the initial interview participants remain constant throughout the study with the exception of the educator. Therefore, it is possible that in the second or third phase of the interview portion of the study, a new educator could decline interview participation, thus disrupting the required interview triad. Every attempt will be made to identify one of the patient’s educators in order to maintain the integrity of the triad; in the event that no educator will agree, the patient and caregiver will continue their participation in the interview process.

The sample size for the interview portion of the study will include 8 patients, 8
caregivers, and up to 24 educators over the duration of the study. Interviews will be recorded using audio-equipment only; participants who are unwilling to participate in audio-recording of interviews will not be included in the interview portion of the research. The findings reported in this dissertation include interview data from 15 total participants, 5 patients, 5 caregivers, and 5 educators. Interview participant demographic information is included in the tables below and will become more useful relative to analysis once the sample is complete.

Table 3

*Interview Participants: Patient Demographic Information*

| Participant Number | Patient’s Diagnosis | Patient’s Age | Patient’s State of Residence | Patient’s Grade | M/F | Patient’s Race (ethnicity) | Pre-Morbid Academic Performance

| P17-1 | Brain tumor | 10 | Ohio | 4 | F | Caucasian | Above average (Std. test scores + grades) |
| P19-1 | Leukemia | 9 | Ohio | 3 | M | Caucasian | Above average (Std. test scores + grades) |
| P21-1 | Other solid tumor | 7 | Ohio | 2 | F | Caucasian | Above average (grades) |
| P22-1 | Lymphoma | 8 | Ohio | 3 | M | Caucasian | Above average (Std. test scores + grades) |
| P24-1 | Brain tumor | 6 | Ohio | KG | M | Caucasian | Average (bench mark + grades) |

a Pre-Morbid Academic Performance is broadly described within 3 categories: Below-average, Average, and Above-average. Pre-morbid academic performance information was collected as part of the scholastic information gathered from each patient’s school: standardized assessment data and overall grades/GPA. Standardized assessment data was used as a primary source for categorizing students. Grades were used as a secondary source to compare standardized test results and as a primary source for categorizing in the absence of testing data. Students were considered above average if they scored above the 75th percentile or were marked “accelerated” or “advanced” on standardized test scores. Grades were adjusted to a four point scale if letter grades were given. Students with GPAs above 3.3 were considered above average. Students with test scores below the 50th percentile or not proficient were considered below average. Students with a GPA below a C average, or 2.0, were considered below average.
Table 4

*Interview Participants: Caregiver Demographic Information*

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>M/F</th>
<th>Caregiver Role</th>
<th>Family Dynamic</th>
<th># of Days Child Resides with Caregiver</th>
<th>Household Size</th>
<th>Household Income</th>
<th>Education Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>P17-2</td>
<td>M</td>
<td>Biological Father</td>
<td>Biological parents living together</td>
<td>All of the time</td>
<td>3</td>
<td>$76,000-$100,000</td>
<td>Vocational or professional training</td>
</tr>
<tr>
<td>P19-2</td>
<td>F</td>
<td>Biological Mother</td>
<td>Biological parents living together</td>
<td>All of the time</td>
<td>5</td>
<td>$76,000-$100,000</td>
<td>High school</td>
</tr>
<tr>
<td>P21-2</td>
<td>F</td>
<td>Biological Mother</td>
<td>Single parent (mother)</td>
<td>4-6 days per week</td>
<td>3</td>
<td>$26,000-$50,000</td>
<td>Some college</td>
</tr>
<tr>
<td>P22-2</td>
<td>F</td>
<td>Biological Mother</td>
<td>Biological parents living together</td>
<td>All of the time</td>
<td>5</td>
<td>$100,000+</td>
<td>Bachelor’s degree</td>
</tr>
<tr>
<td>P24-2</td>
<td>M</td>
<td>Stepfather</td>
<td>Biological parent and stepparent</td>
<td>Other: All the time except every other weekend and every other Monday evening</td>
<td>5</td>
<td>$100,000+</td>
<td>Bachelor’s degree</td>
</tr>
</tbody>
</table>
### Table 5

**Interview Participants: Educator Demographic Information**

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Gender</th>
<th>Professional Role</th>
<th>Relationship with Student&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Years of Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>P17-3</td>
<td>F</td>
<td>Teacher</td>
<td>I saw this student in the hallways</td>
<td>1-5 years</td>
</tr>
<tr>
<td>P19-3</td>
<td>F</td>
<td>Teacher</td>
<td>I saw this student in the hallways</td>
<td>More than 20 years</td>
</tr>
<tr>
<td>P21-3</td>
<td>F</td>
<td>Teacher</td>
<td>I have this student in class</td>
<td>More than 20 years</td>
</tr>
<tr>
<td>P22-3</td>
<td>F</td>
<td>Teacher</td>
<td>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)</td>
<td>11-15 years</td>
</tr>
<tr>
<td>P24-3</td>
<td>F</td>
<td>Teacher</td>
<td>No relationship</td>
<td>11-15 years</td>
</tr>
</tbody>
</table>

<sup>a</sup> At the time of data collection, all educator participants were officially considered a teacher to the patient participants. The relationships listed above are a description of how well the educator participants knew the patients in the academic year prior to the year in which they engaged in this research study.

### Analysis

To fully appreciate the analysis and findings of this study, it is critical to recognize several factors: (1) the data is incomplete as recruitment is ongoing, thus the findings are preliminary; (2) in addition to an incomplete dataset, the data is representative of the first phase in a larger, longitudinal study; and (3) for the purpose of this dissertation, I will describe qualitative analysis and findings only, as the quantitative portion of the study will be described by my research partner.

An inductive approach was specifically chosen as the analysis method for this research given the natural match between the underpinnings of such an approach to the keystones of this study. Thomas (2006) describes, “the primary purpose of the inductive approach is to allow research findings to emerge from the frequent, dominant, or significant themes inherent in raw data, without the restraints imposed by structured methodologies” (p. 238). As professionals in the field in which we seek to improve, we intend to reserve our judgment and learn from the
perceptions of the patients, caregivers, and educators we serve. Thus, an inductive analysis was chosen to allow the data to emerge without restraint.

The qualitative analysis was largely based on Hatch’s (2002) description of an inductive analysis. The research team began by reading the entire dataset (transcribed interviews); subsequent frames of analysis were then identified as conceptual categories.

Figure 1

*Frames of Analysis*

Domains emerged as we recognized relationships within the data and salient domains were identified (see Tables 6-10).

*Salient Domains*

Table 6

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Classroom instruction</td>
<td>Are examples of</td>
<td>Missing Out</td>
</tr>
<tr>
<td>2. Environment &amp; procedures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Social activities &amp; peer interaction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Specials &amp; extracurriculars</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 7

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Academic performance</td>
<td>Are examples of</td>
<td>Premorbid Functioning</td>
</tr>
<tr>
<td>2. Peer interactions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. School-related behaviors</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 8

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Health &amp; safety at home</td>
<td>Are ways to provide</td>
<td>Extra Support</td>
</tr>
<tr>
<td>2. Health &amp; safety at school</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Parent academic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Parent ADLs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Parent peer support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Peers to patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Teacher academic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Teacher ADLs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Teacher peer support</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 9

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Academics</td>
<td>Are examples of</td>
<td>Change</td>
</tr>
<tr>
<td>2. Classroom behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Cognition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Environment &amp; procedures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Peer relationships</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Physical appearance &amp; wellness behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Relationships with teachers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Teacher assessment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Teacher expectations</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 10

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Academic performance</td>
<td>Are examples of</td>
<td>Implications</td>
</tr>
<tr>
<td>2. Cognition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Peer relationships</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Transcribed data sets were coded using NVivo software. Data was reread to ensure that domains which emerged later in the analysis processes were considered for data read early on in the examination. A search for counterevidence was conducted followed by an analysis within domains (see Tables 13-17). Themes across domains were identified and data excerpts were selected to support the elements of the analysis (see Figures 2-4). Throughout the analysis process, memo impressions were recorded and responses to the member check questions at the conclusion of each interview were closely scrutinized to ensure interpretations were an accurate reflection of the participant’s intentions.

