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EDUCATIONAL BARRIERS CHILDHOOD CANCER PATIENTS AND
SURVIVORS EXPERIENCE: CANCER CARE TEAM PERSPECTIVES

by

Karely Mann

A thesis submitted in partial fulfillment of the
requirements for the degree

of

MASTER OF SCIENCE

in

Special Education

Approved:

Michelle McKnight-Lizotte, Ph.D.
Major Professor

Karen D. Hager Martinez, Ph.D.
Committee Member

Barbara J. Fiechtl, M.S.
Committee Member

D. Richard Cutler, Ph.D.
Interim Vice Provost of Graduate
Studies

UTAH STATE UNIVERSITY
Logan, Utah

2021

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ABSTRACT

Educational Barriers Childhood Cancer Patients and Survivors Experience: Cancer Care

Team Perspectives

by

Karely Mann, Master of Science

Utah State University, 2021

Major Professor: Dr. Michelle McKnight-Lizotte

Department: Special Education and Rehabilitation Counseling

School-age cancer patients often experience educational disruptions while receiving cancer treatment. Then, once in survivorship, they can experience long-term side effects that impact how they learn and their progress in the school curriculum. This study was conducted to evaluate educational barriers experienced by cancer patients and cancer survivors and to explore the feasibility of incorporating an education section in survivorship care plans.

Participants were cancer care team members (e.g., oncologists, social workers, nurses) that work at Primary Children's Hospital and regularly interact with patients.

Data were collected via online surveys and individual semi-structured telephone interviews. Questions addressed educational resources, school and hospital communication, survivorship care plans, and educational barriers in survivorship.

Descriptive statistics were calculated for survey responses and interviews were analyzed using thematic content analysis.

Survey response rate was 43.5%, with eight different oncology specialties represented in the participant group. Sixteen interviews were completed and found that cancer care team member roles were fairly well defined and that social workers, the hospital schoolteacher, and the clinic psychologist were most directly involved with helping patients with educational needs. There are four main clinical realities that prevent cancer care team members participating more in educational needs: (a) the balancing act, (b) proper timing, (c) little/no knowledge about IEPs, and (d) caregiver responsibilities.

While many people are invested in helping young people succeed in school after a cancer diagnosis, this study focused on the point of view of the cancer care team as they discussed educational resources during treatment, after treatment, and the late effects that might alter how their patients learn.

(74 pages)

PUBLIC ABSTRACT

Educational Barriers Childhood Cancer Patients and Survivors Experience: Cancer Care
Team Perspectives

Karely Mann

After a child is diagnosed with cancer their life changes dramatically, including their school attendance and education goals. This study was done to find out common schooling and education problems young cancer patients and survivors face and how cancer care team members try to help.

This study focused on the point of view of the cancer care team members. Cancer care team members include nurses, social workers, oncologists, and many other professionals. All cancer care team members who participated in the study took a survey and many of them also agreed to participate in a short interview.

We found that social workers and the hospital schoolteacher are the most likely people on the cancer care team to help young cancer patients with schooling and education concerns. The nurses and oncologists help more with medical concerns that can affect learning.

DEDICATION

To all the cancer care team members around the world. You are loved for all the sunshine you bring into the scariest of situations.

ACKNOWLEDGMENTS

In my opinion, good research takes a full and active village to complete. So, to the village that can claim this research as their own, I want to give you a very warm and very big “thank you”. You are all simply brilliant!

First and foremost, thank you to all the cancer care team members from Primary Children’s Hospital. Your willingness to share your opinions, thoughts and experiences is so very appreciated.

To Dr. Anne Kirchhoff, thank you for your careful training in the art of research. The genesis of this study could not have occurred without you.

To Dr. Karen Hager Martinez, I am most grateful that you dared to take on a special education MS student who strangely wanted to mix cancer research with education. Your experience and wisdom has touched and changed each part of this project.

To Dr. Michelle McKnight-Lizotte, your love for this project and your qualitative expertise brought the color and depth to this research that I was hoping and searching for. A billion times over, “Thank you!”

To my whānau, I’m convinced you’re the best humans on this planet. Dad, you’ve given me the moon by being so attentive to my never-ending academic career. Mum, you’re a genius. I’m so very glad I had you for this degree, you helped me comprehend the complex world of special education. Samson, I just adore you and I loved that we were writing our final projects together; thanks for all the brainstorming and editing help.

And to Storm, my favourite person, your encouragement and your trust in me made all the difference. I'll love you forevermore!

Karely Mann

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EDUCATIONAL BARRIERS CHILDHOOD CANCER PATIENTS AND SURVIVORS EXPERIENCE: CANCER CARE TEAM PERSPECTIVES

In the United States, 10% to 30% of children are actively living with a chronic illness (Thompson, 2009). Chronic illnesses are defined by the Centers for Disease Control and Prevention (CDC) as conditions that last for more than one year, limit daily activities, and/or require consistent medical treatment (2019). Some common chronic illnesses found in children and adolescents are asthma, diabetes, epilepsy, and cancer (Torpy et al., 2010). Such illnesses often require radical lifestyle changes due to frequent hospital or medical office visits, time intensive treatment procedures, and/or unpredictable side effects from treatments. These disruptions can lead to poor educational outcomes (Layte & McCrory, 2013), which may be directly linked to frequent school absences, decreased readiness to learn, and lowered cognitive development in this subpopulation (Fowler et al., 1985). It is vitally important that these students progress through school and continue to gain the cognitive and social development that is associated with education (Lent et al., 1999).

Like other chronic illnesses, a childhood cancer diagnosis can be disruptive to educational goals (Katz & Madan-Swain, 2006). Cancer patients who are in school during their treatment and cancer survivors who have returned to school after treatment may need special supports or accommodations in the classroom to increase their learning outcomes. The term “cancer patient” for this study is defined as an individual who is actively receiving medical treatment for a tumor or malignant growth. Cancer treatment can include chemotherapy, surgery, radiation, hormone therapy, immunotherapy, or a combination of listed treatments. The term “cancer survivor” for this study is defined as an individual who has received a cancer diagnosis but is *not* actively receiving medical

treatment for a tumor or malignant growth. Cancer treatment commonly impacts: (a) levels of fatigue and energy; (b) coordination; (c) the ability to see or hear; (d) the ability to walk; (e) the ability to remember, learn, and/or concentrate; (f) the ability to control emotions and behaviors; and (g) the need to take medications that help with treatment side effects throughout the day (Bach, 2019). Any of these changes can be temporary, they can come and go, or they can be permanent.

Childhood cancer can affect a patient's schooling throughout treatment and into survivorship (Gerhardt et al., 2007; Vance & Eiser, 2002). This is because cancer and the treatment used to eradicate the disease from the body are incredibly harmful and leave lasting marks physically, mentally, and socially (Denlinger et al., 2014). Several learning problems have been correlated with brain trauma caused by some types of cancer treatment. Cancer therapy can cause many different types of long-term effects or late effects, the most common of which include impaired pulmonary, cardiac, endocrine, and nervous system function (Bhakta et al., 2017; Hudon et al., 2013; Oeffinger et al., 2006; Robison & Hudon, 2014). The NCI defines late effects as, "adverse long-term health-related outcomes, which manifest months to years after completion of cancer treatment" (NCI, 2020, General Information section). Up to 33% of childhood cancer survivors experience serious or even life-threatening complications due to their cancer therapy, while 66% live with at least one chronic complication or late effect (Oeffinger & Hudon, 2004). Monitoring late effects and recurrence is a reality for all cancer survivors, and with regular follow-up appointments needed it is typical for childhood cancer survivors to continue to see their primary oncologist regularly for two to five years after treatment is complete (Children's Oncology Group, 2020). During these follow-up appointments

oncologists or cancer care team members could discuss any cognitive or behavioral late effects that could impact the childhood cancer survivor's learning ability and/or education.

The National Academy of Medicine recommends that every cancer survivor receive a survivorship care plan (SCP) at the end of their treatment (Birken et al., 2014; Mayer et al., 2015). SCPs are individualized and detailed documentation given to survivors and their families that summarize cancer treatment and recommendations for follow-up care. SCPs may be one way to encourage cancer care team members to discuss educational needs with childhood cancer survivors and their families.

