

STARS

University of Central Florida
STARS

Honors Undergraduate Theses

UCF Theses and Dissertations

2017

Exploring the Experiences of Learning Mathematics for a Child with Cancer: A Case Study

Elizabeth M. Bello
University of Central Florida

 Part of the [Education Commons](#)

Find similar works at: <https://stars.library.ucf.edu/honorsthesis>

University of Central Florida Libraries <http://library.ucf.edu>

This Open Access is brought to you for free and open access by the UCF Theses and Dissertations at STARS. It has been accepted for inclusion in Honors Undergraduate Theses by an authorized administrator of STARS. For more information, please contact STARS@ucf.edu.

Recommended Citation

Bello, Elizabeth M., "Exploring the Experiences of Learning Mathematics for a Child with Cancer: A Case Study" (2017). *Honors Undergraduate Theses*. 250.

<https://stars.library.ucf.edu/honorsthesis/250>



EXPLORING THE EXPERIENCES OF LEARNING
MATHEMATICS FOR A CHILD WITH CANCER: A CASE
STUDY

By

ELIZABETH BELLO

A thesis submitted in partial fulfillment of the requirements for
the Honors in the Major Program in Elementary Education in the
College of Education and Human Performance and in The
Burnett Honors College
at the University of Central Florida Orlando,
Florida

Fall Term 2017

Thesis Chair: Dr. Megan Nickels

ABSTRACT

In this research report, I utilize interpretative phenomenological analysis (Smith, Flowers, & Larkin, 2009) to examine the mathematics education experiences of a child with cancer. Two qualitative interviews with a 13-year-old male patient with Hodgkin's Lymphoma and his mother were analyzed. Findings revealed several storylines or themes: living with cancer, environmental barriers, and mathematics in virtual school. Grade level mathematics, content knowledge, and delivery during treatment in comparison to the child's healthy peers are also discussed.

DEDICATION

To all children with cancer, may they fight strong.

ACKNOWLEDGMENTS

I would like to express my deepest gratitude to all those who made my thesis possible. Thank you to my parents for their constant support and love. Thank you to Dr. Bush and Dr. Roberts for serving on my committee. A special thank you to Dr. Megan Nickels for supporting me all the way through as my undergraduate thesis advisor and mentor.

TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION	1
CHAPTER TWO: LITERATURE REVIEW	3
Academic Outcomes During and After Treatment for Children with Cancer	3
Cancer Patients and Schooling.....	4
Parental Involvement.....	9
Mathematics Education of Children with Cancer	9
CHAPTER THREE: METHODOLOGY	15
Interpretative Phenomenological Analysis.....	16
Methods of Data Collection	17
Participants	17
Data Analysis	18
Open Coding	19
Axial coding	20
Axial coding	20
CHAPTER FOUR: RESULTS AND ANALYSIS	21
Virtual School	25

CHAPTER FIVE: DISCUSSION 35

 Conclusion and Recommendations 37

 Recommendations for Teaching Children with Cancer 39

APPENDIX A: INTERVIEW QUESTIONNAIRES 42

 Interview Questionnaire 43

APPENDIX B: INSITUTIONAL REVIEW BOARD CONSENT 45

REFERENCES 47

LIST OF TABLES

Table 1: Interpretive Phenomenological Analysis Coding Stages	19
---	----

CHAPTER ONE: INTRODUCTION

Childhood cancer is more common than many believe. 1 in every 285 children are diagnosed with cancer according to the American Cancer Society (2014). With medical treatments advancing, there is a five-year survival rate for approximately 80% of children diagnosed in the United States (American Cancer Society, 2014). Treatment for childhood cancer, including toxic multidrug chemotherapy, radiation therapy and surgery, is severe and sustained, with an average length of three years (Hoffman, 2012). The average age for a child to be diagnosed is 6; corresponding with the age at which many children enter school. Cancer changes a child's world. To them, school represents normalcy and that is quickly taken from them. The chemotherapy that is required for cancer treatment results in many late effects that may impair a child's cognitive abilities. Treatments for cancer (e.g., chemotherapy, radiation) can affect their non-verbal learning, visual-motor performance, mathematical skills, memory and cause other delays and impairments in the child's development (Brown, 1998; Kirkpatrick, 2015; Nickels & Cullen 2017). All facets of a child's life, including school, changes forever (Hoffman, 2012).

Considering the length and severity of treatment of pediatric cancer, access to equitable schooling is undoubtedly an issue. If these children are busy completing their treatments, then it becomes difficult to impossible to attend school regularly and remain on track with their schoolwork. Research is needed to address these concerns. Nickels and Cullen (2017) state, "to date, both the number and diversity of articles on educating children with critical illness ... are insufficient to provide scientific background for strong evidence based interventions for children affected by critical illness" (p. 26).

My purpose in undertaking this research was to learn about the mathematics education experiences of a single child with cancer in order to investigate the mathematics education he received during his cancer treatment. This case study can stand to provide informal comparisons to their healthy peers in the hopes of contributing to a body of literature that will provide evidence-based practices for teaching mathematics to pediatric cancer patients. Specifically, I sought to learn how mathematics had been taught to a 13-year-old male student with Hodgkin's lymphoma both in hospital and home settings since the time of his diagnosis.

I believe that the mathematics education of children with cancer is an issue that needs immediate attention because education is a human right that extends to each and every child regardless of physiological, socio-emotional, or cognitive factors, including that of being diagnosed with a critical illness. Thus, my objective in this study was to explore one pediatric cancer patient's experiences of mathematics education and the perception of the factors that influenced the development and attainment of their mathematical thinking and learning. Parental perception was also regarded as valuable; therefore, interviews with the patient's parents were also considered.

While chapter two provides a review of related research literature, chapter three offers a review of the methods I used to conduct the interviews between the child and his mother and how it was analyzed. Chapter four provides the results from the interviews. This section is broken down with his first and second diagnosis and how he was receiving education during these time periods. Last, chapter five includes my discussion on the results of the interviews. This section is broken down into three storylines that emerged: Living with cancer, Environment, and Mathematics in Virtual School.

CHAPTER TWO: LITERATURE REVIEW

In the following section, I investigate the literature concerning education and children with cancer. To begin to describe the educational circumstances surrounding children with cancer, I first discuss the known cognitive and academic outcomes resulting from disease and treatment. Next, I discuss policy and services available to children with cancer. Here I include information on relevant case studies (although not cancer-specific). Finally, I describe what is known about the teaching and learning of mathematics for children with cancer in order to situate my study.

Academic Outcomes During and After Treatment for Children with Cancer

Childhood cancer and subsequent treatment affects a child's cognitive abilities (Kirkpatrick, 2015). Treatments for cancer (e.g., chemotherapy, radiation) can affect their non-verbal learning, visual-motor performance, mathematical skills, memory and cause other delays and impairments in the child's development (Brown, 1998; Kirkpatrick, 2015; & Nickels & Cullen 2017b). Children who are diagnosed with cancer and receive treatment at a younger age have a higher risk of presenting with underdeveloped areas of the brain and greater cognitive defects, which consequently affects their higher order thinking skills (Kirkpatrick, 2015 & Moore, 2005). Chemotherapy affects the areas of the brain that have been developed after treatment, but not the areas that are developed before treatment. These findings show that a younger age at the time of diagnoses and treatment is related to more negative cognitive effects (Brown, 1998; Kirkpatrick, 2015; Moore 2005).

Mitby, et al (2003) conducted a study using 12,430 cancer survivors, comparing them to their siblings to analyze the utilization of special education services. Children who had been

diagnosed with acute lymphoblastic leukemia (ALL) before they turned five years old quadrupled their chances to be enrolled in special education services. However, findings also indicated students with a cancer history graduate high school at the same rate that children without a cancer history do. This successful graduation rate is likely to do with the fact that they were able to receive the special education assistance they needed to help with their cognitive delays from their treatment (Kirkpatrick, 2015). The rate of special education services for a child with cancer history can be linked to the dose of chemotherapy the child receives. Research shows that with higher doses of chemotherapy, there is an increased chance for the child to be placed in special education services (Jacola, 2016).