To provide evidence of trustworthiness relative to interpretations, we engaged in member checking by: (1) asking participants to confirm a summary of their responses at the conclusion of each interview and (2) matching direct quotes to interpretations. Additionally, a coding agreement was consciously and collaboratively developed in a peer debriefing process to assist with credibility of the inherent subjectivity in qualitative research (Harris, Pryor, & Adams, 1997). Researchers deliberated each code until complete agreement was reached. 13% of the data were blindly re-coded by an experienced qualitative researcher that functioned as an external auditor. The external auditor’s codes were a 100% match to those of the researchers, thus establishing a consistency among findings. Further, we employed the credibility measures outlined by Brantlinger et al. (2005) that applied to our study design to justify the interpretations and decisions of the researchers (see Table 11).
Table 11

*Credibility Measures* (Brantlinger et al., 2005)

<table>
<thead>
<tr>
<th>Measure Description</th>
<th>Study Example</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Data triangulation</strong>: use of varied data sources in a study</td>
<td>Sources include: patient, caregiver &amp; educator participant triads</td>
</tr>
<tr>
<td><strong>Investigator triangulation</strong>: use of several researchers, evaluators, peer debriefers</td>
<td>Investigators include: research assistants conducted &amp; transcribed interviews; two primary investigators (separate from research assistants) engaged in peer debriefing throughout evaluation</td>
</tr>
<tr>
<td><strong>Disconfirming evidence</strong>: after establishing preliminary themes/categories, the researcher looks for evidence inconsistent with these themes (outliers); also known as negative or discrepant case analysis</td>
<td>Outliers: domains with repeated discrepant evidence were eliminated; salient domains with one or less discrepant examples remained and denotations were recorded in memos</td>
</tr>
<tr>
<td><strong>Researcher reflexivity</strong>: researchers attempt to understand and self-disclose their assumptions, beliefs, values, &amp; biases (i.e., being forthright about position/perspective)</td>
<td>Disclosure: investigators have experience providing supportive educational services to the patient population being investigated; experiences directed question formulation; assumptions for phase one data are included in the discussion section</td>
</tr>
<tr>
<td><strong>Collaborative work</strong>: involving multiple researchers in designing a study or concurring about conclusions to ensure that analyses &amp; interpretations are not idiosyncratic and/or biased; could involve interrater reliability checks on the observations made or the coding of data</td>
<td>Collaboration: two primary investigators worked together to design the study, the entire research team created and agreed on transcription rules, &amp; the two primary investigators agreed on all analyses &amp; interpretations</td>
</tr>
<tr>
<td><strong>External auditors</strong>: using outsiders (to the research) to examine if, &amp; confirm that, a researcher's inferences are logical &amp; grounded in findings</td>
<td>External auditor: 13% of the data were blindly re-coded by an experienced qualitative researcher that was an outsider to the research; comparison of codes revealed a 100% match establishing a consistency among findings</td>
</tr>
<tr>
<td><strong>Peer debriefing</strong>: having a colleague or someone familiar with phenomena being studied reviewed &amp; provide critical feedback on descriptions, analyses, &amp; interpretations or a study’s results</td>
<td>Peer debriefing: throughout coding process investigators provided critical feedback to each other &amp;agreements were reached; post coding, one investigator drew conclusions, wrote descriptions of interpretations &amp; summarized results – the second investigator provided critical feedback on all of the aforementioned aspects</td>
</tr>
<tr>
<td><strong>Audit trail</strong>: keeping track of interviews conducted and/or specific times &amp; dates spent observing as well as who was observed on each occasion; used to document &amp; substantiate that sufficient time was spent in the field to claim dependable &amp; confirmable results</td>
<td>Audit trail: interviews are tracked in a database; information retained includes date of interview, participant information (kept confidential), research team member that conducted interview, transcriptionists that transcribed interview, &amp; within transcription record of participant emotion is captured in accordance with transcription rules</td>
</tr>
<tr>
<td><strong>Thick, detailed description</strong>: reporting sufficient quotes &amp; field note descriptions to provide evidence for researchers' interpretations &amp; conclusions</td>
<td>Descriptions: data excerpts, for each triad role, were matched with frames of analysis</td>
</tr>
</tbody>
</table>
Findings

At the conclusion of every interview, each participant was asked if having cancer would result in any immediate or long-term social or educational implications for the patient. While a few participants hinted there may be potential implications, the overwhelming response from all participants was that the patient would not experience any short-term or long-term social or educational effects despite having cancer. This surprising phenomenon was echoed in our pilot findings as well as by McCarthy et al. (1996) in their examination of educators’ views of children with chronic conditions. Initially McCarthy and her colleagues reported that approximately half of the participants denied having concerns related to teaching children with chronic medical conditions, however upon further probing concerns were identified by all participants. Similarly, the participants in our study endorsed remarkable changes in: (1) social interaction; (2) academic delivery, expectations, and assessment; (3) support provided by peers, caregivers, and educators; (4) cognition; (5) environment and procedures; and (6) behavior. These endorsements came in response to questions asking how their (or their child’s or student’s) daily routine changed since diagnosis. The dichotomy in participants’ responses is illustrated in Table 12 and further in Figures 2-4.
Table 12

Sample Questions from Patient Interview

Questions are representative of a small portion of the interview. Parallel questions are asked of caregivers and educators. See Appendix D for complete interview scripts.

**Dichotomy in Participants’ Responses**

<table>
<thead>
<tr>
<th>Daily Routine Questions</th>
<th>Short &amp; Long-Term Implications Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tell me how your teacher(s) work(s) with you in the morning.</td>
<td>• Do you think your experience with (diagnosis) has affected your education (school)?</td>
</tr>
<tr>
<td>• Do you think the time you spend with your teacher(s) is different because you have/had (diagnosis)?</td>
<td>• Do you think your experience with (diagnosis) will affect your education (school) in the future?</td>
</tr>
<tr>
<td>Do you spend time with or talk with friends and classmates in the morning?</td>
<td>• Do you think your experience with (diagnosis) has affected your friendships?</td>
</tr>
<tr>
<td>• If they answer yes, ask – Describe the time you spend with friends or classmates. If they answer no, ask - Why not?</td>
<td>• Do you think your experience with (diagnosis) will affect your future friendships?</td>
</tr>
</tbody>
</table>

Responses to these and similar questions yield rich data to support all participants endorse significant changes in all aspects of the patient’s life as a result of having cancer.

Responses to these questions would lead (in the absence of the data revealed by the daily routine questioning) researchers to believe participants were not concerned about social and educational outcomes despite having cancer.

**Notable Dichotomy**
Figure 2
Examples of Perceived Educational Issues
Patient Data Excerpts

Generally, patients do not perceive that they will experience short or long-term effects (academic or social) despite having cancer; however, the patients frequently undermine their own response(s) through contradictory descriptions as they elaborate on each topic.

- P21-1 "Two people been calling me boys...because I’m half bald" In response to how does it make you feel, "Not really good."
- P22-1 "Eh, no...Because I don’t get to see my friends as often"
- P17-1 "They’re [peers] spending more time with me cuz, my head, and...they know somethins wrong with me."
- P17-1 "It [school work] wasn’t confusing [prior to diagnosis] but now it’s confusing..."
- P17-1 "Cus they’re trying to explain stuff to me. So they’re spending more time with me"
- P22-1 "I’ve been missing a lot of school, so...it’s [homework] been piled up a whole bunch."