Parents of cancer patients may wish to know how their child can receive additional services or accommodations when side effects of treatment impact their child's learning capabilities (American Cancer Society, 2017a, 2017b; Hoffman, 2000). One thing a parent can do is ask the school to do an evaluation of their child to see if the child qualifies for an Individualized Education Program (IEP) or a 504 Plan. According to Section 504 in the Rehabilitation Act of 1973, all children should be afforded an appropriate education which requires "developmental, corrective, and...support services" (Section 300.34). Consequently, Section 504 denotes that children with chronic illnesses or conditions, who demonstrate a need for accommodations are entitled to educational accommodations within general or special education. Cancer and cancer treatment can be the reason a person is eligible for special education and/or accommodations. If a child is found eligible, the Individuals with Disabilities Education Act (IDEA) requires free, appropriate special education services to be provided to the child. The child may be

determined to be eligible under the category of “other health impairment” (OHI). IDEA states that OHI means:

...having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that— (i) Is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome; and (ii) Adversely affects a child’s educational performance. (Center for Parent Information & Resources, 2017, Other Health Impairment section; United States Department of Education, 2015).

In the year 2020 alone, about 11,050 children under the age of 15 were estimated to be diagnosed with cancer in the United States, and approximately 89,500 new cancer cases in Adolescents and Young Adults (AYAs, patients and survivors ages 15 - 39) occurred (American Cancer Society, 2020a, 2020b). Most of these patients will need to re-enter some form of education, if their specific treatment interrupts their schooling. School is important for cancer patients and survivors, and studies have shown that maintaining academic achievement and school participation, where possible, greatly increases quality of life (Katz & Madan-Swain, 2006; Katz et al., 1992). Much of the research conducted regarding childhood cancer patients and their education focuses on the parent’s point of view or the cancer patients’ point of view (Hocking et. al, 2018). Both perspectives are vital in understanding what barriers exist in the transition from hospital to school. Published research has not yet focused on the perspectives of the cancer care team and the conversations they have with patients and families on the effects cancer and cancer treatment has on education.

Literature Review

Hocking et al. (2018) conducted a descriptive study that asked 102 parents of children with cancer their perspectives on the needs and potential educational barriers their children faced. To be included in the study, parents had to read and write in the English language and have a pre-kindergarten through college-age child who was diagnosed with cancer. The study was designed to inform a quality improvement project to enhance school reintegration services at the Children's Hospital of Philadelphia within the hematology/oncology inpatient and outpatient clinics. Using chi-square analyses, the authors compared (a) change in academic performance, (b) parental concern about child's education, (c) teacher concerns, (d) barriers to school participation, (e) completion of a comprehensive evaluation, and (f) the usage of special education services by disease group (Hocking et al., 2018). The disease groups studied were liquid based diseases like Leukemia or Lymphoma, brain tumors, and non-central nervous system (CNS) solid tumors. These specific cancer diagnoses are quite common among childhood cancer patients and are commonly known to affect school performance. Parents completed the HOPE Needs Assessment, a one-time short survey developed by Peterson et al. (2005). The data collected showed that parents of children diagnosed with brain tumors indicated that neurological conditions (e.g., seizures, Posterior Fossa syndrome) contributed largely to the negative changes in their child's education due to problems with language and speech, fine and gross motor skill, and mood changes. St. Jude's Research Hospital defines Posterior Fossa Syndrome (also known as cerebellar mutism) as a condition that can develop after "surgery to remove a brain tumor in the posterior fossa region of the brain" with the most common symptoms being limited or loss of speech (2020, paras. 1-

2). Parents of children diagnosed with liquid based diseases and non-CNS solid tumors found absenteeism and attention/concentration as the most significant negative changes. Parents whose children were in 6th grade to 12th grade were the most concerned about their child's education and how it was affected by their cancer diagnosis. The 6th to 12th graders were far more likely to receive or ask for homebound services. Hocking et al. (2018) mentioned in their discussion that technologies and homebound services need to be investigated further to help with the education of children diagnosed with cancer so these patients, whether living in an inpatient clinic or at home, could participate remotely. When the child was healthy enough to attend school, the parents reported that their children struggled with fatigue, physical limitations, and gastrointestinal problems. The authors argue that generally parents believe that their children diagnosed with cancer are not having their educational needs met and that both the medical and educational systems are failing these patients. The authors stated that "hospital-based providers should closely monitor the school experiences and challenges" their patients experience (Hocking et al., 2018, p. 8). They suggested that specific cancer-caused conditions (e.g., Posterior Fossa) need to be communicated to teachers so they can be aware of the side-effects that cancer treatment can have on the student's education. The authors suggest "pro-active programming overseen by a school reintegration team that involves the family, treatment team, and school staff" that is funded by the hospital should start the conversation concerning the patient's education (Hocking et al., 2018, p. 8). Hocking et al.'s (2018) study is important in starting to understand the parental view of how a cancer diagnosis can affect a child's education.

There are many stakeholders involved when a child is diagnosed with cancer. Family members, friends, teachers, and the cancer care team may all have different ideas and their own priorities in mind for the person diagnosed with cancer. Hocking et al.'s (2018) research outlines the parental perspective and gives ideas on how to best support patients while they are moving back and forth between school, home, and the hospital. However, the researchers did not ask the parents directly what they would want their child's cancer care team to do to help their child's transition back into school. The data collected indicated parents did not feel either the school or hospital was supporting their child with their education, thus further research should be done to specifically ask parents where change could occur. A semi-structured interview may be an effective strategy to gain this type of input. The suggestion of a reintegration team is good, though may be cost-prohibitive. Pediatric hospitals and programs may need to look into grant funding to make that type of solution viable. It is notable that parents involved with this study referenced a need for technologies that would allow their child to participate in school remotely. Further research is needed to test technologies in an oncology setting to see how useful they are for learning and keeping close with social groups they usually engage with at school. There is a social aspect to going to school every day that is not often addressed by the current research. The authors encouraged that the technologies evaluated should not only be focused on education, but on social support as well. Hocking and colleagues repeatedly suggested that the educational transition heavily sits with the cancer care team. The question remains, what would be the best way for the cancer care team to get pertinent information to the school about their patient's likely side effects?

Pini et al. (2013) surveyed two populations: teenagers who have been diagnosed with cancer (ages 13-16 years old) and oncology providers that have focused on working with teenagers. The oncology providers they surveyed were clinical nurse specialists, youth workers, consultants, nurses, social workers, lead nurses, researchers, research nurses, psychologists, multi-disciplinary team coordinators, and dieticians. The teenagers were a mixed group of survivors and patients currently receiving treatment who attended the 2010 United Kingdom Find Your Sense of Tumor (FYSOT) conference, a two-day residential program/conference funded by the Teenage Cancer Trust (TCT). The oncology providers were contacted through the TCT email list. The authors were specifically focused on the data collected from the young teenagers diagnosed with cancer within the last five years and their social and education experience since diagnosis. Both groups took a one-time survey, the teenage participants (N=88) took the survey at the conference on mobile devices and the oncology providers received the survey through email (N=40). The teenage survey contained questions like, "How much of a priority is it for you to continue with your education at the moment?", "How much education did you miss during treatment?", and "Has missing time from education affected your friendships?" (Pini, 2013, p. 321). The oncology provider survey contained questions such as, "What are the main barriers to patients continuing with education during their treatment?" and "In your experience, what facilitates patients continuing with education during their treatment?" (Pini, 2013, p. 323).

Pini et al. (2013) focused on the social impacts that teenagers diagnosed with cancer experienced. Correlations were found between the teenage patients who were able to maintain healthy peer groups during treatment and how easy it was to integrate back

into school. The results showed that 65% of teenage patients thought it “very important” to continue education during cancer treatment. The results from the oncology providers show that there are three main perceived barriers concerning education for teens diagnosed with cancer: (a) unrealistic expectations from patients/parents/school, (b) hospitalization, and (c) the practicalities of accessing education. Like Hocking et al. (2018), the oncology providers thought that the most effective way to facilitate education for teenagers with cancer was a hospital to home to school liaison. The authors concluded that there should be a collaborative education planning session at diagnosis where non-academic variables like peer groups are considered in conjunction with the well-being and recovery of each patient because social success has been proven to help with educational maintenance. The limitations of this article included that the population surveyed were a convenience sample, and they were a motivated and engaged group of oncology patients who were physically well enough to attend the conference. Teenage patients whose treatment kept them at home or in the hospital and out of school for months or even years at a time may have very different views about their education. The authors noted that further research is needed to understand how teenagers experience education after their diagnosis.

The Pini et al. research (2013) is particularly relevant for this study because it is one of the only studies in which the cancer care teams were asked their perspectives on the medical – education gap. The findings of this study revealed that oncology providers were aware that their patients struggle with education after diagnosis, though like Hocking et al. (2018), the authors had very few suggestions for oncology clinics to consider if they wanted to improve the transition from hospital to school for their

patients. This study can greatly expand the work of Pini and colleagues (2013) by asking the cancer care team what solutions they would recommend, what solutions seem feasible, and if a document like an SCP could begin to open up a communication line from the cancer care team to the school. The research has shown the disconnect between the hospital and school, so finding solutions is the next step.