Missing multiple days of school, on top of the medical disadvantages a cancer patient has, makes school more challenging. A striking study found that 51% of childhood cancer patients reported school being difficult as compared to only 14% of their healthy peers. While children with childhood cancer are generally eager to return to school, 31% of students in the study inevitably dropped out. There are many reasons for this to occur, but one reason is the school's attendance policy. The schools in the study did not modify the policy or excuse the absences for the cancer patients, causing them to have to repeat the entire school year (Yi, 2016).

Cancer Patients and Schooling

When a child is diagnosed with a chronic illness, like cancer, the first thought is to get the child better. The health of the child should be a priority of course, but so should schooling. Bessell (2001) argues, "successful school experiences are a strong factor in providing a child with a feeling of normalcy" (p. 346). The child needs a distraction from their now physically and mentally isolated and constricted life, and school is both a necessary and good distraction. When

children are diagnosed with cancer, generally a first thought is, “I want to go back to school,” but more often than not their health is the only facet given priority. (Nickels & Cullen, 2017).

Additionally, parents may not know what rights their newly diagnosed child has in regards to education. Several federal programs exist that may serve children with cancer, including the Individuals with Disabilities Education Act of 2004 and Section 504 of the Rehabilitation Act of 1973. Irwin and Elam (2011) stress that, “while federal legislation guarantees children with disabilities a free and appropriate public education (e.g., Individuals with Disabilities Education Act of 2004), children with chronic illness do not immediately fit into any pre-established programs in schools” (p. 68). Indeed, many barriers often prevent children with cancer from receiving services in a timely manner, if receiving them at all. First, many parents and caregivers believe that it is the responsibility of the school the child attended before diagnosis to reach out to the families to keep them on task with their education. It is, however, the responsibility of the parent(s) to communicate the child’s diagnosis and treatment plan to the school and to request evaluation for services. Schools are not mandated to comply with the request for evaluation, and it is important to note that despite known cognitive and academic outcomes resulting from disease, treatment, and prolonged absenteeism, “time away from school due to cancer treatment does not qualify [a] child as having a special disability requiring special education, according to IDEA classification guidelines” (Hoffman, 2000, para 3). Consequently, many children with cancer will fail to qualify, at least initially, for services under IDEA or Section 504. Parents either are often told no services are available for their child, or they cease trying to receive services for their child because the associated paperwork is too long and burdensome for them to handle (Bessell, 2001). Further, the remaining version of No

Child Left Behind Act (2002), which is in place to help disadvantaged students, does not explicitly refer to students with cancer. Ultimately, this means that schools are often not required to help children with cancer with any specific programs because the law does not mandate them. It is difficult to imagine that a family enduring extensive medical and financial hardship must also combat the education system for their child (Bessell, 2001). Despite the limitations of federal programs for children with cancer, there are many well-intentioned teachers who try and help children with critical illness, inclusive of cancer; however, they are just not equipped to do so.

Akin-Little, Little, Lobst and Nabors (2008) conducted a study of 247 teachers answering survey questions about their preparedness to teach and interact with students that had critical illnesses. A minority of the teachers, 17.5%, reported being well informed about the medical conditions being addressed in the survey, and only 32% of the teachers indicated being confident in meeting the academic needs of children with cancer. A teacher must be informed of a student's academic deficits in order to be able to address the needs the student might have when they return to their classroom. It is important to keep teachers informed about this population of children especially if they are going to have a child with a critical illness in their classroom.

Having teachers that are supportive and helpful can change the whole perspective of school for a cancer patient returning to school. A cancer survivor reported a positive experience in which his teacher had the class welcome him back with applause after completing a round of chemotherapy. Another survivor stated that the encouraging words from her teacher allowed her to victoriously finish her academics. Having a strong support system is key in allowing the child to have a smooth transition back to the classroom (Yi, 2016).

Larcombe et al. (1990) studied the experience of 51 children with cancer returning to school. When considering the results, they found that there are many problems when students return to school. These problems started in the child's absence. Many mothers reported not having access to their child's work from the school as well as a lack of home tutors. When the children returned to school they found it hard to keep up with certain subjects since they often missed the same day every week to attend clinic appointments. It was reported that 51% of the students were worried about falling behind. Additionally, 65% of the students reported tiredness as a physical problem returning to school. Children with cancer worried about being teased about their hair loss when they returned back to school. There was a big behavioral difference between children with cancer and the children in the other categories. There was a high number of children with cancer who showed negative behavior such as aggression and tantrums. Teachers reported that the health service should play a more active role in communicating with the school. Only 13% of teachers of the children with cancer had been notified that the child was returning back to school before they returned. The teacher also reported they needed more medical information to help them deal with the student when they return.

Tseng and Pluta (2015) conducted a case study about a critically ill student who would never be able to go to school because she always needed to be in a sterile environment. Her school would not work with her to develop an Individual Education Plan (IEP); instead requiring her to come to the school to take the tests, which could compromise her health. Her parents wanted her to have an education, and decided to bring her to school in order to get tested, against medical advice. According to state laws where the student resides, she should be receiving a minimum of six hours per week for instruction, in comparison to her healthy peers who receive

six hours per day. The amount she actually received was three hours of instruction, and there was a gap of three weeks between her being designated to receive this and its first occurrence. When the instructor was finally sent for her hospital homebound instruction, the quality of said instruction was not equitable to that of her peers. The first time the instructor was to meet with the student, the student was waiting at the table for two hours, but the instructor did not arrive. After this, the instructor never provided her with an equitable education. She arrived late and did not make up the time for her tardiness and never brought the student's materials, stating the school never provided them to her. The instructor would arrive to their session, leave her two children in the car and constantly go check on them, interrupting the student's instruction time. After these incidents, the family requested a change of instructor for their child. After twelve days, the district located a replacement instructor. The new instructor behaved in the same manner as the first, arriving late and unprepared to sessions. After an hour of teaching the student, the instructor said she would not be returning due to a severe allergies caused by the family cats. Several weeks later they were given another tutor, who was suffered from the same allergies, even though the family had informed the Hospital Homebound program that they had cats.

The student's experience with the lack of education due to the tutors not being able to commit to her is in direct violation to the students IDEA rights, which states that every student is entitled to free and appropriate education. In the time or lack thereof that the instructors were there, they did not have the correct materials to teach her with. During this time the student did not receive an equitable education due to lack of materials and time allotment. Every student with a critical illness, no matter how severe, deserves and has the right to an education.

Parental Involvement

Although it is important for parents to be involved in their child's day-to-day life, it is especially vital for parents to be involved in their child's education when that child is faced with a critical illness. In Wilder's (2014) study, he was researching the impact that parent involvement has on a student's academic achievement. It was found that parent involvement does make a significant difference in the child's achievement. The study showed the highest achievement when the parents show positive beliefs and attitudes towards education. Children are likely to have similar beliefs and attitudes as their parents. Therefore, if their parents share a high parental expectation so will their children and vice versa if they have a low parental expectation.

For children with critical illness, the parent(s) often become the child's primary educator (Nickels, 2017). Now, instead of being able to solely focus on the health and caretaking of the sick child, the parent is taking on another layer of often-new responsibility as teacher. It is a great deal of pressure added to the parents because they not only need to be focusing on the health of their sick child, but also their education. When parents are involved with their child's education it can help them see their progress and any difficulty they are having. If the parent is there every step of the way, as soon as a difficulty arises, they can help them. Sadly, educators do not always see parents as a helpful hand; this is especially true for the parents of children with critical illnesses. Schools are not always welcome to the idea of having the parents in the decision-making process. This is where parents have reported challenges (Tekin, 2015).