Academic Short-term
No short-term academic effects

Academic Long-term
No long-term academic effects

Social Short-term
No short-term social effects

Social Long-term
No long-term social effects

Patient Perspective
Figure 3
Examples of Perceived Educational Issues
Caregiver Data Excerpts

Generally, caregivers do not perceive that their children will experience short or long-term effects (academic or social) despite having cancer; however, the caregivers frequently undermine their own response(s) through contradictory descriptions as they elaborate on each topic.

- **P17-2**: Parent requested accommodation due to “inconsistent information we’d get from her [daughter]…when things were due…It takes her longer to get through her homework [post diagnosis].”
- **P24-2**: “No I don’t think it’s taking him any longer. Um, I think ah, given the circumstances if anything he’s trying to rush and get it done …And, and because of that he’s maybe not concentrating and getting a few things mixed up that he wouldn’t normally get mixed up.”
- **P24-2**: “[He is] not quite as focused [as he used to be prior to diagnosis].” When asked if the attention issue was isolated to homework, “I think it’s true [lack of focus] in, in his whole world.”
- **P19-2**: “I don’t. I mean, I do know that they, somebody is going to come and kind of evaluate him to see where his baseline is to make sure this is not affecting his ability to learn or anything like that […].”
- **P19-2**: “Some of them [peers] they…didn’t want to get too close to him…just seeing their friend in the hospital with tubes and stuff[I think is scary].”
- **P24-2**: “His close friends won’t be affected, only that they haven’t seen each other for so long.”
- **P22-2**: “He’s not been able to really get to spend a lot of time with his friends…he’s FaceTiming as much as…he feels well, but…he’s still going on without him at school… I don’t think that he feels anyone’s intentionally leaving him out.”
- **P24-2**: “I think whatever those [friendships] were meant to be will be, and this will have no impact on him.”
Examples of Perceived Educational Issues
Educator Data Excerpts

Generally, educators do not perceive that their students will experience short or long-term effects (academic or social) despite the child's cancer diagnosis; however, the educators frequently undermine their own response(s) through contradictory descriptions as they elaborate on each topic.

P17-3: "School's working really hard to... make sure she doesn't miss huge concepts, but depending how much she is in, in and out of school... she definitely will miss material, and since we kind of feel guilty about trying to have her make it all up,... I do think she will end up missing some material"

P17-3: "I do think she'll pass the grade, um, I do think that she'll need extra support, and I'm not positive if she'll pass the OAs. But for me (emphasis on "me") that's not the highest concern at this time, so"

P19-3: "I don't foresee any long term educational or learning problems], because he was literally a year or two above to begin with. So, if it slows him down for a while, I, I just feel he'll pick it up later"

P22-3: "I don't think it's gonna affect him academically, unless (emphasis) there's some sort of fall-out from the chemo."

P24-3: "There might be some hesitation from some of his [peers] and some curiosity because of how he does look... they'll probably ask him questions"

P17-3: "I would say she's still seems like she's friends with the same but... she's not as bubbly and open and laughing and joking with friends, and she still does, but I just don't think it's as often..."

P22-3: "It's been good for the, the students to know that you know, some people die of cancer and some people don't. And you know, he's gonna be fine and this is what's happening, and we've just been very honest with them [peers] the whole time"

P24-3: "I don't think it will necessarily affect him. I think um, yeah, I don't know, you know being a five and six year old lad, you know, they send, they tend to be able to move on and, and get over things a lot quicker than older people do so..."
The contradiction that exists in the data is significant given the consistency of the paradox across all triads. Equally as compelling is the universal theme that emerged in the data. Participants in each triad role described a balance that was present that neutralized the changes evident in their (or their child’s or student’s) lives, thus seemingly mitigating the effects of having cancer relative to social and educational outcomes. This resounding theme suggests that missing academic and social interactions, even substantial amounts, can be counterbalanced by extra support from peers, caregivers, and educators - especially if the student experienced premorbid success relative to academic performance or social engagement. This perception was thread throughout the responses of every participant and a very similar notion was reported by Chesler and Barbarin (1986). In their qualitative study, Chesler and Barbarin interviewed 59 parents of school age children with cancer; findings substantiate the aforementioned universal theme in the following ways: students that were not doing well in school prior to diagnosis were experiencing more difficulty catching up on missed work than those that did not struggle prior to diagnosis and parents that perceived their child was experiencing success in school also reported that their child’s school personnel were helpful.

The analysis of salient domains (see Tables 13-17) provides the elements of analysis that cumulatively provide evidence for this universal theme. The interaction of the five salient domains as it relates to this theme is demonstrated in Figure 5.
Table 13

*Analysis within Domains- Missing Out*

<table>
<thead>
<tr>
<th>Cover Term</th>
<th>Included Terms</th>
<th>Descriptors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Classroom Instruction</td>
<td>Missing lectures, readings, activities, practice, classwork, homework due to hospitalizations, outpatient appointments, disease or associated treatment malaise, or avoidance of public interactions due to suppressed immunity. In several cases, missing entire subjects (science, social studies, religion) and in other situations missing parts of every subject</td>
<td></td>
</tr>
<tr>
<td>Environment &amp; Procedures</td>
<td>Late arrival, early departure from school or not attending school in the physical building; absence of student planner (sometimes replaced with parent to teacher email); taking tests at a different time than peers causing patient to miss out on more instruction; abandonment of homework requirements; turns in partial assignments far beyond due date; absence of daily school routines (from getting to and from school and everything in-between)</td>
<td></td>
</tr>
<tr>
<td>Social Activities &amp; Peer Interaction</td>
<td>Missing bus rides (replaced by parental drop off); missing peer interactions that takes place in classrooms; missing peer interactions that take place in neighborhoods; missing eating out at restaurants; missing play time at a friend’s house</td>
<td></td>
</tr>
<tr>
<td>Specials &amp; Extracurriculars</td>
<td>Missing lunch, recess, art, music, computer, gym</td>
<td></td>
</tr>
</tbody>
</table>
Table 14

Analysis within Domains- Premorbid Functioning

<table>
<thead>
<tr>
<th>Cover Term</th>
<th>Included Terms</th>
<th>Descriptors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic Performance</td>
<td>Parent, educator and patient report that patient was/is a strong student in various ways inclusive of categorizing that patient as intelligent, advanced compared to peers, one that is able to accomplish a significant amount of work independently</td>
<td></td>
</tr>
<tr>
<td>Peer Interactions</td>
<td>Parent, educator and patient report that patient was/is more mature than peers, previously had lots of friends, strong and positive personality that attracts many friends</td>
<td></td>
</tr>
<tr>
<td>School-related</td>
<td>Parent, educator and patient report that the patient did or did not enjoy school/homework prior to diagnosis, actively or inactively participated in class/homework, completed work independently or required encouragement</td>
<td></td>
</tr>
</tbody>
</table>
Table 15