A literature review was conducted by Thompson (2015) of 17 peer-reviewed articles focusing on an educator's point of view and the school re-entry process for children (ages 4-18) who live or lived with cancer. All the articles reviewed used either pre-post surveys and/or interviews or meta-analyses. The author rated the research in this field as "low to very low-quality evidence because of small sample sizes, lack of control groups, and the lack of randomized clinical trials or between-site comparison trials" (Thompson, 2015, p. 5). Though this field of research is currently only descriptive and has not yet developed into interventionist work, there were findings that are vital to understand as this type of research continues. All types of school re-entry programs offered were well received by educators and parents. Most of the programs consisted of communication between the cancer care team and the school through written, electronic, or in-person discussions about the diagnosis, the treatment received, and any suggested services that the student might need. The school re-entry programs benefitted educators through increasing knowledge about psychosocial and medical aspects of cancer, which led to more positive attitudes toward students with cancer, and the educators felt more confident and comfortable about how to help manage any symptoms or issues that arose for students during school. As noted above, Hocking et al. (2018) found that parents reported that their children who have or had cancer struggled with fatigue, physical

limitations, and gastrointestinal issues while in school. All these symptoms could be shared with educators, with parental consent, so they can be aware of these common side-effects. The programs that included a school liaison as a piece of the school re-entry program reported more students diagnosed with cancer receiving special education resources than programs that did not have a liaison. Not all children with a cancer diagnosis will need special education services, but some will need significant support. Helms et al. (2014) reported that students enrolled in a school re-entry program not only achieved higher academic scores, but also showed lower rates of depression. The authors suggested that further research should include interventions that test different school re-entry and liaison programs to find the model that is most successful. So far, there is little data describing the costs of different reintegration programs. Optimal timing, school supports, special education resources, best practices, and cost benefit analysis should all be evaluated in future research. In conclusion, the authors did warn that school re-entry programs are most likely to be “non-revenue generating” and could be particularly difficult for oncology clinics that have a large patient volume or for clinics that have a large catchment area and would be working with schools in several different states (Thompson, 2015, p. 6).

A study was recently been published concerning SCPs developed at Primary Children’s Hospital (PCH) hematology/oncology clinic in Salt Lake City, Utah. Under the direction of Drs. Anne Kirchhoff and Richard Lemons, SCPs were created and delivered to 21 acute lymphoblastic leukemia (ALL) cancer patients, their families, and their primary care providers (PCP). Two papers have been published describing the findings. Pannier et al. (2019) reported on the patient and family experiences with

receiving the SCP from their oncologist. Patient and family satisfaction with their SCP was generally high with one participant stating, *“It [the SCP] helps me feel assured that my child will be monitored and cared for in the long term”* (Pannier et al., 2019, p. 3). Most participants believed the SCP should be delivered by the primary oncologist to patients and family members directly after treatment is complete. It should be noted that 95.7% of the parents reported they intended to share the SCP with another medical provider, other family members, and their child’s school, yet only 60.9% did ultimately share the SCP. Concerning this current study these findings are crucial: parents and patients like SCPs and they want to share them with the patient’s school. Currently the SCP that PCH creates does not include a section directly addressing school/education concerns. If a school section was added, during delivery the oncologist could explain that the patient’s treatment could affect them in school in a myriad of ways. The oncologist could also encourage parents to pass the SCP along to the school. This document may be particularly helpful if the parents want special education evaluations done to see if their child qualifies for a 504 plan or an IEP.

The second paper concerning Primary Children’s Hospital SCPs (Mann et al., 2020), described the process that the nurses and oncologists used to create the SCPs for the 21 ALL patients and their families. Six nurses and eight oncologists participated in this study by first creating the SCPs from a template designed specifically for PCH patients. On average, nurses helped create 3.5 SCPs taking about 209 minutes to create the plans and the oncologists help create on average 2.6 SCPS and spent around 47.4 minutes adding the details allotted to them. Nurses found it particularly hard to create the SCP for patients who had complicated treatments or who received part of their treatment

elsewhere. Vaccine records were also notoriously hard to find. Oncologists were surveyed after they delivered the SCPs to the patients and their families; the majority noted that the families understood what an SCP was and how it could be helpful. After the SCP was delivered to the family another copy of the SCP was then sent along to the patient's PCP, along with a survey. The research team discovered that 80% of PCPs thought an SCP could improve the communication between the oncology clinic and the PCP clinic. No studies have been identified that investigated if SCPs can improve the communication line between the hospital and the school. If an SCP can open a communication line between the oncology clinic and PCP clinic, it is feasible that it could help improve communication between the hospital and the school. Adding an education section to the SCP may be a quick and easy way for parents and patients to feel more prepared entering school again by providing a document to deliver to the teachers and administrators.

Conclusion

The literature reviewed provides evidence that parents, patients, and cancer care team members feel that the current system is not effectively supporting childhood cancer patients and survivors as they transition back into school. Few solutions to this system failure have been proposed or studied, particularly for hospitals that have large catchment areas. The oncology clinic at PCH is responsible for patients from Utah, Idaho, Nevada, Montana, Wyoming, and Arizona. Despite the large catchment area, there are inexpensive solutions that PCH could try to help their patients transition back into school more successfully. One potential solution would involve adding a section that addresses potential educational needs to all the SCPs created at PCH. Which leads to the second

solution, establishing a pattern of talking to patients/survivors and families about potential late effects that may affect their education and briefly introducing them to Special Education resources. These two steps could begin to make a difference in the lives of the patients that receive their treatment at PCH.

This research study focused on the cancer care team's point of view to identify strategies they use to help their patients transition back to school. The results of this research may inform cancer teams at PCH about which transition techniques are currently used by their colleagues, and what resources are readily available to their patients. This research also identifies the current communication pathways used by the cancer care teams to discuss educational needs for on-treatment patients and the needs of cancer survivors.

Social workers, child life specialists, oncologists, nurses, patient navigators, pediatric psychologists, and physician assistants from one institution (Primary Children's Hospital in Salt Lake City, UT) were surveyed and interviewed to identify strategies they implement to help students maintain education progress during treatment and then to enter back into their school while living with cancer and into survivorship.

Research Questions

1. What are the current roles and practices of cancer care team members that help support academic progress in their childhood and AYA cancer patients during and after their cancer care?
2. Do cancer care team members believe that adding an education section to their standardized clinic SCP would be beneficial? If so, what resources and items do they think should be included?

Study Purpose

The purpose of this study was to identify resources and systems currently used by the cancer care teams at PCH to help patients and survivors mitigate the impact of treatment on their education. An additional purpose was to explore the potential benefits of adding an education section to the SCPs produced by PCH.

Method

Research Design

This study used a basic triangulation mixed-methods design consisting of a survey completed by all participants, followed by a 15- to 30-minute semi-structured interview for participants who responded on the survey that they would be willing to be interviewed (Cameron, 2011; Creswell, 2011).

Participants

Individuals who are a part of the cancer care team (social workers, child life specialists, oncologists, nurses, etc.) that work at PCH were invited to participate in the study to provide a wholistic view of what educational support is currently provided to school-age children undergoing cancer treatment. PCH has a hospital schoolteacher who consulted on the research questions and procedures, and thus was not included as a participant. To be eligible, each participant needed to be a cancer care team member employed by or associated with PCH in Salt Lake City, UT, and currently treating or working with childhood cancer patients. Individuals were excluded from the study if they did not work at PCH or did not work with childhood cancer patients.

There were 62 eligible cancer care team members (3 child life specialists, 3 certified nursing assistants, 3 dietitians, 1 interpreter, 12 nurse practitioners, 23 oncologists, 1 pediatric oncology psychologist, 1 physician assistant, 10 registered nurses, and 5 social work coordinators) and all were invited to participate in this study. At the end of the study collection period, a total of twenty-seven cancer care team members completed the online survey and sixteen of those twenty-seven participants also completed the semi-structured interview. The participant sample is described in detail in Table 1.

Survey Instrument and Semi-structured Interview

As part of the survey, demographic data were collected on eight characteristics including age, gender, race, ethnicity, job title, years of practice, and number of patients seen per week. Specific questions regarding the educational experiences of their patients were also asked in the survey. Questions concerning how many of their patients attend school, how many have been pulled out of school for cancer treatment, and how many have received either a 504 plan or an IEP were asked. The participants were also asked what resources they were aware of to help their patients with their educational goals and how they refer patients to those resources. In total, there were 15 patient education questions within the survey. See Appendix A for survey questions. The study was developed while referencing the HOPE Needs Assessment developed by Peterson et al. (2005), which is described in the literature review section above. Specifically, the survey created for this study was adapted from the HOPE Needs Assessment, so the questions could better fit the target population (i.e., cancer care team).