Mathematics Education of Children with Cancer

The educational issues facing children with cancer are clearly seen in mathematics education. Nickels and Cullen (2017) argue that there are four conceptualizations of childhood

that affect the mathematics education that children with critical illness receive or do not receive. The authors state that these four conceptualizations are: the sacralized child, the irrational and incompetent child, children as would be adults, and children as a homogenous group (Nickels & Cullen, 2017b). The sacralized child states that historically people have assumed children live an innocent life that is carefree. However, this point does not stand true to all children, an example being the children with cancer. In regards to mathematics education, the teachers of children with critical illness, although they are trying to help their students, end up hindering them by giving them a lighter workload. Ironically, “lightening their burden” may come at the cost of limiting critically ill children’s opportunities to take part in meaningful mathematics instruction and tasks that would allow them to live their life like a healthy child or enter into adulthood able to live the life of their choosing (Nickels & Cullen, 2017). The conceptualization of a child as irrational and incompetent is due to reasons of maturity in terms of physical age and biology (Nickels & Cullen 2017). This affects critically ill children because it shows the perception that children cannot make sound decisions so they must follow what their parents say and choose for them.

“Children’s ability to do mathematics and their beliefs about mathematics may be ignored or subverted by adults, including teachers, parents, and even physicians” (Nickels & Cullen, 2017, p. 25). Children as would-be adults states that childhood is temporary and is just a stop along the way to adulthood. It shows that we value what a child does in adulthood more than the child living out their childhood. Everything in childhood is planned to prepare you for the next step. This affects our critically ill population because unfortunately some of their lives will consist only of childhood. Thus, the view upon them may be such that they offer less to the world potentially due to a simple lack of time and development (Nickels & Cullen, 2017). The last

conceptualization, children as a homogenous group, states, “childhood is a uniform experience” (Nickels & Cullen, 2017, p.26). This affects our critically ill population because they are quite different than other children. They are also different from other critically ill children who are in a different situation than they are. They need special assistance that they are not getting because they are viewed the same as other children, and it is assumed best practice for general population or special education will provide equitable education for them.

Chin and Tsuei (2014) conducted a study using digital games to help children with critical illnesses learn. The study consisted of three children with leukemia. Technology is an important component to help children with critical illness maintain a social connection while being constrained to a sterile environment. They created the Kala Forest system. Although there were some systems already out there, none of them provided experiences the children with leukemia could relate to. The system is intended to engage the children in playing, learning, and sharing. The system allows the students to create narratives about anything they want to talk about in their virtual room. Another player could then walk into their room and comment on what they wrote. This allows the children to share stories with others virtually, since they are not able to physically. The mathematics section contains three different games from which to choose: Apple Catching, Shooting Balloons, and Whack a Mole. The game randomly generates different math problems for the student splaying to complete. The game provides instant feedback and rewards for every correct answer they earn one “Kala dollar”. The three children liked these games but their motivation and interested slowly decreased. One of the children’s father said that he liked that his son was able to play games while learning.

In the second iteration, a monopoly-type game was created to incorporate language arts, face-to-face learning games, a basketball game, and a train game. The reward system was also enhanced so that they could exchange the dollars for a gift and accumulate more dollars and exchange a gift they already have for a better one. One of the participants really enjoyed the basketball game, saying, “I’ve never played basketball before. I hope I have the opportunity to play with my friends one day” (p. 374). This reaction is the essence of these digital games. It allows these children who are critically ill to do something they would not be able to do because of their health. The enhanced reward system also added to more motivation for the students. One of the mothers expressed that she liked the enhanced games because it provides a more school-like experience that is helping him prepare for when he does get to attend school. Overall, the digital games provide motivation for the children to learn, which is necessary in their circumstances. It is important for children who are critically ill to approximate the most normal experiences that they can. These online games provide them with similar experiences of playing online learning games as well as providing them social interactions as part of the games; albeit a virtual and social interaction.

Nickels and Cullen (2017) conducted a study to see how teaching critically ill children mathematics with robotics would help them learn mathematics. The authors studied a 14-year-old child with Acute Lymphoblastic Leukemia for 52 weeks. The child, with the pseudonym of Amelia, stated a strong dislike for math at the start of the study but that she would be willing to attempt mathematical work because of the appeal of a chance to learn using a robotics setup. Using different parts of a robotics kit provided to her by the authors, she was able to create and communicate mathematical arguments needed to solve each robotics task given to her. She was

able to think critically to come up with the answers she needed. As the task-based interviews and the lessons went on, there was also evidence of Amelia being proud of herself for working so well in addition to evidence of the robotics play leading to the inductive creation of mathematical content knowledge.

Literature Review Summary

The literature reviewed indicates many potential concerns for children with cancer including cognitive development and impairment and schooling. Chemotherapy at a younger age has been linked to have more cognitive effects on a child (Brown, 1998; Kirkpatrick, 2015; Moore, 2005). The higher the dose the child receives can be linked to an increase chance of the child being placed in special education services (Jacola, 2016). Missing multiple days of school, on top of the medical disadvantages a cancer patient has, makes school more challenging. A striking 51% of childhood cancer patient reported school being difficult as compared to only 14% of their healthy peers (Yi, 2016).

Cancer patients are not receiving an equitable education to their healthy peers when they are not attending the traditional classroom. Tseng and Pluta (2015) study shows that hospital homebound is not an equitable form of education. The student had to change instructors three times and there were significant delays between the assignments of the new instructor, causing her not have an education during these times. When the instructors did arrive, they came late and unprepared. This experience is in direct violation to the student's IDEA rights, which states that every child is entitled to a free and appropriate education. Teachers who are teaching students with critical illness in mathematics often try to lighten the student's workload (Tseng & Pluta, 2015). Although teachers are trying to help their students, it hinders their opportunity to learn to

their fullest potential and thus, to live their life as other healthy children (Nickles & Cullen, 2017).

In the next chapter, I outline the methodology used to conduct this study. I conducted two separate interviews with the patient and his mother, using 12 semi-structured interview questions. I used Interpretive Phenomenological Analysis to analyze the transcripts from the interview.

CHAPTER THREE: METHODOLOGY

This study utilized a qualitative analysis of a case study of one child with non-Hodgkin's lymphoma. Two interviews, one with the child and another with the mother provided insights into their experiences by discussing the child's mathematics education. Both interviews highlight information that may expose their understanding of the factors that may have influenced the development and attainment of the child's mathematical thinking and learning. Interpretative phenomenological analysis (IPA) methodology informed the data collection and organization. This study chose a theoretical framework based in positioning theory for data analysis.

Situating the Author

During Chris's year of virtual school I was one of his tutors. Based upon the recommendation of my thesis chair (also one of Chris's tutors), I tutored Chris in language arts. I met with Chris once each week for approximately two-hours. In a typical tutoring session, I would help Chris with his assignments. We would work on as many modules as we could per session, as his mother wanted to get as ahead as possible in the event of hospital stays. I would also be present during the time Chris took his tests. I would have to help him understand the questions, as they would be vague and difficult to understand what exactly the question was asking.

During my year with Chris I came to know him and his family on a personal level. I was very invested in Chris's education as well as his health. Going over to him for tutoring sessions was a priority for me. Chris looked forward to seeing me every week and he would be excited to work with me. There were times were Chris was not focused on his work and just wanted to talk

to me. At times I would get frustrated with this because I wanted to complete his assignments but then I realized that at this point in his life I was one of his only friends. He would not see any other people besides his family and other tutors. Besides tutoring him I became a support system, it gave his parents a stress off their shoulders when I would be able to complete assignments with him, this meant they did not have to and could take off their educator hats and just be his parents. Chris and his mother would often times become very frustrated with one another because of his school work, there was no separation between the two and that is why I was so glad to be able to be a help for them.

Interpretative Phenomenological Analysis

In the United Kingdom in the 1990s, Interpretive Phenomenological Analysis (IPA) was developed by Edmund Husserl (English, 2014). The purpose of this qualitative methodology is to discover the different aspects of the participants' perspectives, which would include quality, texture, and meaning of the subjective experience (Madill & Gough, 2008; Willig, 2008). Researchers have different roles within IPA, as they have to understand the participants' views, opinions, principles and experiences of awareness. IPA tends to focus more heavily on the in-depth aspects of an individual's experience. IPA allows the researcher to have a deeper understanding and a more complete connection to the participant. Therefore, it should be recognized that the researcher's biases and their life experiences may influence analysis and the participants themselves. Through this, one can reason that any analysis gathered is the researcher's interpretation of the experience. The researcher is using the life experiences of the participant "to develop an insider's perspective of the experiences of another person" (English, 2014, p. 4).