**Analysis within Domains- Ways to Provide Extra Support**

<table>
<thead>
<tr>
<th>Cover Term</th>
<th>Item Terms</th>
<th>Descriptors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health &amp; Safety at Home</td>
<td>Physical actions to protect the patient’s port, established rules/procedures to minimize risk associated with suppressed immunity</td>
<td></td>
</tr>
<tr>
<td>Health &amp; Safety at School</td>
<td>Alternate plans at school for patient to avoid perceived danger (avoiding recess to protect head, provisions made to avoid busy hallways), alternate furniture to decrease discomfort (higher chair for patient to raise chest higher to avoid port hitting table), excused and encouraged absences when rate of contagious illness in school building is significant, avoidance of after school program due to perceived limited oversight of safety precautions, teacher facilitates class meetings to discuss the importance of not bumping patient and not partnering with patient if peer feels ill</td>
<td></td>
</tr>
<tr>
<td>Parent Academic</td>
<td>Varying levels of parental assistance with homework, increased parent/teacher communication for parent to seek guidance on assignments/aspects of the curriculum/school day, increased communication between parent and patient about school day, parent picking up and dropping off assignments</td>
<td></td>
</tr>
<tr>
<td>Parent ADLs</td>
<td>Assistance with showering, cleaning wounds to avoid infection, administration of medications</td>
<td></td>
</tr>
<tr>
<td>Parent Peer Support</td>
<td>Parent talking with peers about diagnosis, treatment and associated implications</td>
<td></td>
</tr>
<tr>
<td>Peers to Patient</td>
<td>Peers providing assistance at school (carrying books, staying in at recess with patient), peers spending more time with patient (wanting to sit near peer all the time, spending extra time at lunch with patient), group displays of support (all wearing hats or shaving heads), peers being more careful with physical actions around patient, virtual support (blogging, Skype)</td>
<td></td>
</tr>
<tr>
<td>Teacher Academic</td>
<td>Copying pages of manual for parent, re-teaching, 1:1 support at school or home, reduction or prioritization of work, increased parent/teacher communication for parent to seek guidance on assignments/aspects of the curriculum/school day, alternate means of assessment, alternate assignments, assistance with classroom procedures, accommodations for writing (fine motor aspect) demands, preparing packets of work for hospital teacher or to be done at home, communicating with hospital teacher, alternate school schedule to increase time spent in core classes</td>
<td></td>
</tr>
<tr>
<td>Teacher ADLs</td>
<td>Accommodating patient requiring longer time period to eat and accommodating for fine motor deficit</td>
<td></td>
</tr>
<tr>
<td>Teacher Peer Support</td>
<td>Arranging for peers to support lengthened lunch time and alternate recess activities, organizing group displays of support (sending cards home, ordering bracelets, hate day), talking with peers about precautions, answering questions and encouraging normalcy</td>
<td></td>
</tr>
</tbody>
</table>
### Table 16

**Analysis within Domains - Change**

<table>
<thead>
<tr>
<th>Cover Term</th>
<th>Item Terms</th>
<th>Descriptors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academics</td>
<td>Focus on core content, elimination of “specials,” elimination of specific courses, modified delivery of content, varying adults responsible for instruction, reduction in amount of content or work, accepting unique experiences in place of lessons (i.e. accepting blog with updates on cancer as a writing assignment(s))</td>
<td></td>
</tr>
<tr>
<td>Classroom Behavior</td>
<td>Interactions with peers, interactions with teachers, participation in class discussions/group work/partner work, willingness to work independently, willingness to push through challenging work, attention to task, willingness to seek and accept help, fine motor fatigue</td>
<td></td>
</tr>
<tr>
<td>Cognition</td>
<td>Repetition of explanations, comprehension of material, retention of content/procedures/expectations, process time, focus</td>
<td></td>
</tr>
<tr>
<td>Environment &amp; Procedures</td>
<td>Location of instruction, flexible due dates, alternate schedules, changes in eating or sleeping habits, transportation to and from school, modifications to recess/gym/lunch/transition, homework procedures, family routines that influence school, frequency and method of communicating with the teacher, altered after school care plans</td>
<td></td>
</tr>
<tr>
<td>Peer Relationships</td>
<td>Amount of time spent with peers, style of play, peers taking on role of caregiver, peers treating patient differently, frequency of virtual communication, discussion topics with peers, peers reacting to changes in appearance</td>
<td></td>
</tr>
<tr>
<td>Physical Appearance &amp; Wellness Behavior</td>
<td>Loss of hair, wearing hats all the time, swollen face, increase in sedentary activities and decrease in physical activities, maximizing periods during the day when patient has energy, napping when otherwise would not require naps</td>
<td></td>
</tr>
<tr>
<td>Relationships with Teachers</td>
<td>Comfort level with adults, willingness to talk with adults, interaction with teacher is more personal</td>
<td></td>
</tr>
<tr>
<td>Teacher Assessment</td>
<td>Observation, oral responses, decrease in number of assessments, altered schedule of assessments, emphasis on broad concepts instead of specifics that peers are expected to know, taking tests at home, 1:1 assistance with tests, flexible deadlines, alternate assignments, absence of assessment</td>
<td></td>
</tr>
<tr>
<td>Teacher Expectations</td>
<td>Decreased amount of completed work expected, less homework, achieve proficiency in limited core subjects and with broad concepts, same long-term expectations regardless of reduction in short-term expectations</td>
<td></td>
</tr>
</tbody>
</table>
Table 17

*Analysis within Domains- Implications*

<table>
<thead>
<tr>
<th>Cover Term</th>
<th>Item Terms</th>
<th>Descriptors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic Performance</td>
<td>Acknowledgement of missing content and work, however belief is patient will achieve the same academic short and long-term goals despite having cancer (no concern with grade promotion, college or career), some acknowledgment that patient may continue to require extra support</td>
<td></td>
</tr>
<tr>
<td>Cognition</td>
<td>Acknowledgement of slower processing speed and material being confusing, one patient suggests issues with cognition could cause a short-term problem in school that will not last long-term, educators expressed some hesitation and concern for the possibility of long-term cognitive effects, several patients and parents believe the patient will not suffer any short or long-term implications relative to cognition despite having cancer</td>
<td></td>
</tr>
<tr>
<td>Peer Relationships</td>
<td>Acknowledgement of changes in the way patient interacts with peers, some participants endorse short-term implications such as children being more interested or kind and some being afraid, however all participants believe there will not be any long-term implications relative to peer relationships despite having cancer</td>
<td></td>
</tr>
</tbody>
</table>
A detailed examination of the data provides strong evidence that children diagnosed with cancer experience significant changes in their daily routines. Additionally, as a result of being diagnosed with cancer, children miss out on substantial amounts of educational and social interactions. However, as these changes and missed opportunities continue to accumulate over time, it is the belief of the patients, caregivers, and educators in this study that negative outcomes can be averted by providing patients with extra support. This is especially true for patients that experienced premorbid success in their academic performance and social interactions. It does not appear that the participants believe that patients that struggled academically or socially prior to diagnosis will experience negative outcomes given the extra support they receive from peers, caregivers, and educators. Rather, patients are even less likely to experience educational and social issues if they did not struggle in these areas before being diagnosed with cancer.
Figure 6 illustrates the phenomenon discovered in the data. While patients diagnosed with cancer experience significant change and miss out on a myriad of experiences, their educational and social outcomes can be preserved by receiving extra support and relying on their premorbid academic and social successes. In the absence of receiving extra support or for a patient that struggled academically or socially prior to diagnosis, their academic and social outcomes may not remain as stable as those that receive extra support and had premorbid academic and social success. The illustration demonstrates a “Stable Table;” pictorially representing a patient that will likely not experience negative academic or social outcomes according to the participants in this study. However, in the absence of one or more legs in the table, data suggests the respective outcomes become vulnerable (less stable).
The findings illustrated in Figures 5 and 6 are further evidenced by tabulating the raw data. The pervasive impact of the interpretations is cataloged in Enumeration Tables 18-23. The data in these tables provide impressive confirmation that the findings are endorsed by participants across triads.
Enumeration Tables