The survey was coded and distributed through the University of Utah REDCap system. REDCap is a secure web application for building and managing online surveys. REDCap allows easy data downloads to Excel and contains features that allow branching logic. REDCap's interface is clean and appealing, while also being simple for participants to use.

Semi-structured interviews are commonly used in qualitative research (DeJonckheere, 2019). This method of interviewing is a conversation between the researcher and the participant that is guided by a flexible interview script that includes clarifying comments, follow-up questions, and probes. Semi-structured interviews allow the researcher to gather open-ended data about a participant's feelings or beliefs around potentially sensitive topics (DeJonckheere, 2019). The semi-structured interview format was chosen so participants could freely talk about the current educational support given and needed, as well as any other issues that affect educational support. This study was created to be exploratory and descriptive, and the semi-structured format allowed that exploration to take place. The semi-structured interview included questions about any known resources, types of interactions with patients, how often they are involved with education plans, etc. See Appendix B for interview questions.

Procedures

Participants were identified through publicly published staff lists of PCH through the Intermountain Provider Directory. Participants were emailed a description of the study and within that email a REDCap survey link was included. Once participants clicked on the survey link, they were directed to a REDCap webpage that described the study and contained a consent form. REDCap allows for participants to electronically

sign the consent form; all participants signed the digital consent form. During the recruitment period, non-responders received follow-up emails a maximum of two times to their work email addresses. The introductory email was sent, then the second and third emails were sent seven days apart to allow the participants time to complete the survey.

All participants were asked if they would be willing to participate in a 15- to 30-minute recorded phone interview. If the participant checked “Yes”, the participant was contacted through email to schedule a time for a phone interview to take place. If the participant did not respond to the first email, a second was sent a week later. If there was still no response seven days after the second email was sent, one last email was sent. All interviews took place over the phone and were recorded using a password-protected audio recorder. The interview audio was then immediately uploaded into a restricted-access Utah State University Box file and deleted from the password-protected audio recorder. A procedure flowchart is located in Appendix D.

A transcription service, often used by Utah State University researchers, transcribed all interview recordings word-for-word. Once the transcriptions were sent back, they were deidentified to remove names of individuals. For example, if a colleague’s name is mentioned, the name was deleted and replaced with [SOCIAL WORKER NAME].

IRB approval was obtained on December 18, 2020, and the first wave of recruitment emails were sent out starting on February 9, 2021. As the surveys were taken, participants who marked that they would agree to an interview were immediately contacted through email to set up a time for the interview to take place. Once all recruitment procedures were completed, and sufficient time had passed for surveys to be taken, the survey data was exported from REDCap into Excel and saved in the restricted-access folder in Utah

State University Box. As mentioned above, after all interviews were completed, the recorded interviews were transcribed and saved in Utah State University Box. Each participant was given the option of providing an email address to be entered in a drawing for one of five \$50 Amazon gift cards.

Data analysis began after the survey was closed and all interviews were conducted. Descriptive data were pulled from the survey. An inductive thematic analysis was used with the interview transcripts, as described in the Data Analysis section below.

Materials

Recruitment materials. The three recruitment emails included a description of the study objectives and the study procedures. All recruitment materials that were sent to participants were approved by the Utah State University IRB. No flyers or social media recruitment materials were used. See Appendix C for the recruitment email language.

Informed consent form. Informed consent via an IRB approved consent form was signed by all participants before they took the survey. The consent form described the study in its entirety, including the procedures they would participate in, the benefits, and the potential risks. The consent form clearly stated that all study procedures were voluntary, and participants could stop study procedures at any time and refuse to participate without explanation. The consent form was accessed through REDCap and was signed electronically before they could access the survey.

Data collection and storage. Survey data were collected on the University of Utah's REDCap platform. Once all the surveys were collected, the survey data were exported and saved in restricted-access Utah State University Box files. The names of the

participants were collected on the survey. Any identifying information, including the participant's name, collected on the survey was not and will not be published in any manner, as that information was only used for tracking purposes to make follow-up contacts to non-responders and to identify potential interviewees.

After an interview was recorded, the audio file was uploaded to a secure Utah State University Box account. All audio files were transcribed and deidentified. The deidentified transcribed interviews were stored and analyzed in a Microsoft Word file that is also saved in the secure Utah State University Box account.

Hardware. Surveys could be filled out using the participant's computer or smart device. The interviews were recorded on a handheld password-protected audio recorder. All files stored and saved on a restricted-access Utah State University Box account.

Data Analysis

Descriptive statistics were used to analyze and summarize all survey data. For demographics, frequencies and percentages are reported using the overall number of surveys as a denominator. The majority of survey questions were multiple choice; for these items, frequency and percentages of each response option were summarized. Open-text responses were summarized and, where applicable, reported in text as quotes.

The interviews were recorded, transcribed, and quality checked against the audio files to ensure accuracy. All interviews were transcribed by Accurate Secretarial LLC, a secure and reputable transcription service. Interview questions were developed (Appendix B) to be mostly open ended to explore emergent themes about childhood cancer patients and how they transition back into education after diagnosis, during their treatment, and into survivorship. Other interview questions were close ended so that

education referral procedures could be described. All interview data were analyzed using thematic analysis, as described below (Braun & Clarke, 2006).

Thematic analysis is a broadly used and foundational method to comprehend the richness of qualitative data (Braun & Clarke, 2006). This analysis technique was created to notice patterns and can be used to analyze a variety of media like a collection newspaper articles, historical videos, and even a set of semi-structured interviews with cancer care providers. For data collected in the form of interviews or focus groups there are generally two different approaches to thematic analysis: (a) an inductive approach, or (b) a deductive approach. An inductive approach is data-driven, with themes reported as they are found in the interview transcripts. There is no pre-existing coding frame being used during analysis, instead the themes found within the interviews can create a coding frame. Inductive analysis is often seen as ‘bottom up’ while deductive coding is seen as ‘top down’. The deductive approach is more analyst driven and would contain a pre-existing coding frame (Creswell & Creswell, 2018). This type of analysis is less detailed. For this study we took an inductive thematic analysis approach, using two researchers throughout the analysis: KM, the thesis student and MML the thesis mentor.

The first step of analysis is called “get a sense of the whole” where both KM and MML read through all sixteen transcripts separately to become familiar with the data (Creswell & Creswell, 2018). In the next step, both researchers looked through the transcripts a second time while writing notes and compiling lists of the ideas that started to be repeated and ideas that were unique. From there the two researchers met for the first time to see how their notes compared and within that meeting they identified similarities

in their notes and talked through the differing sections. After deciding on a preliminary organization scheme the researchers returned to the transcripts and went through each thoroughly looking for any ideas that were missed and to test whether the data fit their scheme. For the next meeting both researchers brought their notes again and began to alter the scheme slightly together. During the data analysis process, complicated ideas were simplified into themes and through further conversation the researchers (KM, MML) agreed on how each of those themes fit together. Before the third meeting occurred, KM created a concept map to demonstrate the relationship among themes. Concept maps allow both the researchers and readers to easily identify the overarching study themes as well as the interconnections between themes. Alterations and further edits were made until there was consensus between both researchers (Figure 1, Table 3).

Results

Survey Results

The following paragraphs present all the findings of this study, both the survey results through descriptive statistics and the interview results through a thematic analysis.

Demographics. After the data collection phase ended, there was a 43.5% response rate, with twenty-seven surveys completed. This falls within the percentage range that Bartel Sheehan (2001) identifies as acceptable. Of those twenty-seven survey participants, sixteen (59%) agreed to also share their ideas and experiences during a phone interview. Participants comprised of professionals from eight different specialties including two child life specialists, a dietitian, an oncologist in fellowship training, an interpreter, seven nurses, ten oncologists, two physician assistants, and three social workers. The majority of cancer care team members reported finishing their medical

training six or more years ago (66.6%) and have worked at PCH for three years or more (74.0%). Most participants were female (70.3%), white (88.9%), and non-Hispanic or Latino (92.6%). The number of patients seen per week varied per specialty but most reported interacting with eleven to thirty patients every week (81.4%). See Table 1 for all demographic data.

