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Examining Parent Information Needs in Pediatric Cancer

Katherine Inman

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Examining Parent Information Needs in Pediatric Cancer

Abstract
Parents of children with cancer receive information about how to care for their child’s health during diagnosis, treatment, and post treatment inflation is critical to this care; however, parents are often left with information needs when their child is done with treatment. Many parents lack enough information about neurocognitive late effects (NCLE) and how to handle the psychological functioning of their child post treatment. The purpose of this study was to analyze parents’ information needs post treatment using qualitative data collected from a survey. Qualitative content analysis was utilized to examine 45 parent responses. Four themes were constructed: (a) the long-term impact of the survivor’s cancer treatment; (b) concerns about the mental and physical functioning of the survivor; (c) parent and family functioning; (d) and accessing information and help. Parents had greater need for information related to the theme of long-term impact of the survivor’s cancer treatment, specifically relating to the long-term effects of treatment/NCLE/late effects, their concerns about the psychological and emotional functioning of the survivor, and their concerns about the survivor becoming an independent adult. Results showed that parents need more information provided to them by healthcare professionals (HCPs) about NCLE, the psychological and emotional functioning of the survivor, and where to access resources on issues post treatment.

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IN PEDIATRIC CANCER

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Tables of Contents

I. Abstract ....................................................................................... Page 3

II. Introduction ................................................................................. Page 4
   B. Parent Information Needs .......................................................... Page 6
   C. Information Needs on Neurocognitive Late Effects ................. Page 8
   D. Interventions for Neurocognitive Late Effects ....................... Page 12
   E. Types of Qualitative Research .................................................. Page 15
   F. Qualitative Research on Parent Information Need .................. Page 16

III. Methods ................................................................................. Page 18
   A. Participants ............................................................................... Page 18
   B. Procedure ................................................................................ Page 18
   C. Measures .................................................................................. Page 19
      i. Demographic Information .................................................... Page 19
      ii. Parent Needs/Program Content .......................................... Page 20
   D. Data Analysis .......................................................................... Page 20

IV. Results .................................................................................... Page 20

V. Discussion ................................................................................ Page 25

VI. References ................................................................................ Page 30

VII. Appendices ............................................................................. Page 34
   A. Table 1 ................................................................................... Page 34
   B. Table 2 ................................................................................... Page 35
   C. Figure 1 ................................................................................ Page 36
Abstract:

Parents of children with cancer receive information about how to care for their child’s health during diagnosis, treatment, and post treatment. Information is critical to this care; however, parents are often left with information needs when their child is done with treatment. Many parents lack enough information about neurocognitive late effects (NCLE) and how to handle the psychological functioning of their child post treatment. The purpose of this study was to analyze parents’ information needs post treatment using qualitative data collected from a survey. Qualitative content analysis was utilized to examine 45 parent responses. Four themes were constructed: (a) the long-term impact of the survivor’s cancer treatment; (b) concerns about the mental and physical functioning of the survivor; (c) parent and family functioning; (d) and accessing information and help. Parents had greater need for information related to the theme of long-term impact of the survivor’s cancer treatment, specifically relating to the long-term effects of treatment/NCLE/late effects, their concerns about the psychological and emotional functioning of the survivor, and their concerns about the survivor becoming an independent adult. Results showed that parents need more information provided to them by healthcare professionals (HCPs) about NCLE, the psychological and emotional functioning of the survivor, and where to access resources on issues post treatment.
EXAMINING PARENT INFORMATION NEEDS