Methods of Data Collection

In order to gather the best information, I chose the semi-structured interview method. Using this, I created a schedule of interviews comprised of open questions and prompts. It is best to use open ended questions to allow the participants to disclose as much information as they are comfortable giving (Willig, 2008; Gillham, 2005). This approach is able to allow for the strong element of discovery as the semi-structured elements let the subjects express freely and guide the direction of the interview. I did not stop the participant if discussions roamed to other topics not in the questions provided. This method allowed me to interpret the data in different ways and achieve a better understanding. Therefore, the way I see the world is the way I perceived their results. While the process included elements of tedium in the creation of the interview schedule and the transferring and transcription of the audio accounts, the process allowed me to maintain the focus of what was to be assembled. Participants, in this manner, are then given the opportunity to discover and discuss their experiences and insights on the matter.

A semi-structured interview schedule comprised of 12 open-ended and non-directive questions was designed to capture participants' subjective experiences of mathematics education and their understanding of the factors that influenced the development and attainment of mathematical learning. The interviews were conducted by the author and her thesis chair on January 20, 2017 at the participants' home. Interviews lasted two hours and 10 minutes and were recorded on the application SuperNote on mobile devices.

Participants

Two participants were interviewed. They were both given pseudonyms. The first participant was a sixth grade, 13-year old male Hodgkin's Lymphoma patient. The second

participant was his mother, age 49. They are from the southeastern United States and are Caucasian. Participant characteristics are outlined in full in the results section of this thesis.

Data Analysis

For this study, all of the audio recordings from the interviews were subsequently uploaded into a password protected iPad. They were then transcribed by the author to ensure quality and understanding of the material. After all of the recordings had been transcribed, the author listened to each of the interviews separately two times, in order to ensure the credibility of the original transcription.

The transcripts were analyzed using a system of coding. Coding is a process where the researcher selects, separates and makes sense of the data. Then, they move from concrete statements in the data to analytic interpretations (Charmaz, 2006). Charmaz (2006) defined coding as shaping the analytic frame from which a researcher builds their analysis.

Transcripts were analyzed in three stages using a system of open, axial and theoretical coding (Charmaz, 2006; Strauss & Corbin 1990). Throughout the analysis process, constant comparison was simultaneously employed. The overall process of IPA analysis is depicted in Table I.

Table 1: Interpretive Phenomenological Analysis Coding Stages

Raw Data	Open Coding	Axial Coding 1	Axial Coding 2
Reading and transcribing of interviews	Reading the data closely and labelling each line of the written text with individual units of meaning or code (Glaser, 1978).	Codes which are similar are grouped together into subcategories forming an initial analytic framework.	Identification of conceptual links between the individual subcategories by asking “How are these related?”

Open Coding

The first level of analysis is open coding, where the researcher deciphers the data. In this case, the researcher looked at the transcripts and found data that seemed relevant to the study in order to better inform, collect, and analyze the data (Charmaz, 2006). The first step is for the author to take the transcript, read the data closely, and label each line of the written text with individual units of meaning or code (Glaser, 1978). For example, with the coding, the author color coordinated all of the pieces from the transcripts that could be grouped into categories. As the author read each line she asked: “What does this mean?” and “How can this be defined?” (Charmaz, 2006, pp. 51). Within and across the transcripts, the author checked and compared data to ensure the open coding captured the meaning of the data. The author repeats this step with each transcript.

Axial coding

Axial coding is the second stage of analytic interpretation, now separated into open coding, starts to be pieced back together into a coherent whole (Strauss & Corbin, 1990). This takes place in two stages. The first stage of axial coding involves the researcher reviewing the codes, or in this case the highlighted sections of the transcripts, and looking for similarities between them. Codes which have similar components tend to be grouped together into subcategories; this forms an initial analytic framework. The second stage of axial coding helps clarify and extend which ideas are the strongest causing the researcher to be more selective and conceptual (Charmaz, 2006; Glaser, 1978). By looking for conceptual links between individual subcategories, the researcher is asking, “How are these related?” The end of this stage gives the researcher a clear view of the most important topics that came from the transcripts. In this research, three categories were revealed as most prominent in the transcripts: living with cancer, environment, and practical and prejudicial barriers.

In the next chapter, I outline the results gathered from the transcripts. This section is broken down by his first and second diagnosis.

CHAPTER FOUR: RESULTS AND ANALYSIS

This section is organized by the following: the first section is Chris's first diagnosis. This section encompasses informing his school and his hospital homebound instruction. It then moves on to his second diagnosis. This section discusses informing his new school, virtual school, and his stem cell interruption.

First Diagnosis

On February 17, 2015 at age eleven, grade 4, Chris was diagnosed with classic Hodgkin's lymphoma nodular sclerosing type, stage IIA non-favorable. Hodgkin's lymphoma is a cancer that originates in an individual's lymph system, consisting of white blood cells called lymphocytes. Nodular sclerosing type is the most common type of Hodgkin's lymphoma in developed countries being the most common in young adults and it tends to start in the lymph nodes in the neck or chest (American Cancer Society, 2017). Chris's initial treatment was comprised of five consecutive days of intravenous chemotherapy (inclusive of Adriamycin® (doxorubicin), Bleomycin, Vinblastine, Dacarbazine (DTIC)), which repeated on day 14 followed by infusions of Neupogen (i.e., a drug used to stimulate the production of white blood cells to prevent infections caused by chemotherapy) for five days. On day 28 this cycle of treatment repeated, followed by 17 rounds of radiation.

When describing her feelings about learning about her child's diagnosis of cancer, Lisa explained:

I don't think that Drs. really explain anything. I mean they explain the side effects like you can get a rash you can get mouth sores, your hair loss. Those are the kinds of things

that they tell you. They don't tell you that your kid is going to be an emotional train wreck.

In line with what Lisa said, Chris reported having a difficult time adjusting to being in an isolated environment following his diagnosis. When he was admitted to the hospital there might be eight kids present on his floor instead of a classroom of 25 peers. Additionally, these children may have ages ranging from toddlers to late teens. Furthermore, the children might not want to come out of their room or be medically unable to do so. This was a sharp contrast to a classroom environment with like aged peers. During his hospital stays there were child life specialists that were extremely adept at keeping his focus off the treatment and engaged in enjoyable activities, such as painting, listening to music, and playing video games. During the time when the child life specialists were present, the focus was not on academics, and Lisa felt the transition from this environment to one with scholastic focus was challenging for Chris. When Chris returned from the hospital he had to continue working on his virtual school but this was difficult for him due to the fact that he did not work on his studies while in the hospital. When he went home, all he had was his immediate family, who were also occupied with their own work and school commitments. With the constant change in environment, Lisa felt the lack of consistency was difficult for Chris in adjusting to his new normal.

Informing the School

Midway through the first treatment cycle, Chris's mother, Lisa, was first in contact with his school. The school, an elementary charter school in the Southeastern United States, although informed of Chris's diagnosis because his mother informed them,, did not initiate the contact. Instead Lisa called to inquire about what arrangements could be made for him. The school was, however, familiar with hospital/homebound practices because another student had previously been diagnosed with cancer and was served through that system. Lisa reported, "There was another girl there that had cancer when Chris was in first grade. They were in school together, and she had it when she was in first grade. So they had kind of already done it and knew what they needed to do." Given their familiarity, Lisa was able to schedule a meeting within a week.