Table 1

Demographics

	Total (N=27)	
	N	%
Gender^a		
Male	6	22.2
Female	19	70.3
Specialty		
Child life specialist	2	7.4
Dietitian	1	3.7
Fellow	1	3.7
Interpreter	1	3.7
Nurse	7	25.9
Oncologist	10	37.0
Physician Assistant	2	7.4
Social Worker	3	11.1
Years since training^a		
Less than 1	4	14.8
1-2	2	7.4
3-5	2	7.4
6-10	8	29.6
11 or more	10	37.0
Years at PCH		
Less than 1	5	18.5
1-2	2	7.4
3-5	7	25.9
6-10	6	22.2
11 or more	7	25.9
Ethnicity		
Hispanic or Latino	1	3.7
Non-Hispanic or Latino	25	92.6
Prefer not to answer	1	3.7
Race		
Asian	1	3.7
White	24	88.9
Other	1	3.7
Prefer not to answer	1	3.7

Number of patients per week		
1-10	2	7.4
11-20	13	48.1
21-30	9	33.3
31-40	2	7.4
More than 40	1	3.7

^aMissing responses

Cancer care team caseload characteristics. Within the survey several questions were asked to try and understand the cancer care team members' points of view and clinical situations regarding the schooling/educational barriers their patients face. Most cancer care team members (74.1%) work primarily with on-treatment patients, reporting that about 75-100% of their patients are currently receiving cancer treatment. It is important to note that most participants (70.4%) believed that about 75% to 100% of their patients attended school during and after treatment. Equally, the same percentage (70.4%) estimated that most of their patients (75-100%) at some point during or after treatment were pulled out, quit, or delayed their schooling in some form. Recognizing that cancer treatment impacts all children differently, 44.5% of cancer care team members reported that their patients were absent from school for more than a month each time it was medically necessary to pull out of school. In summary, most of the cancer care team members surveyed were working with on-treatment patients who regularly attended school, but also may have needed to leave school for large durations of time due to their cancer treatment (See Table 2 for caseload characteristics).

Only three of the twenty-seven survey participants marked that they are in regular contact with their patients' schools: two social workers and one nurse. When contacting the school, those three participants most often connected with a school counselor and a school nurse. There were 63.0% of cancer care team members who were unsure if their

patients had an IEP or 504 plan and more than a third of participants (40.7%) were unsure how their patients connected (email, phone calls, etc.) with their school while hospitalized. Of those who did know how their patients connected with their school, 48.2% said email was commonly used and another 48.2% marked video conferencing platforms like Zoom (*participants could choose more than one option*).

Finally, all participants in the survey were asked if their patients received survivorship care plans (SCPs) during or at the end of treatment; 44.5% were unsure, 18.5% said “yes” their patients do receive SCPs, and 37% of cancer care team members said “no” they do not.

Table 2

Cancer Care Team Caseload Characteristics

	Total (N=27)	
	N	%
Estimated percentage of patients on-treatment		
~ 25%	1	3.7
~ 50%	6	22.2
~ 75%	12	44.5
~ 100%	8	29.6
Estimated percentage of patients attending school during/after treatment		
Unsure	1	3.7
< 10%	2	7.4
~ 25%	1	3.7
~ 50%	4	14.8
~ 75%	15	55.6
~ 100%	4	14.8
Estimated percentage of patients that are pulled out/quit/delayed schooling during/after treatment		
Unsure	1	3.7
~ 25%	4	14.8
~ 50%	3	11.1
~ 75%	12	44.5
~ 100%	7	25.9
Days out of school^a		
Less than a week per occurrence	8	29.6
1-3 weeks per occurrence	9	33.3
More than a month per occurrence	12	44.5

Other	3	11.1
Unsure	3	11.1
Regular conversations with school personnel		
Yes	3	11.1
No	24	88.9
Estimated percentage of patients that have an IEP or 504 plan		
Unsure	17	63.0
~ 25%	3	11.1
~ 50%	5	18.5
~ 75%	1	3.7
~ 100%	1	3.7
Contacted to attend IEP or 504 meeting		
Yes	1	3.7
No	26	96.3
How patients connect with school^a		
Unsure	11	40.7
Email	13	48.2
Video conference (e.g. Zoom)	13	48.2
Phone calls	4	14.8
Text	5	18.5
Other	2	7.4
Your patients receive survivorship care plans		
Unsure	12	44.5
Yes	5	18.5
No	10	37.0

^aParticipants could choose multiple answers

Most common education questions and concerns. Within the survey there were two open ended questions that asked about common education concerns patients and families voiced to their cancer care team members: “What are common questions patients, survivors and/or families ask you concerning educational needs?” and “What types of educational concerns do patients and families mention? *(please list any and all examples you can think of).*” In response to the first, there were four common questions (listed in order of frequency) the participants mentioned repeatedly: (a) When should my child attend school during and after treatment? (b) What precautions need to be taken when my child returns to school? (c) Will my child live with any long-term learning difficulties? And (d) Can we get a doctor’s note for missing school because of their

cancer treatment? In response to the second open ended question, there were five common concerns (listed in order of frequency) cancer care team members hear from patients and families: (a) worry about the patient falling behind and missing too much school, (b) peer interactions, (c) negative affects to cognitive function, (d) exposure to illnesses at school, and (e) worry about patients experiencing chemo brain and fatigue at school. “Peer interactions” was a broad category that included the worry about being left out of their friend group, difficulty assimilating with peers, and not knowing how to explain cancer to classmates.

Who is responsible for school concerns? Within the survey there was one open-ended question that asked, “In your opinion, who out of the medical team should be responsible for helping or checking on schooling concerns that patients or family members have?” The top answers were social workers (twenty-one responses) and the hospital schoolteacher (11 responses). Both oncologists and nurses were mentioned five times. Interestingly there were four responses that referenced that the full cancer care team should be responsible for schooling concerns. This idea of responsibility will be further explored in the interview results section.

Interview Results

Sixteen interviews were conducted with a variety of cancer care team members, and through thematic analysis four primary themes were identified in the data: (a) the different roles that cancer care team members fulfill when addressing schooling/education worries, (b) the clinical realities cancer care team members face in helping patients with schooling/educational concerns, (c) the hope of small changes that

could provide clarity and resources regarding education, and (d) suggestions for what to include in a future SCP education section. All subthemes are detailed below.

Interviews lasted between 9:08 minutes to 23:19 minutes and averaged 14:45 minutes. The concept map and table are provided to give a visual representation of the qualitative data (See Figure 1 and Table 3).

Cancer care team roles. One major theme that ran throughout the interviews was the delineation of roles each cancer care team member holds relevant to education. Participants could describe what they do to help patients and they could also say who they refer patients to when schooling concerns come up. Generally, oncologists, physician assistants (PAs), fellows, and nurses regularly check in with patients with a series of questions that include school questions. One oncologist stated, *“You know, I ask what grade they’re in, what classes, what’s your favorite class, what’s your least favorite class, find out how things are going, if they’re doing [school] virtually, how often they’re going to school...”* Several cancer care team members mention that these type of school questions can reveal a lot about the patient’s life, even beyond educational concerns; *“It’s a good indicator of how a patient is doing if they’re able to go to school.”* The other large role that oncologists, PAs, fellows, and nurses take on is talking through potential learning and cognitive side effects the patient may experience throughout treatment and into survivorship. They are also the cancer care team members that field most of the questions that patients and families have about school and education. Often, patients are quickly referred to social workers, the hospital schoolteacher, and/or the clinic psychologist.

The cancer care team members who do the most with schooling and education concerns are the social workers, the oncology-specific hospital schoolteacher, and the clinic's pediatric psychologist. Social workers are responsible for a lot of 'non-medical' questions, a category that schooling falls into. Social workers know many resources for patients inside and outside of the hospital, they work closely with the hospital schoolteacher and they can also act as an intermediary between the hospital and the school, *"so our social worker is very helpful with getting information over to the school, like to the administrators."* The social workers who participated in the interview also mentioned that they often refer patients to the hospital schoolteacher and the psychologist for cognitive testing. The oncology-specific hospital schoolteacher is a cancer care team member who solely focuses on schooling/educational barriers and worries, *"Just off the top of my head I feel like [HOSPITAL SCHOOLTEACHER'S NAME] does the majority of the school help."* From the interviews, most cancer care team members have little to do with IEPs and 504 plans, but most participants believed that special education accommodations would be the hospital schoolteachers' responsibility. It should be noted here that most participants refer their patients to the hospital schoolteacher, but they did not appear to fully understand what the hospital schoolteacher's job description includes or how the hospital schoolteacher helps their patients with schooling concerns. The clinic psychologist was noted most often when participants stated that neuropsychological and cognitive testing is available through their clinic. To be clear, both the hospital schoolteacher and psychologist were not interviewed for this study, so their roles are described only by other participants.

Lastly, the child life specialists and the interpreter do much less with schooling and education issues. Child life specialists make referrals and they role play with patients when they are nervous about peer interactions,

“...for example, right now, like I have a patient who’s young who has [CANCER DIAGNOSIS] she’s probably about eight, and so we role play talking about like, hey, when someone comes up and says, what happened to your leg, what are you going to say...”