Table 18

<table>
<thead>
<tr>
<th>Cover Term</th>
<th>Included Terms</th>
<th>Patients</th>
<th>Caregivers</th>
<th>Educators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Missing Out</td>
<td>Classroom instruction</td>
<td>4/5</td>
<td>5/5</td>
<td>5/5</td>
</tr>
<tr>
<td></td>
<td>Environment &amp; procedures</td>
<td>4/5</td>
<td>5/5</td>
<td>5/5</td>
</tr>
<tr>
<td></td>
<td>Social activities &amp; peer</td>
<td>5/5</td>
<td>4/5</td>
<td>5/5</td>
</tr>
<tr>
<td></td>
<td>interaction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Specials &amp; extracurriculars</td>
<td>5/5</td>
<td>4/5</td>
<td>5/5</td>
</tr>
</tbody>
</table>

Table 19

<table>
<thead>
<tr>
<th>Cover Term</th>
<th>Included Terms</th>
<th>Patients</th>
<th>Caregivers</th>
<th>Educators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Premorbid Functioning</td>
<td>Academic performance</td>
<td>3/5</td>
<td>4/5</td>
<td>5/5</td>
</tr>
<tr>
<td></td>
<td>Peer interactions</td>
<td>4/5</td>
<td>5/5</td>
<td>5/5</td>
</tr>
<tr>
<td></td>
<td>School-related behaviors</td>
<td>4/5</td>
<td>3/5</td>
<td>4/5</td>
</tr>
</tbody>
</table>

Table 20

<table>
<thead>
<tr>
<th>Cover Term</th>
<th>Included Terms</th>
<th>Patients</th>
<th>Caregivers</th>
<th>Educators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extra Support</td>
<td>Health &amp; safety at home</td>
<td>4/5</td>
<td>5/5</td>
<td>1/5</td>
</tr>
<tr>
<td></td>
<td>Health &amp; safety at school</td>
<td>2/5</td>
<td>5/5</td>
<td>4/5</td>
</tr>
<tr>
<td></td>
<td>Parent academic</td>
<td>3/5</td>
<td>5/5</td>
<td>4/5</td>
</tr>
<tr>
<td></td>
<td>Parent ADL’s</td>
<td>4/5</td>
<td>5/5</td>
<td>0/5</td>
</tr>
<tr>
<td></td>
<td>Parent peer support</td>
<td>1/5</td>
<td>3/5</td>
<td>1/5</td>
</tr>
<tr>
<td></td>
<td>Peers to patient</td>
<td>5/5</td>
<td>5/5</td>
<td>4/5</td>
</tr>
<tr>
<td></td>
<td>Teacher academic</td>
<td>5/5</td>
<td>4/5</td>
<td>5/5</td>
</tr>
<tr>
<td></td>
<td>Teacher ADL’s</td>
<td>1/5</td>
<td>1/5</td>
<td>1/5</td>
</tr>
<tr>
<td></td>
<td>Teacher peer support</td>
<td>2/5</td>
<td>3/5</td>
<td>4/5</td>
</tr>
</tbody>
</table>
Table 21

<table>
<thead>
<tr>
<th>Cover Term</th>
<th>Included Terms</th>
<th>Patients</th>
<th>Caregivers</th>
<th>Educators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change</td>
<td>Academics</td>
<td>5/5</td>
<td>5/5</td>
<td>5/5</td>
</tr>
<tr>
<td></td>
<td>Classroom behavior</td>
<td>4/5</td>
<td>5/5</td>
<td>5/5</td>
</tr>
<tr>
<td></td>
<td>Cognition</td>
<td>1/5</td>
<td>3/5</td>
<td>2/5</td>
</tr>
<tr>
<td></td>
<td>Environment &amp; procedures</td>
<td>5/5</td>
<td>5/5</td>
<td>5/5</td>
</tr>
<tr>
<td></td>
<td>Peer relationships</td>
<td>5/5</td>
<td>5/5</td>
<td>5/5</td>
</tr>
<tr>
<td></td>
<td>Physical appearance &amp; wellness behaviors</td>
<td>4/5</td>
<td>5/5</td>
<td>5/5</td>
</tr>
<tr>
<td></td>
<td>Relationship with teachers</td>
<td>3/5</td>
<td>3/5</td>
<td>5/5</td>
</tr>
<tr>
<td></td>
<td>Teacher assessment</td>
<td>5/5</td>
<td>4/5</td>
<td>5/5</td>
</tr>
<tr>
<td></td>
<td>Teacher expectations</td>
<td>3/5</td>
<td>2/5</td>
<td>4/5</td>
</tr>
</tbody>
</table>

Table 22

<table>
<thead>
<tr>
<th>Cover Term</th>
<th>Included Terms</th>
<th>Patients</th>
<th>Caregivers</th>
<th>Educators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implications</td>
<td>Academic performance: short-term</td>
<td>4/5</td>
<td>4/5</td>
<td>2/5</td>
</tr>
<tr>
<td></td>
<td>Academic performance: long-term</td>
<td>5/5</td>
<td>5/5</td>
<td>4/5(^a)</td>
</tr>
<tr>
<td></td>
<td>Cognition: short-term</td>
<td>4/5</td>
<td>4/5</td>
<td>4/5</td>
</tr>
<tr>
<td></td>
<td>Cognition: long-term</td>
<td>5/5</td>
<td>5/5</td>
<td>4/5(^a)</td>
</tr>
<tr>
<td></td>
<td>Peer relationships: short-term</td>
<td>3/5</td>
<td>3/5</td>
<td>2/5</td>
</tr>
<tr>
<td></td>
<td>Peer relationships: long-term</td>
<td>4/5(^a)</td>
<td>5/5</td>
<td>4/5(^a)</td>
</tr>
</tbody>
</table>

\(^a\) One participant in this category explicitly described feeling unsure about how to respond to this question.
Table 23

<table>
<thead>
<tr>
<th>Cover Term</th>
<th>Included Terms</th>
<th>Patients</th>
<th>Caregivers</th>
<th>Educators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implications</td>
<td>Academic performance: short-term</td>
<td>1/5</td>
<td>1/5</td>
<td>3/5</td>
</tr>
<tr>
<td></td>
<td>Academic performance: long-term</td>
<td>0/5</td>
<td>0/5</td>
<td>0/5^a</td>
</tr>
<tr>
<td></td>
<td>Cognition: short-term</td>
<td>1/5</td>
<td>1/5</td>
<td>1/5</td>
</tr>
<tr>
<td></td>
<td>Cognition: long-term</td>
<td>0/5</td>
<td>0/5</td>
<td>0/5^a</td>
</tr>
<tr>
<td></td>
<td>Peer relationships: short-term</td>
<td>2/5</td>
<td>2/5</td>
<td>3/5</td>
</tr>
<tr>
<td></td>
<td>Peer relationships: long-term</td>
<td>0/5^a</td>
<td>0/5</td>
<td>0/5^a</td>
</tr>
</tbody>
</table>

^a One participant in this category explicitly described feeling unsure about how to respond to this question.

**Limitations**

While we anticipate a diverse pool of participants relative to age, gender, diagnosis, state of residence and socio-economic level, the sample is incomplete (as recruitment is ongoing) and therefore does not represent the diversity we expect to represent. Furthermore, all participants will receive support from a coordinator in the School Intervention Program. The opportunity to expand this research to multiple centers across the country exists, however the variability in the way other centers provide, or do not provide, school support will create an interesting dynamic as we examine future results.