Present at the meeting were Lisa, the principal of the school, staff from the county, a registered nurse, and a representative from the hospital homebound program. At the time of the meeting, Chris was already being served for Attention Deficit Disorder (ADD) under a 504 plan. Despite expediting what is usually a lengthy process (i.e., scheduling accommodation meetings with the school), the result of the meeting was that no additional accommodations were prescribed. Chris's 504 plan was renamed a 504 medical plan, and the hospital/homebound service was explained to Lisa. Under hospital/homebound education plan, Chris was entitled to receive one hour of tutoring per core discipline per week—mathematics, language arts, science, and social studies. The hour was to be inclusive of the time comprised not only of instruction time but also the tutor arriving at the house, preparing for the lesson, using the restroom, etc. If Chris were to become unexpectedly ill beyond what was normal for his condition or if he needed to be seen at a medical appointment, the hospital/homebound instructor was not required to make

up that session. However, because Chris was to be enrolled in the hospital/homebound program in the second half of the school year, when students were preparing for the standardized state testing, the school determined he would receive one hour of instruction per week for reading and one hour of instruction per week for mathematics. Chris was still to be held accountable for completing his social studies and science course work despite not receiving instruction.

Hospital Homebound Instruction

The hospital/homebound tutor Chris was provided with was an eighth grade mathematics teacher, Mr. Adams. Mr. Adams was employed as a full time teacher for the county in which Chris lived and arranged to provide the one-hour of mathematics instruction after his school day one day per week. Mr. Adams was not provided with a curriculum guide or materials for Chris's lesson. He therefore decided to teach Chris the same content he was teaching his eighth grade mathematics students. Lisa reported, "He was teaching Chris eighth grade math, which was great. Chris got the eighth grade math but missed out on the fourth and the fifth and the sixth". He did not miss out on the 7th grade instruction because he is in 6th grade.

His healthy peers were receiving one hour of mathematics instruction per day minimum, totaling at least five hours of mathematics instruction per week in comparison. Also, in contrast to Chris, they were receiving grade level and developmentally appropriate mathematics instruction.

Second Diagnosis

On July 10, 2016, Chris's cancer recurred. His new diagnosis was Hodgkin's lymphoma, nodular sclerosing type, stage III non-favorable. His initial treatment following this diagnosis consisted of eight rounds of the 21-day cycle chemotherapy (again inclusive of Adriamycin®

(doxorubicin), Bleomycin, Vinblastine, Dacarbazine (DTIC)). Following the eight rounds of treatment, Chris was still not in remission and his pediatric oncologist determined that his best chance for survival was to receive a stem cell transplant (i.e., a method of replacing cells that have been damaged by treatments with stem cells that will make new healthy blood cells), harvesting his own stem cells. The stem cell transplant carried extreme risk of infection; due to this it was impossible for Chris to attend school with his peers for the entire sixth grade year. Per this, Lisa elected for Chris to enroll in the state's virtual school program.

Informing the School

When Lisa informed his new middle school about Chris missing the entire year due to his diagnosis, the process was very lengthy. Chris started virtual school four weeks late, in the beginning of the school year, after Lisa made the decision for him to attend virtual school. The four week delay was due to time waiting on county assessments to be performed. The county assessments were needed to determine which program would be best for him: either virtual school or hospital homebound. It was ultimately the family's choice, but they had to go to his school and have a meeting with the teachers and staff, and that took four weeks including the process of setting up virtual school. This process caused him to be out of school without an education for a month.

Virtual School

Over the course of his cancer treatments Chris missed a great deal of traditional schooling. During his first diagnosis in fourth grade, he was in hospital homebound for three months of school. In this second diagnosis, he was in virtual school for the entire school year. This is approximately 270 days of school for which Chris had non-traditional education with no

peer interactions. Comparatively, his twin sister had only been absent from traditional school for approximately two days of school per year. Chris never liked missing school. Before he was diagnosed, he had perfect attendance. Chris's environmental isolation through virtual school was a stark contrast to the social interactions that he previously enjoyed.

The virtual school courses were set up by subject. In each subject, there were chapters and modules within the chapters that needed to be completed by a deadline. For all the courses, including mathematics, there were about 5-8 pages of instruction per module. The mathematics course provided a limited amount of practice problems within the instructional pages; it was mostly text to read. After each lesson was complete there was a multiple-choice quiz, usually with five questions. After the quiz was completed Chris would move on to the next lesson. The online module system did not show how to correctly solve the problem if your answer was incorrect. There is no immediate feedback provided for the students. There would be chapter tests after all lessons in the chapter was completed.

Chris's low executive functioning ADD combined with cognitive side effects from chemotherapy, which he and his mother refer to as his "chemo brain," affected his memory, so he needed more directed instruction than the virtual school was able to provide. Generally, if Chris did not have a list of things to do previously written for him, it was difficult for him to stay on task. This was not just an academic issue, but one of life skills as well. For example, Lisa would include on Chris's daily list to make his bed, pull your sheets up to the top of the pillow, etc. If he had a list with this level of detail, the likelihood of him completing the task was substantially higher. This level of organization was something his mother felt that the virtual school could not offer him, as the degree of student-teacher interaction that would lead to this

type of individual accommodation is limited. Lisa felt this caused him to struggle immensely with virtual school.

To supplement virtual school, Chris had four tutors that Lisa obtained on her own. This positioned Lisa not only as Chris's primary educator, but also as a recruiter for Chris's learning needs. She is not a teacher but a parent wanted the best education for her child. Mr. Adams, who was his hospital homebound instructor, volunteered to help him during his second diagnosis with his mathematics course, as the county does not provide tutors for students enrolled in the virtual school. He would come to tutor Chris whenever he could. He did not have a routine schedule with Chris for his tutoring sessions. The additional three tutors were a professor at a nearby university and two of her students who are studying to be elementary teachers. The two students would tutor him in language arts and history. The professor would tutor him in mathematics. Similarly, she also did not have a routine schedule with him. The tutors that Lisa obtained for Chris had inconsistent schedules due to daytime commitments. For a child like Chris who thrives on a consistent schedule, this provided a new layer of challenges for an already difficult situation. Lisa felt that Chris's focus tends to be better in the mornings, but the tutors usually only came later in the day.

The reason Lisa decided to obtain tutors for Chris, especially for mathematics, was because she was not able to teach him. Also, Chris stated that he found the mathematics in virtual school to be more difficult compared to his traditional school. He reported:

I would say it's a little bit harder [in virtual school] because you don't have a teacher really to work out the problems with you, well you do its just that you cant raise your hand

and ask her a question you might have to call her up and stuff. And in a normal school you can work things out with your friends and I only have myself in this one.

Chris felt he was only successful in mathematics instruction when tutors were helping him. Chris revealed to that mathematics can be extremely frustrating especially in the virtual school setting. He cried much of the time, because he did not know what to do. He would be getting the answers wrong, even after repeating the questions multiple times. Chris noted he would still have incorrect answers, because there was not immediate feedback to scaffold his mistakes. His parents sometimes stepped in to figure out the answer, when they were able to help him.

His mother felt that Chris was largely self-teaching himself through virtual school. She had the impression that virtual school would primarily include pre-recorded lessons for each subject where you could watch a teacher conducting the lesson much like a traditional classroom. Lisa stated that she was very surprised that this was not the case. For the most part, the virtual school required you to read through the module, which is about 5-8 pages long, and then complete a multiple-choice quiz or an assignment that corresponds with the module. The quizzes could be taken multiple times, so realistically you could take it until you get 100 percent. This stands in sharp contrast to the way Chris's typical classroom worked. Lisa felt that Chris worked better when he was given constant feedback and monitoring. There were also times where Chris was stuck in trying to work on a problem independently and when he then reached out to his mother or the tutors, sometimes they were also stuck and without timely ability to communicate about discrepancies. If Chris asked the virtual school teacher for an explanation on incorrect responses, Chris had to wait for the teacher to respond via email. So, significant time delays ensued. In a typical classroom, students are able to ask a teacher about their mistakes before they

take the test, so they have timely feedback for the next lesson. The teacher, in turn, is able to provide this feedback, clarify directions, and assist students on the spot. In Chris's position as a virtual school student, he struggled with direction and clarification.