The interpreter has very little to do with schooling barriers, but they are the main contact for Spanish speaking patients and so can refer patients to social work, the hospital schoolteacher, and the psychologist. The interpreter holds a lot of trust amongst the Spanish-speaking population. A more detailed list of cancer care team member roles with educational concerns can be found on Table 3. Please note that the roles listed in Table 3 include, both firsthand descriptions and secondhand descriptions. For example, if a nurse mentioned the tasks they commonly engage in to help their patients with education, those items were included in Table 3. If that same nurse also mentioned that social workers help patients and families set up homebound school, that task was also listed in Table 3 under “Social Worker”.

Table 3

Cancer Care Team Member Roles in Addressing Schooling and Education Concerns

<p>Child Life Specialist</p>	<ul style="list-style-type: none"> ▪ Role play school situations ▪ Role play how to answer questions peers may have ▪ Does not discuss medical concerns ▪ Advocate for patients wishes regarding schooling concerns ▪ Refer to hospital schoolteacher ▪ Refer to social worker
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Hospital Schoolteacher^a	<ul style="list-style-type: none"> ▪ Accepts referrals ▪ Help with school reentry as requested ▪ Point of contact for patients and survivors with schooling concerns ▪ Provides in-patient clinic schooling support ▪ Provides out-patient clinic schooling support ▪ Sets up homebound schooling as requested ▪ Participates in IEPs and 504 plans ▪ Works closely with social workers to resolve schooling concerns ▪ Coordinates between the school and the medical team ▪ Considered the education expert by other cancer care team members ▪ Organized volunteers from local university to tutor patients in hospital
Interpreter	<ul style="list-style-type: none"> ▪ Point of contact for Spanish-speaking patients ▪ Refer patients to hospital schoolteacher, social worker or psychologist ▪ Translate all school-based conversations for patients and families
Nurse	<ul style="list-style-type: none"> ▪ Refer to hospital schoolteacher ▪ Refer to social worker ▪ Screen for neurocognitive changes ▪ School check-in conversations patients (e.g. grades, energy level, friends) ▪ Introduce schooling resources (e.g. scholarships) ▪ Contact school nurse ▪ Give medical advice on when to or when not to attend school
Oncologist	<ul style="list-style-type: none"> ▪ School check-in conversations patients (e.g. grades, energy level, friends) ▪ Refer to hospital schoolteacher ▪ Refer to social worker ▪ Refer to psychologist ▪ Discuss potential cognitive side effects at diagnosis ▪ Discuss potential cognitive side effects throughout treatment and into survivorship ▪ Informed consent for cancer treatment procedures that could affect cognitive abilities ▪ Discuss long-term effects from cancer treatment ▪ Give medical advice on when to or when not to attend school ▪ Rarely involved with school logistics or IEPs
Psychologist^b	<ul style="list-style-type: none"> ▪ Neurocognitive testing ▪ "...help with strategies if they're like having a hard time with motivation..." ▪ Help with behavioral concerns ▪ Reaches out to the school with neurocognitive or psychological evaluation results ▪ Discuss IEP or 504 plan options ▪ Answer questions and discuss concerns with patients and families ▪ "...writing letters and making recommendations to the schools." ▪ Patients referred to psychologist when failing classes

Social Worker	<ul style="list-style-type: none"> ▪ Takes referrals ▪ Refer patients to hospital schoolteacher ▪ Refer patients to psychologist ▪ Support families with schooling concerns ▪ Screen for schooling concerns ▪ “Go-to person for any non-medical needs...” ▪ Reach out to the school ▪ Can help with IEPs and 504 plans ▪ Sets up homebound schooling ▪ Talk through special education resources with patients and families
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^aHospital schoolteacher was not interviewed because they helped design the study

^bPsychologist did not respond to survey or interview invitations

Clinical realities. The overall theme, “clinical realities” captures the idea that cancer care team members work within a complex medical system in which they cannot do everything for every patient no matter how much they want to. Four sub-themes were noted within clinical realities to further explain the realities and barriers cancer care team members experience: (a) the balancing act, (b) proper timing, (c) little/no experience with special education, and (d) caregiver responsibility.

Balancing Act. It was common for oncologists and nurses to mention that their first priority will always be to do everything they can to save their patient’s life and to care for them medically. Often, they find barriers preventing them from being able to provide truly wholistic care, so other priorities can often be neglected. One oncologist said,

“I feel like it’s just so hard, too, when kids, you know, kids are, your focus is saving their lives and getting them through therapy and everything, so I feel like that’s, [school is] one of the things that’s like oftentimes not fully addressed, just because there’s so many other things that are important.”

Proper timing. Another barrier that emerged from the interviews was the complicated art of finding the right time to talk to patients and families about long term

side effects that could affect learning and cognition. Almost all cancer care team members commented that during the diagnosis and prognosis talk that patients and families will have all known side effects detailed out to them. Yet, within the same breath they also mention these conversations are overwhelming and contain a lot of information so some parents may not be able to digest or remember everything that was mentioned to them that day, *“So I’ll bring that up at diagnosis when we talk about treatment plan, but that’s usually a time the family’s pretty overwhelmed and probably doesn’t retain much of that information.”* It may be necessary to repeat this type of information a couple more times as treatment continues and into survivorship.

Little/no experience with special education. Through the interviews, it became clear that most cancer care team members do not participate in IEP development or meetings. Similarly, many participants were unfamiliar with many of the accommodations or services that could be provided to their patients through special education, *“No. [IEP’s are] like a mystery to me. I don’t actually understand what it is, but I know that it’s like a learning plan that helps them.”* Social workers, the hospital schoolteacher, and psychologists seem to be the most familiar with education plans.

Caregiver responsibility. The final subtheme within clinical realities is the idea that the cancer patient’s caregiver often shoulders most of the school and education responsibilities. Caregivers regularly act as the bridge between their child’s school and the hospital by organizing homebound instruction or contacting teachers to update them about their child’s diagnosis, etc. Though several cancer care team members did mention that some parents are able to bridge the school and hospital gap well, there are others that do not have the resources or time to bridge that gap as well as they would like to.

Hopes. In conjunction with clinical realities, cancer care team members also expressed some hopes they have for improving how they help patients with schooling concerns. One idea suggested in the interview script was adding an education section to the clinic's SCP outline, this hope and potential solution will be described in the next section. Emergent themes included cancer care team members asking for a resource training to be given to them by the social workers and hospital schoolteacher who are considered the experts in schooling and education,

"I think bigger provider education would probably be beneficial because then we, because we see these patients fairly frequently, and so if I can identify and then go, oh, I know which resource I need to point you at, I think we'd be able to better serve our patients."

It was also requested that a structure be created that could help schooling specific information be passed to all members of the cancer care team,

"...a way to disseminate information better about how our patients are doing, if there's things we should be looking out for. I just feel, you know, if a patient is going to school and having problems, we don't necessarily know about it."

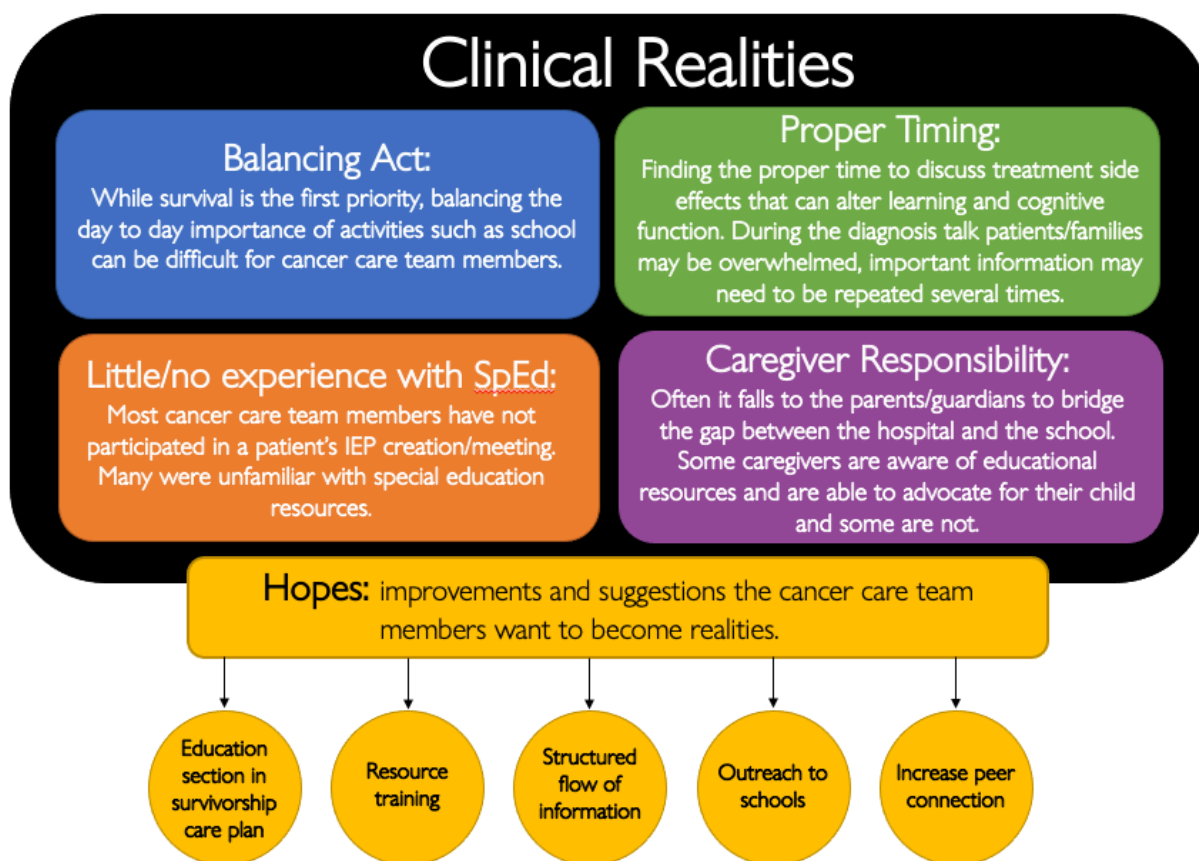
The social workers interviewed mentioned that they used to go into their patients' school to help educate teachers and classmates about cancer. Several cancer care team members would like this to become more regular in the future,