The educators included in this analysis range in experience and their relationship with patient participants vary, however all educators included in this analysis are from the state of Ohio. Educators recruited for inclusion in the study will eventually represent a more diverse group of professionals as they will be from at least three different states representing a wide range of school districts. Another limitation regarding this group of participants is the way in which they are selected to be approached for recruitment. The patient and caregiver nominate (suggest) the order in which we approach the patient’s educators. While some participants may naturally nominate a homeroom teacher, others will nominate a teacher they have known for an
extended period of time or perhaps a favorite teacher. Within the pilot study and to date in the longitudinal study, a tendency to suggest cooperative educators that will likely comply with research participation seems to be the educators that patients and families initially nominate. While this is generally helpful in recruiting willing participants, we feel as though it may influence our results. The potential for fewer concerns to be reported by cooperative educators is a possibility as cooperative teachers may be less likely to view supporting patients as burdensome and less cooperative teachers could be less likely to support the patients in the school setting and thus have more concerns. We explored multiple ways to overcome this limitation, however given the wide age range of participants (some patients will have a homeroom teacher while others will not, some patients will have two teachers while others will have eight teachers) included in the study; we were not able to identify a seamless method to avert this limitation. Fortunately, we have the flexibility to approach multiple educators in the event the initial educator we approach is unable or unwilling to participate. Also, having three different educators tied to each patient will naturally provide variability.

**Discussion**

All of the participants articulated their belief that the patient participants (including the patients themselves) would not experience any (or very little) negative short or long-term outcomes despite having cancer. This sentiment is evident in the following caregiver’s (P17-2) statement (this was in response to the question asking if the caregiver thought the child would experience any short-term educational effects as a result of diagnosis):

…education wise, she’s, she’s still doing well in the areas she did well in before and she’s still struggling in the areas that she was struggling in before so, nothing there that I can see right now, um, is telling me that anything has really changed.
We haven’t received any information from school saying something got way worse. Um, so everything seems to be kind of on the same pace.

Yet thread throughout participants’ responses is a recurrent acknowledgement that the patient participants are: (1) behind in their school work and lessons; (2) missing instruction, assignments, and assessments; (3) missing opportunities for peer interaction; (4) experiencing changes in social relationships; (5) experiencing changes in environment and procedures; (6) experiencing changes in cognition and behavior; and (7) requiring and receiving more help than is typical from peers, caregivers and educators. An example of the dichotomy in participants’ own responses is illustrated below as the same caregiver (P17-2) that provided the quote listed above also stated the following:

“Well the homework time, has gotten longer. It takes her longer to get through her homework. Yes, definitely.”

“I don’t think we were getting all the information we needed from school, …[parent requested accommodation from school due to] inconsistent information we’d get from her [caregiver’s daughter], on, when things were due, and when certain tests were going to happen and things like that.”

While an incomplete dataset and only having a portion of a longitudinal study complete makes it difficult to draw concrete conclusions, a plausible explanation for this contradiction in the data may be relative perceptions; meaning that participants are rationalizing that the changes in routine and the missed educational and social opportunities are irrelevant compared to receiving treatment for cancer. Subconsciously
participants could be thinking that having and receiving treatment for cancer undermines the need for an equal educational experience compared to peers without a chronic illness. The following quotations allude to this possibility:

(Patient P24-1) In response to questioning asking if patient was worried about their own learning due to missing school, “Uh, no! Cause I’m going on to first grade and that means I don’t have to go to kindergarten.”

(Educator P22-3) He’ll [patient] be fine in fourth grade, so I would promote ‘em anyway. Um, again, he’s missing most of this trimester [third trimester], so I’m not really sure. But like I said, he was here for may- (pause) three-fourths if not a little bit more of the second trimester, so I already had, every day grades like I would normally have.

(Educator P17-3) As far as writing, I’m allowing her [patient] to do a lot shorter of writing pieces then I would have expected in the past…No I’m not overly concerned at this point, and, I mean, that’s partly just based on, I don’t wanna worry myself or worry her or her parents, if I don’t really have a background for any sort of basis about what, she might be facing.

It is also possible that the experience of either undergoing treatment or caring for a child or student receiving treatment is overwhelming, thus acknowledging a potential set back becomes unbearable. One caregiver (P24-2) shares “if he [caregiver’s son] was, you know able
to go to school right now, he would be at the same spot as before the tumor, so.” In a similar vein, one educator (P24-3) states:

I hope what I’m feeling and thinking is correct, and um, and I just, I have strong feelings for [patient] and everything, you know, that he’s [patient] gone through and, um, he just, like I said, he’s very intelligent kid, so I just see that staying with him and, ya know, and coming back if he’s lost a little bit of it, I think it will, it will come back.

Difficulty recognizing obstacles could especially be true of participants in this initial phase given the diagnosis is relatively new to participants at this stage. While a summation from a complete dataset is forthcoming, enough evidence presently exists to warrant the addition of several questions to the interview script for the third and final phase. To fully appreciate the trend that is emerging in this phase one data, we will add questions to the final interview to better understand the phenomenon captured in this initial time point. Examples of additional questions may include:

(1) During the first interview, you shared that you were you not concerned that (patient name) was missing classroom instruction. Why weren’t you concerned at that time?

(2) Are you concerned about the previously missed instruction now?

Perhaps this data represents healthy perspectives; that is, battling and beating cancer is more important than memorizing multiplication facts, for example. If this is the case, it still seems important to acknowledge the vulnerabilities for patients by understanding the consequences of experiencing such dramatic changes in routine and missing a substantial number of educational and social opportunities. To accept the data
at face value thereby agreeing that patients diagnosed with cancer who miss significant educational and social opportunities and who experience significant changes to their routine are not at risk for experiencing negative educational and social outcomes seems irresponsible. If missing a considerable amount of instruction and assignments coupled with altered expectations, assessments, and social interactions does not have a negative impact on our students with chronic illnesses, then what is the rationale to support the requirements for children without chronic medical conditions to attend school five days a week (for approximately 180 days) and to master grade level standards according to state approved assessment tools?

   Cancer is a diagnosis that generally evokes empathy from most people. Educators’ sympathy can unintentionally become a barrier to achievement and/or equal opportunity for students with chronic illnesses. This possibility is captured in the following educator (P17-3) statement, “we kind of feel guilty about trying to have her make it all up.” Henning and Fritz (1983) report, “pity pushed others [teachers] unhelpfully in the opposite direction, so that they made no demands or tolerated extreme behavior without setting limits” (p. 263). Empathy harnessed appropriately as school support can clearly be helpful as noted by our data (one of the critical components in the universal theme and also represented as table legs in the “Stable Table”). According to the participants in this study, extra support reduces the risk for negative outcomes. I would argue that this support is essential, especially considering that participants do not believe patients face great academic and social risk in the face of a cancer diagnosis.

   **Implications**

   The primary purpose of this research is to identify the perceived educational issues according to patients with a chronic illness, their caregivers, and their educators, and to use the perceptions of these stakeholders to appropriately align the services provided to the recipients of
the services with their perceived educational needs. Kliebenstein and Broome (2000) intended for the results of their study, in which 21 parents (whose children diagnosed were with a variety of chronic conditions) were interviewed and 24 questionnaires were completed by school personnel, to be used in a similar way:

The identification of recurrent themes for parents and school personnel in this study provides an opportunity to define a process for assessing needs of both groups [parents and teachers] and to design and implement interventions to ensure a positive school reentry process for all involved. (p. 582).

Interestingly, Kliebenstein and Broome discuss the importance of embracing the themes identified in their study, such as the importance of collaboration and investing all parties in the child’s education and illness care to plan for a successful school reentry, yet they never suggest identifying the perceptions of the actual students.

As previously mentioned, this study is novel in its aim to link the beliefs of all stakeholders inclusive of the patients themselves. At the conclusion of this longitudinal study, we expect to identify themes to assist in the development of processes for assessing needs as Kliebenstein and Broome suggest is possible given their results from a similar study design. The unique dimensions we include (capturing beliefs at multiple time points and including the patients’ perceptions) will complete the picture for all stakeholders.