There were also discussion-based assessments (DBAs). In these assessments, Chris had to set up an appointment, so that the teacher could call him on the phone to assess his knowledge for the unit. Lisa explained that you could be zipping along the material, then a DBA would follow. If it is Monday and the teacher does not have an appointment until Friday, students would have to wait a week to take the chapter test. Students need a passcode from the teacher once you have successfully completed the DBA in order to unlock the test. By that time, Lisa felt Chris had already forgotten much of the material he had learned. Furthermore, Chris was trying to work over winter break to catch up to the rest of the class. Over the break, some virtual teachers were not working, because they had vacation time as well, but Chris was not able to obtain the passwords to take the tests.

Lisa additionally felt that the mathematics assessments were not always measuring what they should. For some assignments, students are asked to write out in words how to do the problem, and how they came to the solution. Lisa felt that this was very difficult to write out, especially for Chris. He has always loved mathematics and knew how to solve the problem, but he had a great deal of trouble expressing this. Plus, a mathematics test that had 10 problems might take an hour or more to complete, because he had to write out the steps in words. Sometimes the tests did not ask for the solutions to the problems, just how to solve it. One of the mathematics assessments asked for him to draw a number line, but there was not an option for

him to upload a picture of a drawing. So, he wrote out, “First, I draw a line; then, I add 10 tick marks and continue on for each step.”

Another problem with the virtual mathematics course, his mother expressed, was that there were not enough practice problems. Specifically, she felt that there was a lack of example problems to prepare for the assessments. If a student got the question wrong, it did not provide them with an explanation. Lisa chose to pay for the program IXL so that Chris could have access to more practice problems. On IXL an explanation was provided on why you get the problem incorrect. In the virtual school, if Chris got the couple of practice problems incorrect, Lisa felt that Chris would never understand what his mistake was. Then, she resorted to finding videos on YouTube to help. However, searching through YouTube was a battle in itself, Lisa said, to find a video that was pertinent to the material Chris needed.

Even with all of the additional help and tutoring that Chris received, school was still a struggle for him. His mother stated that when considering his daily work on a scale from 1-10, his success was a 9. Yet, if a test were placed in front of him, and he had to complete it independently and unaided, his daily work success would change to 1 or 2 on that same scale. His mother believes that he does better when he is assisted with his work. There is a discrepancy because Chris is aided quite largely with his daily work. His mother wanted to make sure that he received 100% on all of his assignments and that they were completed before deadlines and hospital stays.

The tests that Chris had to take are all completely online. This gave him the opportunity to use his notes during the test. Lisa said, “If Chris can get 100 on the test, [he is] going pass all of his classes.” Since the test allowed you to re-take it several times, he continued to attempt the

test until he earned an A. She was concerned for the future when he will no longer have this option once he returns back to the classroom. Many of the tests are only five questions long and thus a perfect score was needed mathematically to achieve an A, and this proved difficult.

Chris's current grade in mathematics was inflated, according to this mother. He would probably have an 80% if the option were not presented to take the tests more than one time to receive a higher grade. Lisa thought that Chris took the tests prematurely due to a lack of review material. Once they exhausted all their options to study, he just took the test. Since there was an option to retake the test, taking it the first time and not receiving a good grade allowed him to see the various questions types so he could prepare for the test retake.

When Chris was compared to his twin sister Ally, who attended a regular classroom setting, no difference in mathematics content between the virtual and traditional delivery systems was detected. However, Ally was bringing home worksheets, homework, and spent an hour and ten minutes in class with a teacher while Chris was not. If he understood the material, it sometimes took him 15 minutes to finish the lesson, but it was not with a teacher. Sometimes it would take him two hours on a single lesson during in which he was crying and frustrated because neither he nor his parents understood. Lisa felt that this provided an enormous challenge to his continued learning compounded with his intense health needs.

His mother and Chris each stated that Chris is good at mathematics. He had always gotten an A in mathematics while he was in school. However, in order for him to understand, he needed to have it explained to him more thoroughly than the virtual school provided, and he needed more repetition than he was getting. Chris explained that he enjoys mathematics, "It's fun and challenging". His mother believed this is why he got so frustrated when he did not

understand or when no one could explain it to him properly. Now, a subject he really enjoyed became a learning battle due to educational inequities.

Chris did not enjoy any of the multi-step math problems, according to his mother. He had a more difficult time try to solve a problem that requires 10 steps than 3 steps. If it was not explained in a way he understood the first time, he seemed to check out even if it was explained differently the second time. He just seemed to believe that if he did not understand it the first time, he was never going to understand it. He tended to not read the entire word problem. So, he found an answer, but it just was not focused on what the problem was asking. In a traditional school setting, the teacher would be physically present to ensure the students are learning how to carefully read the problems to determine what they need in order to successfully solve it. Virtual School did not provide something comparable unless he had a tutor working with him.

His mother was comfortable providing his mathematics education the first time he was working on the lesson. Yet, once he did not understand, she was uncomfortable nor did she enjoy it. His parents tried the best that they could to explain it to him, but they only knew the traditional algorithm so when he didn't understand it one way, then they were out of options. They are not teachers; they were never trained or prepared for this situation. Lisa stated that no parent expects to have to be their child's primary educational support. They were especially uncomfortable teaching him the through Common Core methods. Unfortunately for them, that was the way the virtual school explained it and how Chris has learned it in the past. When his mother was trying to teach him the way she learned, it was confusing to him.

With the hospital homebound program, his parents were satisfied with the instructor that he had, Mr. Adams. He was very kind and helpful to Chris. They were not satisfied with the

material he was teaching Chris. They did not believe that Chris receiving only one hour each week was acceptable for him. This was one of the reasons they elected to enroll him in the virtual school instead. They were wholly dissatisfied with the virtual school experience. As aforementioned, it did not provide the student teacher interaction that Chris needed to be successful in learning. His mother believed that the virtual school was not self-contained enough for her son to do it alone, which was why she had to hire four tutors and help him with it every day. Lisa asked the virtual school teachers if there were any links or videos that could supplement Chris. They responded with links for him to use. This frustrated Lisa and the tutors because the teachers did not provide these before being prompted to do so.

Interruption of Virtual School for Stem Cell Transplant

During January following Chris's second diagnosis and midway through his progress in virtual school, Chris was hospitalized for his stem cell transplant. The treatment with the stem cell transplant lasted about six weeks. While he was in the hospital, he did not complete any of his schoolwork. The tutors were not able to come to his hospital room, as he had to be in a completely sterile environment, causing isolation. He had no immune system and was only able to see his immediate family and essential personnel during the time. This time period was hard for Chris. He missed the interactions with his friends. Being in the hospital is not something Chris enjoys. After that treatment, he had at least 17 rounds of radiation to erase the newly infected areas of cancer. The radiation was daily Monday through Friday at the hospital. The radiation is a relatively fast process, but Chris was strapped down in order to immobilize him and he could not move. The administration of the radiation took about 20 minutes, and the daily

commute to the treatment is approximately 45 minutes each way. These six weeks of school impacted Chris's learning in his virtual school. It is not easy going back to working on academics after not thinking about it for six. When Chris came back to working on his virtual school he was more behind than he already was from the rest of the class. He had to work twice as hard to be able to catch up and finish the course in the allotted time.

CHAPTER FIVE: DISCUSSION

Mathematics in Virtual School

Most apparent in the data is a lack of equity in Chris's education after he was diagnosed and while being treated. The biggest contributor to the lack of equity was the virtual school. Chris was extremely dependent on myself and his mother to successfully complete his work and his tests. He would always wait for me to arrive before beginning to work on any of his assignments. He would not proactively start his work unless he had assistance. Chris stated that he is not able to ask teachers any questions by simply raising his hand, as he would in the traditional school setting. He also is not able to work out problems with his peers; he is all alone. The mathematics course did not accurately measuring his knowledge but the ability to write out the answers to the questions it asked. He is not able to upload a picture of his work, instead he must write it out step by step. Chris's self-identified strong suit is not in writing. Therefore, he found it very difficult and frustrating to complete these assignments although he mathematically understood and had the correct answer. It would be very simple to provide Chris with an accommodation using the Universal Design for Learning (UDL). Allowing him to use multiple means of representation for all of his assignments would solve this problem entirely. Instead, this poses a question of equity; in the traditional school setting the teacher is able to collect Chris's mathematics computations therefore not requiring him to write it out in words step by step. It is saddening that Chris's excitement about mathematics has faded because of the way that virtual school required him to complete his assignments. The lack of teacher and peer interaction

contributes heavily to the inequality of education Chris received. He was not able to receive immediate feedback from his teachers on his knowledge and he was not being monitored closely.