IN PEDIATRIC CANCER

Introduction

In families experiencing a diagnosis of pediatric cancer, the information given to parents during diagnosis, treatment, and post treatment is critical for the care of their child (Trask, Welch, Manley, Jelalian, & Schwartz, 2009). During diagnosis, parents are confronted with a tremendous amount of information about the disease their child is facing (Ringnér, Jansson, & Graneheim, 2011). Information needs change throughout the child’s cancer experience and evolve past the initial diagnosis to the method of treatment and how to manage symptoms. The need for information about what to expect post treatment becomes more salient as the treatment regimen comes to an end; however, while parents are known to have substantial information needs, they are not always met by the team of health care professionals (HCPs) working with their child (Ringnér et al., 2011; Vetsch et al., 2015; Wakefield, Butow, Fleming, Daniel, & Cohn, 2012). Often, parents have many unanswered questions about survivorship post treatment, especially pertaining to long-term adverse outcomes such as neurocognitive late effects (NCLE), what deficits their child might experience, and how to cope with transitioning their child back to school after this distressing time, suggesting they might not be receiving enough information from HCPs about post treatment (Askins & Moore, 2008; Patel et al., 2013; Ringnér et al., 2011; Shultz et al., 2017; Vetsch et al., 2015; Wakefield et al., 2012). The aims of this study are: 1) to analyze qualitative data gathered from a survey given to parents of childhood cancer survivors exploring their survivorship-related information needs and areas where parents perceived it would be helpful to have more information provided to them by HCPs; and 2) to identify common themes where information is
needed, in order to inform parent education in the future.

*Healthcare Professionals Views of Information Needs*

HCPs in pediatric oncology, such as oncologists and nurses, view parent information needs through a specific lens of what they think is important to address. In a study conducted by Bradlyn, Kato, Beale, and Cole (2004), pediatric oncology professionals were surveyed to see what they interpreted as the most important information needs of patients and their parents. Overall, HCPs viewed themselves as effective communicators. They perceived that information needs, such as symptoms and health changes, were superior to psychological needs, such as coping and communication, especially during diagnosis. Communicating information during treatment was more vital to professionals than at the time of initial diagnosis, since parents and patients were perceived to be less capable of retaining information at diagnosis because of high distress (Bradlyn, Kato, Beale, & Cole, 2004; Ringnér et al., 2011). During treatment, patients and family members were perceived to be less distressed about the initial diagnosis and therefore able to retain more information since they had come to better terms with the reality of their child’s cancer (Bradlyn et al., 2004).

Kelly (2005) surveyed nurses with an average of 20 years of experience in pediatric oncology to assess what information they viewed as vital to communicate to families. At the time of diagnosis, nurses focused on coping, information about the child’s cancer, and the treatments available. Contrary to the findings of Bradlyn and colleagues (2004), nurses saw diagnosis as an important time to educate parents on their child’s cancer, treatments, and symptoms they would face (Kelly, 2005). This highlights
information found in the literature that states it is extremely important to parents to receive information early, even at diagnosis, even if the parents are only able to retain a small amount due to distress (Kelly, 2005; Kerr, Harrison, Medves, Tranmer, & Fitch, 2007). Nurses stated that general information about cancer treatment was the essential educational factor on which they focused a substantial amount of time in discussion with parents. Once treatment was completed, the educational focus moved toward teaching families about going home and transitioning back to school (Kelly, 2005). These findings differ slightly from the findings of Bradlyn and colleagues (2004), which indicated that HCPs found psychological factors not as vital to communicate to families as medical factors, especially during diagnosis.

Parent Information Needs

To gather information about what type of information parents need to receive during diagnosis, Kerr, Harrison, Medves, Trammer, and Fitch (2007) adapted the Cancer Patients Needs Questionnaire (CPNQ; Foot & Sanson-Fisher, 1995) and distributed it to parents at a cancer center in Ontario. The parents who completed the survey stated they had more emotional and informational needs over psychosocial, spiritual, physical, and practical needs (Kerr et al., 2007). Parents wanted to discuss coping with their child’s experience, the consequences of painful cancer treatments, and how to deal with fear about the future and the possibility of the cancer recurring (Kerr et al., 2007). Though parents have a critical need for psychological information, HCPs are focused on accurately communicating about complicated treatments and diagnoses (Bradlyn et al., 2004; Kerr et al., 2007).
The process of understanding terminology, diagnosis, and treatment is a confusing and stressful learning process for most parents and often more frustrating to learn during this high stress time (Ringnér et al., 2011). Parents desire detailed written information about diagnosis, tests, treatments, and symptoms, thus making referencing what the oncologist and care team told them easier, since most information was presented to them orally (Kerr et al., 2007; Trask et al., 2009; Vetsch et al., 2015). Having information repeated was also valuable as it allowed parents to ask questions and remember more clearly what was said. As a support, parents valued having multiple people there when information was given (Kerr et al., 2007).