"I think it would be really beneficial if we had someone in a more active role who would be able to go to schools and talk to the kids in the classroom about, you know, what the patient's going through and just kind of give them an idea of what's happening and what to expect."

This hope, to expand into community involvement again, might also help with increasing peer connection. Many of the cancer care team members were very worried about the lack of peer connection their patients feel being away from school and not knowing many children in their same situation,

“I just can’t stress enough like how important peer connection is for kids moving forward, because you’re like you’re not the only one with this and you’re not alone, so whatever we can do to help that social development is huge moving forward.”

SCP suggestions. Interview participants were asked, “Do you think it would be a good idea to include an education section on the SCPs delivered to patients?” All participants gave an affirmative answer. The cancer care team members gave suggestions on the resources that should be included in this education section: (a) links and QR codes to hospital/school/national resources, (b) special education (IEP) or accommodation (504) plans, (c) scholarship opportunities, (d) neuro-psych testing and screening opportunities, and (e) hospital schoolteacher contact information. Several participants also thought the education section should detail out treatment specific guidance on anticipated side effects, for example brain tumor patients would have different guidance than leukemia patients.

Figure 1*Thematic Analysis Visual***Discussion**

A cancer diagnosis affects every aspect of a patient's life, including education. A typical childhood and adolescent cancer patient's education can be disrupted by doctor appointments, treatment sessions, scans, side-effects, being immunocompromised, and much more (Layte & McCrory, 2013). Once cancer treatment is complete, cancer survivors may have late effects that have altered their learning and cognitive abilities like an inability to concentrate, or losing the ability to see, hear, or speak (Bach, 2019). There

have been several studies that have focused on the patient and parent perspective concerning childhood cancer patients and their educational needs but not very many studies have included the cancer care team while investigating this subject. Additionally, there are no studies, to my knowledge, that specifically look at the educational needs of childhood and adolescent cancer survivors from the perspective of cancer care team members.

There are many cancer care team members that take part in aiding patients with schooling concerns and they all seem to have rather distinct roles. Based on participant responses in this study, doctors and nurses focus on discussing side effects and checking in with patients regularly about school. The social workers, hospital schoolteacher, and psychologist take on most of the work needed to help patients with their specific schooling concerns like contacting school personnel and participating in education plans (e.g., IEP or 504 plan). This clear definition of roles could help the cancer care team members understand what resources and aid their coworkers offer to the patients they share. A simple list of cancer care team members and the roles they fulfill a PCH can be found on Table 3. This information could also help in creating a process map to highlight the current procedures implemented when a patient or survivor needs schooling/educational help and what resources are available to them at PCH. Process mapping can be used to increase understanding of the current procedures, analyze how the current procedures could be improved, and later be used to show new employees how to refer patients and survivors to the most helpful educational resources (Marriott, 2018).

Through the data gathered in the interviews, there seems to be an unspoken referral system already in place at PCH (e.g. most cancer care team members refer patients to either the hospital schoolteacher, social worker or psychologist) but there are other simple alterations that could make every cancer care team member feel more informed and involved, the first is a simple training on school and education resources. Within the interviews it was discovered that most cancer care team members know their responsibilities concerning education (e.g., who to refer patients too) but they rarely understand what other cancer care team members regularly do to help patients with their education. For example, if an oncologist notices a schooling or education issue and refers that patient to the hospital schoolteacher or social worker, they do not know what resources and solutions the schoolteacher and social worker can offer. Every cancer care team member seems to be in their own lane, without a deep understanding of what their coworkers do and know. It was mentioned within the results that four cancer care team members thought everyone on the care team (e.g., social worker, nurse, oncologist) is responsible for schooling and education barriers. The first step to being more aware of what other coworkers do could be to have a training where resources and processes are explained, cancer care team members mention how they help their patients with schooling concerns, and experiences are shared.

A recent focus at the hematology/oncology clinic in PCH has been survivorship and SCPs (Mann, 2020). Within this thesis study, cancer care team members were asked when they discuss late effects with their patients and most mentioned that this conversation starts at diagnosis but is brought up throughout treatment and again at the end of treatment. When patients are admitted into the in-patient clinic, cancer care team

members have more control and power to help patients with their education through the hospital schoolteacher. Once patients reach survivorship, cancer care team members may be less involved as they see their patients with lessening frequency after treatment is complete. Yet, ending treatment does not remove educational barriers and worries for patients. While cancer care teams should *not* be responsible for the education of their patients, they do have specific knowledge about how cancer treatment can affect behavior and cognitive abilities. One solution that could regulate the education and late effects discussion, is adding an education section in the SCPs created for patients. Adding an education section to the SCP was viewed very positively by the participants in this study and could create a good opportunity for cancer care team members to discuss late effects with their patients again. When oncologists deliver the SCP, they sit down with the family and briefly talk through each section. During such discussions, education related questions may arise and the oncologist or other cancer care team member could help clarify and settle any worries. Additionally, this study highlighted that there is a large communication gap that exists between the hospital and the school after a cancer diagnosis is given. Adding an education section to the PCH clinic SCP outline could also aide in helping to narrow this communication gap. The most common people to traverse that gap are parents, social workers, and the hospital schoolteacher. If parents, social workers and the hospital schoolteacher had a document in hand that describes the treatment the patient received and academic impacts the cancer care team identifies, the communication gap may lessen and the process for addressing educational concerns may become more efficient. There are a lot of people on the medical and school teams who

care about these children; if everyone could communicate better it could facilitate working together to best support the patient/survivor.

This study had a couple limitations that should be considered. One limitation is that this study was conducted at a single hospital setting. PCH does include a large catchment area, so it is possible that our findings may be similar to other pediatric hospitals with large geographic areas, but determining that would require additional research. Another limitation is that our sample size was small, being limited to cancer care team members who regularly see patients. Despite these limitations, this study is amongst the first that surveys and interviews the cancer care team and tries to understand their perspectives and ideas.

Additional studies could pilot the education section created for the PCH SCP and survey and interview patients and caregivers to see if that section was helpful and what they would suggest could be added or deleted. For larger future studies, researchers should include several pediatric hematology/oncology clinics to increase the sample size and allow for generalizability of the results regarding barriers encountered or procedures used to help cancer patients and survivors with their educational goals. Different procedures and practices could be detailed so other clinics could replicate the educational resources that seem most helpful to cancer patients, survivors, and their families at their hospitals. Additionally, future studies could look into what barriers teachers and educators face while trying to support a child or adolescent diagnosed with cancer. A study that was able to talk with all four populations: (a) patients, (b) parents, (c) cancer care team, and (d) teachers within focus groups or interviews may begin to detail out

what collectively is hard during cancer treatment and survivorship for everyone invested in the cancer patient's education. Potential solutions could also arise that could start to be incorporated in schools and hospital clinics alike.

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APPENDICES

Appendix A. Survey**DEMOGRAPHICS**

1) How many years has it been since you completed your medical/professional training?

- Less than 1 year
- 1-2 years
- 3-5 years
- 6-10 years
- 11 or more

2) How many years have you worked at Primary Children's Hospital?