As I ponder the findings that emerged in this analysis, I can’t help but think of the students battling diseases misunderstood or unrecognized by the general public. Those with debilitating diagnoses less common than cancer must struggle even more than those with well recognized diseases. The contradictory evidence in this study speaks to the lack
of attention given to social and educational outcomes and the lack of preparedness for the educational and social obstacles those individuals with cancer will likely experience in their journey toward healing and survivorship. Students with less recognizable diagnoses are at greater risk than students with cancer in my opinion, especially given our new appreciation for the perception that students with chronic illnesses require extra support to achieve positive outcomes.

Anthony, Gil and Schanberg (2003) surveyed 69 child-parent dyads (children were diagnosed with a rheumatic or pulmonary disease) to determine the degree to which parental perceptions predict school and social adjustment in children with chronic medical conditions. Their results validate the notion that professionals must understand the perceptions of stakeholders to efficiently target interventions. Illuminating the perceptions of patients, caregivers, and educators associated with various illnesses seems critical to understand the ways in which adults can positively influence educational and social outcomes for students with chronic illnesses. To design and employ effective interventions, existing perceptions within the population needing support must be identified. Results from this study will guide professionals in establishing much needed standards of practice in the field of education for those working with students with chronic medical conditions.
References


Harris, J., Pryor, J., & Adams, S. (N.d.). The challenge of intercoder agreement in qualitative inquiry. *Unpublished manuscript, University of Texas at Austin.*


NVivo qualitative data analysis software; QSR International Pty Ltd. Version 10, 2012.


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.*

---

§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).
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
Mary.Kay.Irwin@cchmc.org

Megan Elam, Co-Investigator
(513) 803-3272
Megan.Elam1@cchmc.org

RECEIVED
MAY 06 2011
INSTITUTIONAL REVIEW BOARD
University of Cincinnati
## Appendix B: Recruitment Materials

### Criteria Eligibility Form

<table>
<thead>
<tr>
<th>Study Identification Number:</th>
<th>Answer:</th>
<th>Researcher’s Initials:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient’s Initials:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| 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 histological 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

<table>
<thead>
<tr>
<th>Recruiting and Data Collection Checklist</th>
<th>Researcher’s Initials/Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Complete the Criteria Eligibility Checklist (Including obtaining attending physician’s signature)</td>
<td></td>
</tr>
</tbody>
</table>
| 2. Determine if participants will be asked to complete interview using interview eligibility form  
  a. Please 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 | |
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
</table>
| 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 C: Consent Forms

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
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
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
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 what 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

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Appendix D: Interview Materials

Interview Script

Patient Interview Protocol:

In the beginning of the recording, the interviewer will state the following:

- Patient’s name
- Interviewer’s name
- Date and time of interview
- Study phase

I am going to ask you about your daily routine. As we go through these questions, think about how your daily routine has changed now that you have/had (diagnosis).

1. Describe the details of your routine:
   
   1A. During waking up time
   
   1B. During breakfast
   
   1C. As you get ready for the day (i.e., getting dressed, brushing teeth, etc.)

2. Do you attend school at this time?  
(If this patient attends school most of the time, use questions in set A; if this patient does not attend school, use questions in set B; if this patient attends school intermittently, use questions in set A AND B. For patients that answer both sets of questions, make it clear that when they answer Set A questions, they should do so for the days they spend in school. For the Set B questions, remind them to answer these questions according to the days they spend at home/hospital.

Questions Set A:  
Remember, as we go through these questions, think about how your daily routine has changed now that you have/had (diagnosis).

   2A. How do you get to school?  
      - Describe the (ride, walk, drive)

   2B. What is the first thing you do when you arrive at school?

   2C. What do you do before lunch?

   2D. Tell me how your teacher(s) work(s) with you in the morning.  
      - Do you think the time you spend with your teacher(s) is different because you have/had (diagnosis)?

   2E. Do you spend time with or talk with friends and classmates in the morning?
If they answer yes, ask – Describe the time you spend with friends or classmates.
If they answer no, ask - Why not?
Do you think the things you talk about with your friends or classmates are different because you have/had (diagnosis)?
Do you think the way your friends or classmates act around you is different because you have/had (diagnosis)?

2F. Where do you eat lunch?
- Who do you eat with?
- Do you think the things you talk about at lunch are different because you have/had (diagnosis)?

2G. What do you do after lunch?

2H. Tell me how your teacher(s) work(s) with you in the afternoon.
- Do you think the time you spend with your teacher(s) is different because you have/had (diagnosis)?

2I. Do you spend time with or talk with friends and classmates in the afternoon?
- If they answer yes, ask – Describe the time you spend with friends or classmates.
- If they answer no, ask - Why not?
- Do you think the things you talk about with your friends or classmates are different because you have/had (diagnosis)?
- Do you think the way your friends or classmates act around you is different because you have/had (diagnosis)?

2J. How do you prepare to go home for the day?

2K. How do you get home from school?
- Describe the (ride, walk, drive)

Questions Set B:

2L. How do you spend your morning?

2M. Describe lunchtime.

2N. How do you spend your afternoon?

2O. Do you work on school work during the day?
- If yes, does anyone help you? Who?

2P. Do you have any contact with your teacher(s)?

2Q. Do you talk with your friends during the day?

3. Where do you spend your late afternoons?
4. What do you do before dinner?

5. Do you have homework?
   • If yes, how long does it take you to do your homework?
   • Do you have the same amount of homework as your classmates?
   • Do you get help with your homework? If so, who helps you?

6. What do you do for dinner?

7. How do you spend your evenings?

8. Describe bedtime.

9. Do you think your experience with (diagnosis) has affected your friendships? Do you think your experience with (diagnosis) will affect your future friendships?

10. Do you think your experience with (diagnosis) has affected your education (school)? Do you think your experience with (diagnosis) will affect your education (school) in the future?

11. Is there anything else that you would like for me to know?

**Caregiver Interview Protocol:**

In the beginning of the recording, the interviewer will state the following:

- Caregiver’s name and relationship to (name of patient)
- Interviewer’s name
- Date and time of interview
- Study phase

I am going to ask you about (name of patient)’s daily routine. As we go through these questions, think about how his/her daily routine has changed now that he/she has/had (diagnosis).

1. Describe the details of (name of patient)’s routine:
   
   1A. During waking up time
   
   1B. During breakfast
   
   1C. As he/she gets ready for the day (i.e., getting dressed, brushing teeth, etc.)

2. Does (name of patient) attend school at this time?  
   
   (If the patient attends school most of the time, use questions in set A; if the patient does not attend school, use questions in set B; if the patient attends school intermittently, use questions in set A **AND** B. For caregivers that answer both sets of questions, make it clear that when they answer Set A questions, they should do so for the days their child spends in school. For the Set B questions, remind them to answer these questions according to the days their child spends at home/hospital.)
Questions Set A:
Remember, as we go through these questions, think about how (name of patient)'s daily routine has changed now that he/she has/had (diagnosis).

2A. How does (name of patient) get to school?
   • If you take him/her to school, describe the ride.

2B. How does (name of patient) get home from school?
   • If you pick him/her up from school, describe the ride.

2C. Do you talk with (name of patient) about the school day?
   • What does (name of patient) mention about his/her interactions with teachers?
   • What does (name of patient) mention about his/her social interactions?
   • What does (name of patient) mention about school work?

Questions Set B:

2D. How does (name of patient) spend his/her morning?

2E. Describe lunchtime.

2F. How does (name of patient) spend his/her afternoon?

2G. Does (name of patient) work on school work during the day?
   • If yes, does anyone help him/her? Who?