Information during diagnosis is desired and helpful, even though it is a distressing time, since it helps parents to make sense of what is going on and to feel conscientious about their child’s cancer treatment (Gibbins, Steinhardt, & Beinart, 2012; Kelly, 2005; Kerr et al., 2007; Ringnér et al., 2011). Ringnér and colleagues (2011) found that when parents received an adequate amount of information, that information was repeated often, and it was given in manageable amounts, parents felt supported and respected by HCPs and more optimistic about treatment. When parents lacked information, they felt more fearful about the future and worried that they wouldn’t be supported by their child’s HCPs (Ringnér et al., 2011). Post treatment is also a time when information needs may increase as this time can be a source of confusion and stress for parents (Ringnér et al., 2011; Wakefield et al., 2012).

Wakefield, Butow, Fleming, Daniel, and Cohn (2012) investigated how mothers handled a lack of information during cancer treatment and post treatment. Mothers deemed they did not receive enough information about how to confront and handle the
end of their child’s treatment (Vetsch et al., 2015; Wakefield et al., 2012). Other mothers expressed how emotional needs are as important as information needs, and how those needs often go unmet; this can lead mothers to feeling isolated and unsupported (Kerr et al., 2007). Support from co-workers, hospital staff, and significant others during this serious time was vitally important to both parents (Gibbins et al., 2012). While mothers struggled with lack of information about their child’s future and their need for emotional support, fathers struggled with feeling helpless and incapable of fixing the situation. Even when information was provided, they still had little to no control over their child’s condition (Gibbins et al., 2012; Trask et al., 2009). A lack of information from HCPs during transition times, such as diagnosis, treatment, and post treatment, can be a source of confusion and stress. Parents need to learn about their child’s cancer, what treatments they need, and how to treat side effects. They must confront the reality that their child is sick (Kelly, 2005). Information is essential for them to feel prepared for decisions they will have to make about treatment and the future of their child’s health (Gibbins et al., 2012).

**Information Needs on Neurocognitive Late Effects**

In the literature about parent information needs, information needs about NCLE were often unmet at the end of cancer treatment. Neurocognitive sequelae are often prevalent in children with tumors in the central nervous system (CNS) and in patients with leukemia, such as acute lymphoblastic leukemia (ALL; Askins & Moore, 2008; Northman, Ross, Morris, & Tarquini, 2015; Patel, Wong, Cuevas, & Van Horn, 2013; Trask et al., 2009). Craniospinal irradiation, intrathecal chemotherapy, and surgery are most commonly used to treat children with CNS tumors and ALL (Askins & Moore,
These therapies increase the likelihood of long-term cancer-free survival, but exposure to high levels of chemicals and radiation during treatment increases the risk for NCLE post treatment (Reeves et al., 2007).