During his first diagnosis, he received a less than appropriate education by only receiving one hour of mathematics education per week. These sessions were not made up if Chris was feeling ill or had a doctor appointment. Due to his diagnosis, Chris would be feeling ill or have to go to doctor appointments frequently.

It is worrisome how Chris will be able to successfully complete the next school year when he will be in a traditional classroom. He has spent two years of his life with a subpar education and is now expected to be at the same level of understanding with his peers that have received an appropriate education. It would break my heart to see Chris getting so frustrated with his schoolwork. School should not be an uphill battle for a child to complete as an educator, I wanted more for him.

Living with Cancer

What does it mean to be living with cancer to a 13-year-old boy? It means having to be worried about fighting for your life every day. Chris was always a strong believer that he was never going to die. This is something that stood out during our interview. It is unimaginable that the thought running through a 13-year-old boy's mind is not dying. Chris has endured more in his 13 years of life than most adults will ever experience in their lifetime. He spent days being pricked and sat through high doses of toxic chemicals running through his body. He would come home not being able to get out of bed due to the aftermath of the chemo. However, he still had a positive demeanor with everyone he encountered.

Environmental Biases

Chris's environment has severely been changed since his diagnosis. He went from playing at school and outside with his friends to being isolated in hospital rooms and at home. When I asked Chris about his friends, he mentioned a video game character as a friend. It is apparent that his severe isolation is impeding his ability to maintain friendships. In regards to his educational environment, it is his home. This is not an equitable environment to his peers. He was completing assignments with no peer interaction, thus again hindering his social skills. In his typical school setting he was able to work out his problems with his peers, which he misses very much. In his home he had the distraction of his video games and other outside influences. He was very upset constantly about not being able to be with his friends, especially during the stem cell transplant. He was tired of only being at home. Missing friend interaction is a big deal for a child at school. School is their normalcy, not being able to have his friends and schools made it all that more apparent for Chris that his life was not normal. He attended school events, when medically possible, with his sister and enjoys every minute of it. When I asked him what school he attends, he answered his charter school. He only said virtual school when prompted to give this answer. This shows that he never believed he ever left his school and that virtual school was not his real school.

Conclusion and Recommendations

The further implications for this study would be providing Chris and Lisa's perspective of the tutors. It would showcase Chris's academic experiences in a different light than his mother's. I would also like to compare to the learning experiences of two children that have cancer to study how their experiences differ or are similar. I believe this is needed because all

children are not a homogenous group. Two children that both have cancer are experiencing it in a completely different way.

For the 2015-2016 school year there were 7,705 full time students statewide served in the virtual school where Chris lives (Florida Virtual School, 2017). That is a large number of the population of students that might be having the same challenges that Chris is having. A further study can be conducted in order to inquire if students are having the same difficulties as Chris did. This again goes back to children are not a homogenous group. A child with cancer and a child who is healthy that is choosing to do virtual school live completely different lives but both may be experiencing the same lack of teaching involvement with their education.

Around 15,780 school aged children in the United States were diagnosed with cancer in 2016 (National Cancer Institute, 2017). Many of these children need to be placed in virtual school or in hospital homebound. Neither of the options provide an equitable education for these children. A further study can be conducted to inquire about children with other types of critical illnesses and their experience with the education system to determine what if any techniques and programs could help the cancer populations.

The information that resulted from this study is enlightening. It brings to light the inequalities of education that students with critical illness have compared to their healthy peers. It especially brings out mathematics inequalities such as not being able to accurately show the understanding of their mathematics knowledge. A student now heavily relies on writing and language skills in ways the traditional classroom does not see to show mathematics proficiency. Further studies can use the results from the virtual school experience that Chris encountered to find a solution to this problem of lack of student to teacher interaction. Lawmakers can use the

information from my study to provide children with cancer federal assistance. School districts can conduct professional development in teaching students with critical illness.

Both participants recognized several influences in regards to the mathematics education experienced by the child. The biggest influence appeared to be environment and accounted for more than half of all codes during analysis. The influence of the environment (i.e., hospital, home, clinic, and virtual school) were not perceived well and resulted in low quality, rote memorization mathematical tasks. Effects stemming from all three storylines were accumulative over time, with a gap widening both academically and socially between the child and his peers. In order for researchers to investigate interventions for teaching mathematics to children with cancer, a body of literature must first exist that provides evidence of the current experiences and perceptions of children living with cancer. This research report will provide useful information on the concerns of learning mathematics for children with cancer, and what limitations, especially environmental, must be overcome to assure an equitable mathematics education.

Recommendations for Teaching Children with Cancer

After experiencing firsthand the obstacles that children with cancer face with their education the following recommendations are positioned to advocate for these children during this difficult time.

In the virtual school setting there needs to be more teacher-student interaction. Chris always mentioned to me how he wished he could just raise his hand and ask his teacher a question. It would be extremely beneficial for the virtual schoolteachers to hold virtual office hours in which they would be able to Facetime or Skype with the students. This would give the students a face to the name of the person who is responsible for their education. It would also

allow students to have peace of mind knowing that if they have any questions they would like to address with their teacher there are designated times in which they are able to do so. Having virtual office hours would make virtual school less of a difficult transition. When a child has cancer, they are already so isolated from their classmates, friends, and teachers; this would give them less isolation. Most pediatric cancer patients want an opportunity to have their life be as normal to what is used to be before their diagnosis as possible.

In the typical school setting when the child is absent for a prolonged period of time, due to medical reasons, it would be helpful if the teacher kept in touch with student. If the possibility is available for the student's current classroom teacher to be their hospital homebound tutor, I think that would be extremely beneficial. There is already a student teacher relationship that would help the student's transition.

In the student's time of absence it is important for the teacher and the class at their home school not to forget about them. The student still feels a part of their class even when they are not attending it physically; they want to keep in contact with their friends when they are not able to. Due to the wonderful technological advances that we have in our world today it is simple to virtually keep in contact. One way would be for the class to Facetime or Skype with the student a couple times a month. This allows the child who is sick to still feel a part of the class despite their absence. Another way could be that the class write him or her letters or cards just to let them know they are thinking about them. This also allows the child to respond back to his or her classmates giving them something to do that brings them to their normalcy of school.

There are many accommodations that can be made when there is a sick child in any classroom. It is up to the classroom teacher to provide these so that every child in their class is given the respect they deserve, even if they are not physically present.

APPENDIX A: INTERVIEW QUESTIONNAIRES

Interview Questionnaire

Child Interview Protocol Questions

1. Tell me about yourself.
2. You have (name of critical illness). What would you want me and others to know about (name of critical illness)
3. How many times have you been hospitalized? Can you tell me what a typical day is like when you are inpatient? How about when you are at the clinic?
4. Describe your treatment. How long will your treatment last?
5. Do you go to school? Tell me about your school. Tell me how having (name of critical illness) has changed school for you.
6. What kind of things can you learn on your own? What aspects of school encourage or discourage you to learn?
7. Do you remember learning math when you were young? Tell me about that. What do you remember about learning?
8. Do you learn mathematics outside of school? What mathematics were you doing/learning? What was different about your learning compared to math class? What was similar?
9. Are you good at mathematics? How do you know?
10. Do you like or dislike mathematics? Why? What do you like about doing math? What do you not like?
11. Who or what influenced (either positively or negatively) your feelings about mathematics?
12. Is there anything you wanted to talk about that we didn't get to?