2H. Does (name of patient) have any contact with his/her teacher(s)?

2I. Does (name of patient) talk with his/her friends during the day?

3. Where does (name of patient) spend his/her late afternoons?

4. What does (name of patient) do before dinner?

5. Does (name of patient) have homework?
   • If yes, how long does it take (name of patient) to do his/her homework?
   • Does (name of patient) have the same amount of homework as his/her classmates?
   • Does (name of patient) get help with his/her homework? If so, who helps him/her?

6. What does (name of patient) do for dinner?

7. How does (name of patient) spend his/her evenings?

8. Describe bedtime.

9. Do you think (name of patient)'s experience with (diagnosis) has affected his/her friendships? Do you think his/her experience with (diagnosis) will affect his/her future friendships?
10. Do you think (name of patient)’s experience with (diagnosis) has affected his/her education? Do you think his/her experience with (diagnosis) will affect his/her education in the future?

11. Is there anything else that you would like for me to know?

Educator Interview Protocol:

In the beginning of the recording, the interviewer will state the following:

- Educator’s name and relationship to (name of patient)
- Interviewer’s name
- Date and time of interview
- Study phase

I am going to ask you about (name of patient)’s daily routine. As we go through these questions, think about how his/her daily routine has changed now that he/she has/had (diagnosis).

1. Does (name of patient) attend school at this time? (If the patient attends school most of the time, use questions in set A; if the patient does not attend school, use questions in set B; if the patient attends school intermittently, use questions in set A AND B. For educators that answer both sets of questions, make it clear that when they answer Set A questions, they should do so for the days the student spends in school. For the Set B questions, remind them to answer these questions according to the days the student spends at home/hospital.

Questions Set A:
Remember, as we go through these questions, think about how (name of patient)’s daily routine has changed now that he/she has/had (diagnosis).

1A. What is the first thing (name of patient) does when he/she arrives at school?

1B. What does (name of patient) do before lunch?

1C. Tell me how you work with (name of patient) in the morning.
   - Do you think the time you spend with (name of patient) in the morning is different because he/she has/had (diagnosis)?

1D. Does (name of patient) spend time with or talk with friends and classmates in the morning?
   - If they answer yes, ask – Describe your observations of (name of patient) spending time with friends or classmates in the morning.
   - If they answer no, ask - Why not?
   - Do you think the way (name of patient)’s friends or classmates interact with him/her is different because he/she has/had (diagnosis)?

1E. Where does (name of patient) eat lunch?
   - Who does (name of patient) eat with?
   - Do you think (name of patient)’s lunch experience is different because he/she has/had (diagnosis)?
1F. What does (name of patient) do after lunch?

1G. Tell me how you work with (name of patient) in the afternoon.
   • Do you think the time you spend with (name of patient) in the afternoon is different because he/she has/had (diagnosis)?

1H. Does (name of patient) spend time with or talk with friends and classmates in the afternoon?
   • If they answer yes, ask – Describe the time you observe (name of patient) spending with friends or classmates in the afternoon.
   • If they answer no, ask - Why not?
   • Do you think the way (name of patient)’s friends or classmates interact with him/her is different because he/she has/had (diagnosis)?

1I. How does (name of patient) prepare to go home for the day?

Questions Set B:

1J. How do you prepare school work for (name of patient) when she is not able to attend school?

1K. To your knowledge, does (name of patient) work on school work during the day?
   • If yes, does anyone help him/her? Who?

1L. Do you have any contact with (name of patient) throughout the day?
   • If yes, in what way do you have contact with (name of patient)?
   • If no, how often do you have contact with (name of patient) and in what way?

1M. To your knowledge, does (name of patient) have contact with his/her friends during the day?

1N. Does (name of patient) have the same amount of homework as his/her classmates?

2. Do you assess (name of patient) in the same way that you assess your other students and why or why not?

3. Do you assign (name of patient) grades in the same way that you assign grades to your other students and why or why not?

4. Do you think (name of patient)’s experience with (diagnosis) has affected his/her friendships? Do you think his/her experience with (diagnosis) will affect his/her future friendships?

5. Do you think (name of patient) experience with (diagnosis) has affected his/her education? Do you think his/her experience with (diagnosis) will affect his/her education in the future?

6. Is there anything else that you would like for me to know?
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<th>If this happens...</th>
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<tr>
<td><strong>Title</strong></td>
<td>Each interview will have the following information titled at the top of the document: Interviewer name, interviewee ID number, date of interview, and location of interview</td>
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<td><strong>Spacing</strong></td>
<td>Each line of typing will be single spaced with an extra space after each title, question title, and at the end of researcher and interviewee text.</td>
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<td><strong>Use of patient’s name within interview</strong></td>
<td>During initial transcription, transcribers use patient’s first initial. Prior to saving the document, transcribers use the “find all”/“replace” function and change initial to be patient’s abbreviated participation number (ex. P01-1; P01 is participant number, 1 is role in the triad; 1= patient, 2= caregiver, 3=educator)</td>
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<td><strong>Use of other participant’s name within the interview</strong></td>
<td>Use participant ID number</td>
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<tr>
<td><strong>Use of name of nonparticipant</strong></td>
<td>Interviewer will ask to clarify who the person is that the interviewee is discussing, transcribing will take place using the nonparticipant’s initials</td>
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<tr>
<td><strong>How to save</strong></td>
<td>Transcribers save the document four times 1-Original transcription 2-Cross transcription done in track changes 3-Final with track changes accepted by original transcriber 4-Final transcription saved in NVivo</td>
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<td><strong>Punctuation</strong></td>
<td>Punctuation will be used when obviously needed for ending, pauses, and questions.</td>
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<td><strong>If something is inaudible</strong></td>
<td>Transcribers will rewind and replay 3 times, after third attempt, if audio remains inaudible, the phrase “Inaudible” will be typed</td>
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<td><strong>Any identifiable information</strong></td>
<td>Remove from transcription</td>
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<td><strong>If interviewer is providing affirming “uh huhs”, “yeahs” without adding content to the discussion</strong></td>
<td>Affirmations will not be included in transcription</td>
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<td><strong>Text Styling</strong></td>
<td>The following styles will be used in the transcription: Title=List Paragraph Question title= Heading 1 Researcher title= Heading 2 Interviewee title= Heading 3 Researcher text= Subtitle Interviewee text= Normal In addition line numbers will be used in Word but removed in NVivo</td>
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<td><strong>Emotionality</strong></td>
<td>Transcriptionist will indicate noteworthy emotion in parenthesis following statement (for example: participant said last statement in a sarcastic tone, participant emphasized previous statement by raising voice, participant cried throughout the interview and/or following previous statement, also include similar phrases for laughter inflection, etc.) Interviewer should take notes during interview to document noteworthy emotion</td>
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Appendix E: Miscellaneous Materials

*Perceptions Participant Folder Check-Out*

Instructions:

- Blue research folders should not leave the SIP office
- Each time a blue research folder is removed from the locked file cabinet it must be signed out/in below
- Immediately following the consent of a new participant a new blue research folder must be made and put in the locked file cabinet

<table>
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<tr>
<th>Date</th>
<th>Participant ID</th>
<th>Item Removed (ie. Entire folder, adult consent form, etc)</th>
<th>Time Out</th>
<th>Researcher Initials</th>
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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)
**School Data Records Collection Table**

<table>
<thead>
<tr>
<th></th>
<th>Previous School Year (2010-2011)</th>
<th>Current School Year (2011-2012)</th>
</tr>
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<tr>
<td><strong>Absences</strong></td>
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<tr>
<td><strong>GPA</strong></td>
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<tr>
<td><strong>Standardized Tests</strong></td>
<td>Name of Standardized Test:</td>
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