- Less than 1 year
- 1-2 years
- 3-5 years
- 6-10 years
- 11 or more

3) What is your specialty?

- Nurse
- Physician assistant
- Social worker
- Child life specialist
- Palliative care physician
- Oncologist
- Psychologist
- Other: _____

4) As a (PIPING LOGIC TO INSERT SPECIALTY), please describe your day to day responsibilities.

5) During a typical week, how many patients do you see?

6) Approximately what percentage of your current pediatric patients have a cancer history?

- <10%
- ~ 25%
- ~ 50%
- ~ 75%
- ~ 100%
- Unsure

7) I identify my gender as:

- Female
- Male
- Non-binary/third gender
- Prefer not to disclose
- Prefer to self-identify: _____

8) Which ethnicity do you consider yourself to be?

- Hispanic or Latino
- Not Hispanic or Latino
- Do not know
- Prefer not to answer

9) What race do you consider yourself to be? (*Select all that apply*)

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander

- White
- Other: _____
- Prefer not to answer

PATIENT EDUCATION QUESTIONS

10) What percentage of your current patients would you estimate are considered “on-treatment”?

- <10%
- ~ 25%
- ~ 50%
- ~ 75%
- ~ 100%
- Unsure

11) What percentage of your current patients would you estimate are attending school (pre-k -12 public/private/homeschool, technical college, university, etc.)?

- <10%
- ~ 25%
- ~ 50%
- ~ 75%
- ~ 100%
- Unsure

12) Of your patients who attend school, what percentage would you estimate have had to be pulled out, quit or delay schooling of any kind during or after treatment?

- <10%
- ~ 25%
- ~ 50%
- ~ 75%
- ~ 100%
- Unsure

13) Please list below all the resources you are aware of that Primary Children's Hospital provides for patients who need school assistance.

14) In your opinion, who out of the medical team should be responsible for helping or checking on schooling concerns that patients or family members have?

15) Do you have regular conversations with school personnel about your patients' special needs related to cancer treatment, side-effects, etc.?

Yes

No

15a) If YES, with whom do you speak?

Administrator (e.g., principal, vice principal, special education director)

Counselor

General education teacher

School nurse

School psychologist

School social worker

Special education teacher

Other: _____

15b) And how often do you speak with them?

Once a week

Once a month

As needed

Other: _____

16) Approximately how many days are your patients absent from school, due to cancer treatment/recovery from treatment (check all that apply to one or more of your patients):

- Occasional days throughout the school year (less than a week per occurrence)
- 1-3 weeks per occurrence
- More than a month per occurrence
- Other: _____
- Unsure

17) Approximately what percentage of your patients have an Individualized Education Plan (IEP) or a Section 504 plan?

- <10%
- ~ 25%
- ~ 50%
- ~ 75%
- ~ 100%
- Unsure

18) Have you ever been contacted to attend an Individualized Education Plan meeting with your patient's/survivors' teachers and parents?

- Yes
- No

19) When hospitalized, how do your patients usually connect with their school?
(*Select all that apply*)

- Email
- Video conference such as Skype, Zoom, Google Hangouts, etc.
- Phone calls
- Texts
- Unsure
- Other: _____

20) What are common questions patients, survivors and/or families ask you concerning educational needs?

21) What types of educational concerns do patients and families mention to you?
(Please list any and all examples you can think of)

22) Do you know Lisa Darling, and her role in helping patients at PCH?

Yes

No

22a) IF yes, besides Lisa and her services, do you know of any other resources that are available for patients concerning educational help?

23) Do your patients receive a Survivorship Care Plan?

Yes

No

Unsure

23a) IF yes, what percentage of your patients receive a Survivorship Care Plan?

<10%

- ~ 25%
- ~ 50%
- ~ 75%
- ~ 100%
- Unsure

23b) Do you participate in the creation of Survivorship Care Plans?

- Yes
- No

24) Would you be willing to participate in a 15-30 minute phone interview concerning this topic?

- Yes
- No

24a) Please indicate which is your preferred method of contact to schedule interview time:

- Telephone call: _____
- Email: _____

24b) Please indicate which days would be best for the telephone interview:

- Monday
- Tuesday
- Wednesday
- Thursday
- Friday
- Saturday

24c) Lastly please indicate what time of day would be best for the telephone interview:

- Morning
- Afternoon
- Evening

Appendix B. Interview Guide

Thank you for taking our survey and agreeing to this interview. It will take about 15-20 minutes.

You don't have to answer any questions that you don't want to. There are no right or wrong answers.

All the information that you share is confidential.

With your permission, I will turn on an audio recorder now. The recorder is here to help me so I don't have to write notes while we are talking. This recording will be saved in a secure BOX account and deleted from this device to make sure all your responses are secure and stay confidential. Is that okay with you?

- Yes —————> Continue interview.
- No —————> Thank you for your time.

JOB DESCRIPTION

- A. How often do you help patients with educational concerns?
 - i. Educational concerns can mean worries about missing school, side effects of treatment and how that will alter their learning, IEPs or 504 plans, etc.
- B. Who, in your opinion, is supposed to help families and patients when they have educational concerns? And why?
 - i. Any hospital staff members? Parents and teachers?
 - ii. Does your position at the hospital include helping patients and families with educational concerns?

CURRENT PROCEDURES

- A. If you know a patient is struggling with school, what do you do?
 - i. What resources do you give them? Who do you send them too?
- B. IF CHECKED YES IN SURVEY, #18 (Have you ever been contacted to attend an Individualized Education Plan meeting with your patient's/survivors' teachers and parents?)
 - i. If so, did you participate in the meeting? Describe your experience in the meeting.
 - ii. Have you ever heard of any of your colleagues attending an IEP meeting? Was that colleague a social worker, nurse, oncologists?

- C. Research has shown that some pediatric cancer treatment procedures can alter how a child learns and their ability to learn. Do you discuss potential side effects that can alter learning with patients/survivors and families?
 - i. If so, when do you have this discussion?
 - ii. Is there certain diagnosis or treatment regimen for which you usually discuss educational concerns with your patients? (e.g., brain tumors or chemo heavy treatments)

- D. Do you know what a Survivorship Care Plan is?
 - i. Do you think it would be a good idea to include an education section on the SCPs delivered to patients?

- E. In your opinion, is there anything else that a hospital or clinic could or should do to help patients/survivors and families with any educational concerns?

CLOSING

- A. Was anything upsetting during this interview?

- B. Is there anything else that you'd like to tell us?

Thank you for participating!

Appendix C. Recruitment Email Outline

FIRST ATTEMPT

Dear XXXX,

As a staff member in the hematology/oncology clinic within Primary Children's Hospital, you are eligible to participate in a study focused on understanding the educational needs of and resources available to pediatric cancer patients, survivors, and their families.

The study will involve:

- 1 online survey
 - Approximately 15 minutes to complete
- 1 optional phone interview
 - Approximately 15-30 minutes to complete

To take your survey please click the link below:

INSERT LINK HERE

If you have any questions at all, please do not hesitate to call or e-mail me at the contact information listed below. I will be contacting you twice more times over the next 2 weeks to see if you are interested in this research opportunity. If you rather not be contacted any more, feel free to send me an email.

Thank you for participating!

Karely Mann

Karely.mann@hci.utah.edu

Mobile: 801-864-5837

SECOND ATTEMPT**Dear XXXX,**

An email was sent to you last week inviting you to participate in a brief new study focused on understanding the educational needs and resources available to pediatric cancer patients, survivors and their families.

The study will involve:

- 1 online survey
 - Approximately 15 minutes to complete
- 1 optional phone interview
 - Approximately 15-30 minutes to complete

To take your survey please click the link below:

INSERT LINK HERE

If you have any questions at all, please do not hesitate to call or e-mail me at the contact information listed below. I will be contacting you once more to see if you are interested in this research opportunity. If you rather not be contacted any more, feel free to send me an email.

Thank you for participating!**Karely Mann**Karely.mann@hci.utah.edu

Mobile: 801-864-5837

THIRD/FINAL ATTEMPT**Dear XXXX,**

This will be your last contact for this study. I want to invite you to participate in a brief new study focused on understanding the educational needs and resources available to pediatric cancer patients, survivors and their families.

The study will involve:

- 1 online survey
 - Approximately 15 minutes to complete
- 1 optional phone interview
 - Approximately 15-30 minutes to complete

To take your survey please click the link below:

INSERT LINK HERE

If you have any questions at all, please do not hesitate to call or e-mail me at the contact information listed below.

Thank you for participating!**Karely Mann**Karely.mann@hci.utah.edu

Mobile: 801-864-5837

Appendix D. Procedure Flowchart