Parent Interview Protocol Questions

1. Tell me about yourself. What is your occupation?
2. Tell me about Chris?
3. How comfortable do you feel providing mathematics instruction to your child?
4. How long did it take the school to contact you after your child's diagnosis?
5. Did anyone from the school give you information about services your child could receive? If so who?
6. Did your child receive a 504 or IEP plan after their diagnosis?
7. Your child has (name of critical illness). What would you want me and other teachers to know about (name of critical illness)?
8. How many times has your child been hospitalized? Approximately how many days of school has your child missed? Can you tell me what a typical day is like for your child when your child is inpatient? How about when they are at the clinic?
9. Describe your child's treatment. How long will the treatment last?
10. Does your child go to school? Tell me about the school. Tell me how having (name of critical illness) has changed school for your child.
11. Do you think your child is good at mathematics? How do you know?
12. Do you think your child likes or dislikes mathematics? Why? What does your child like about doing math? What do they not like?
13. Are you satisfied with the mathematics education your child has received during their hospital or home bound and virtual school stays?
14. Is there anything you wanted to talk about that we didn't get to?

APPENDIX B: INSITUTIONAL REVIEW BOARD CONSENT



University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901, 407-882-2012 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

NOT HUMAN RESEARCH DETERMINATION

From : **UCF Institutional Review Board #1**
FWA00000351, IRB00001138

To : **Megan Nickels, Ph.D. and Co-PI: Elizabeth M. Bello**

Date : **November 15, 2016**

Dear Researcher:

On 11/15/2016 the IRB determined that the following proposed activity is not human research as defined by DHHS regulations at 45 CFR 46 or FDA regulations at 21 CFR 50/56:

Type of Review: Not Human Research Determination
Project Title: Experiences Learning Mathematics and Grade Level
Competency for Children with Cancer
Investigator: Megan Nickels, Ph.D.
IRB ID: SBE-16-12574
Funding Agency:
Grant Title:
Research ID: n/a

University of Central Florida IRB review and approval is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are to be made and there are questions about whether these activities are research involving human subjects, please contact the IRB office to discuss the proposed changes.

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

A handwritten signature in black ink, appearing to read "Patria Davis".

Signature applied by Patria Davis on 11/15/2016 04:41:56 PM EST


IRB Coordinator

REFERENCES

- American Cancer Society. (2014). *Cancer facts & figures 2014*. Retrieved from <https://www.cancer.org/latest-news/2014-childhood-cancer-statistics-10-key-facts.html>
- American Cancer Society (2017). *What is Hodgkin Lymphoma?*. Retrieved from https://www.cancer.org/cancer/hodgkin-lymphoma/about/what-is-hodgkin-disease.html#written_by
- Bessell, A. G. (2001). Children surviving cancer: Psychosocial adjustment, quality of life, and school experiences. *Exceptional Children*, 67(3), 345–359.
- Bessel, A. G. (2001). Educating Children with Chronic Illness. *Exceptional Parent Magazine*, 44-48.
- Brown, R. T., Madan-Swain, A., Walco, G. A., Cherrick, I., Ievers, C. E., Conte, P. M., et al. (1998). Cognitive and academic late effects among children previously treated for acute lymphocytic leukemia receiving chemotherapy as CNS prophylaxis. *Journal of Pediatric Psychology*, 23(5), 333–340.
- Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London, UK: Sage.
- Chin, J. C., & Tsuei, M. (2014). A Multi-modal Digital Game-based Learning Environment for Hospitalized Children with Chronic Illnesses. *Educational Technology & Society*, 17(4), 366—378.

- English, B. (2014). Interpretative phenomenological analysis: The experiences of parents of a child diagnosed with autism. *SAGE Research Methods Cases*.
doi: 10.4135/978144627305013519220
- Florida Virtual School. (2017). Florida Virtual School District Enrollment Summary 2015-2016. Retrieved from <https://flvs.net/docs/default-source/district/flvs-district-enrollment-summary.pdf?sfvrsn=2>
- Glaser, B.G. (1978). Theoretical sensitivity: advances in the methodology of grounded theory. Mill Valley, California: Sociology Press.
- Hoffman, R. (2000). Your child and the individualized education program (IEP). *Candelighters Childhood Cancer Foundation Newsletter*. Retrieved from <https://www.acco.org/your-child-and-the-individualized-education-program-iep/>
- Hoffman, R. I. (Ed.). (2012). *Education the child with cancer: A guide for parents and teachers* (2nd ed.). Kensington, MD: American Childhood Cancer Organization.
- Irwin, M. K., & Elam, M. (2011). Are we leaving children with chronic illness behind? *Physical Disabilities: Education and Related Services*, 30(2), 67-80.
- Jacola, L. M., Edelstein, K., Liu, W., Pui, C. H., Hayashi, R., Kadan-Lottick, N. S., & Armstrong, G. T. (2016). Cognitive, behaviour, and academic functioning in adolescent and young adult survivors of childhood acute lymphoblastic leukaemia: a report from the Childhood Cancer Survivor Study. *The Lancet Psychiatry*, 3(10), 965-972.
- Kirkpatrick, K. M. (2015). School issues and educational strategies for survivors of childhood cancer. In G. A. Mucci & L. R. Torno (Eds.), *Handbook of long term care of the childhood cancer survivor* (pp. 358—365). New York, NY: Springer.

doi:10.1007/978-1-4899-7584-3_22

- Larcombe, I. J., Walker, J., Charlton, A., Meller, S., Jones, P. M., & Mott, M. G. (1990). Impact of childhood cancer on return to normal schooling. *BMJ*, *301*(6744), 169—171.
- Madill, A. & Gough, B. (2008). Qualitative research and its place in psychological science. *Psychological methods*, *13*(3), 254—271.
- Mitby, P. A., Robison, L. L., Whitton, J. A., Zevon, M. A., Gibbs, I. C., Tersak, J. M., ... & Mertens, A. C. (2003). Utilization of special education services and educational attainment among long-term survivors of childhood cancer. *Cancer*, *97*(4), 1115-1126.
- Moore, B. D. (2005). Neurocognitive outcomes in survivors of childhood cancer. *Journal of Pediatric Psychology*, *30*(1), 51–63. 
- Nabors, L. A., Little, S. G., Akin-Little, A., & Iobst, E. A. (2008). Teacher knowledge of and confidence in meeting the needs of children with chronic medical conditions: Pediatric psychology's contribution to education. *Psychology in the Schools*, *45*(3), 217-226.
- National Cancer Institute. (2017). Cancer statistics. Retrieved from <https://www.cancer.gov/about-cancer/understanding/statistics>
- Nickels, M. & Cullen, C. J. (2017). Mathematical thinking and learning through robotics play for children with critical illness: The case of Amelia. *Journal for Research in Mathematics Education*. *48*(1). 22—77. doi: 10.5951/jresematheduc.48.1.0022
- No Child Left Behind Act (2002).
- Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, research, practice*. London, UK: Sage.
- Strauss, A. & Corbin, J. (1990). *Basics of qualitative research*. London, UK: Sage.

- Tekin, A. K. (2015). Parent involvement in the education of children with chronic diseases: Working and sharing for children. In M. Gordon (Ed.), *Challenges surrounding the education of children with chronic diseases* (pp. 151-164). Hershey, PA: Information Science Reference.
- Tseng, M., & Pluta, R. M. (2016). Educating students with chronic illness: How the old service model fails. In M. Gordon (Ed.), *Challenges surrounding the education of children with chronic diseases* (pp. 227-246). Hershey, PA: Information Science Reference.
- Wilder, S. (2014). Effects of parental involvement on academic achievement: a meta-synthesis. *Educational Review*, 66(3), 377-397.
- Willig, C. (2008). *Introducing Qualitative Research in Psychology*. Second edition. Open University.
- Yi, J., Kim, M. A., Hong, J. S., & Akter, J. (2016). Childhood cancer survivors' experiences in school re-entry in South Korea: Focusing on academic problems and peer victimization. *Children and Youth Services Review*, 67, 263-269.