NCLE manifest as cognitive deficits seen in survivors, including lower intelligence quotient (IQ), difficulties with attention and memory, slower information processing, and executive functioning weaknesses (Askins & Moore, 2008; Patel et al., 2014). NCLE symptoms can resemble attention-deficit disorders since executive functioning, responsible for switching between tasks, maintaining information, and thinking through decisions, can be impaired. (Askins & Moore, 2008; Reeves et al., 2007; Van der Plas, Nieman, Butcher, Hitzler, Weksberg, Ito, & Schachar., 2015). NCLE also can appear similar to a cognitive profile called “sluggish cognitive tempo” (SCT) which also shares some overlap with symptoms of Attention-Deficit Hyperactivity Disorder (ADHD). Children with SCT exhibit behaviors such as daydreaming, lethargy, and disorganization. Deficits in academic functioning and achievement are also noted for this population of children with ADHD and SCT (Reeves et al., 2007). Reeves and colleagues (2007) conducted a study on children one-year post treatment for ALL with NCLE to assess whether survivors were presenting with symptoms of SCT. Siblings were used as the control group for comparison. Using the Wechsler Intelligence Scale for Children-Third Edition (WISC-III) and Child Behavior Checklist to assess siblings and patients, results showed that patients had significantly impaired intellectual functioning and exhibited significantly more SCT symptoms than their siblings, suggesting SCT behaviors could be part of NCLE (Achenbach, 1991; Reeves et al., 2007; WISC III (Wechsler Intelligence Scale for Children), 1992).
Parents whose children had CNS tumors or ALL report feeling that there was not enough information and preparation for the NCLE their child might experience once they transitioned home (Askins & Moore, 2008; Ringnér et al., 2011; Vetsch et al., 2015; Wakefield et al., 2012). Trask and colleagues (2009) surveyed parents whose children had CNS tumors or ALL to understand their NCLE information needs. Parents did not have as many information needs and were more satisfied with the information they received when they believed their child was not at a high risk for NCLE; however, when parents believed their child was more susceptible to NCLE, they were not satisfied with the information they received and desired more information (Trask et al., 2009). Parents’ information needs varied depending on the type of treatment their child received as well. If a child received intrathecal chemotherapy, parents reported having more information needs about NCLE than parents whose children had craniospinal irradiation (Trask et al., 2009).

Shultz and colleagues (2017) found that 40% of parents whose children were treated for CNS tumors and leukemia underestimated their child’s risk for NCLE by over 40% when compared to their oncologists’ estimate. This finding suggests that oncologists may not be adequately educating parents about their child’s risk for NCLE. A lack of information from the oncologist could lead to parents investigating on their own by using the internet. This could lead to misinformation and unneeded stress about the future of their child. Research has found that parents are still mostly relying on information from their oncologist, but in times when information from HCPs is lacking, families turn to the internet, even though it often causes anxiety and stress about their child’s cancer (Gibbins
et al., 2012; Ringnér et al., 2011; Trask et al., 2009; Vetsch et al., 2015; Wakefield et al., 2012).

Providing parents with information about NCLE is vital, since surgery, intrathecal chemotherapy, and craniospinal irradiation may have a serious effect on childhood cancer survivors even years after they have finished treatment. Cognitive deficits, abnormal dependence on parents, and lower executive functioning may lead parents to be concerned, worried, and fearful about their child’s future and how they will manage as an adult (Patel et al., 2013). Patel and colleagues (2013) assessed parents of CNS cancer survivors to understand how they viewed their child’s executive functioning abilities and perceived stress in relation to their child’s neurocognitive deficits. Parents were given the Parenting Stress Index Short Form (PSI/SF), which assesses their perceived stress, and then completed the Behavior Rating Inventory of Executive Functioning-Behavioral Regulation Index and Metacognitive Index (BRIEF-BRI; BRIEF-MCI) to gauge their assessment of their child’s executive functioning deficits (Abidin, 1990; Gioia, Isquit, Guy, Kenworthy, 2000). Children with diagnosed NCLE were given the Wechsler Intelligence Scale for Children-Fourth Edition (WISC-IV) to assess their executive functioning skills and their cognitive deficits (Psychological Corporation, 2003). Results showed that parents were stressed when their child’s executive functioning was impaired due to NCLE. This suggests that executive functioning impairments due to NCLE may impact parent stress (Patel et al., 2013). It is important that parents are prepared for their child’s deficits, so unneeded stress during an already distressing time is not incurred from a lack of information from HCPs.
Interventions for Neurocognitive Late Effects

Interventions and models of care for children with NCLE are being investigated since few programs exist that aim to help with the impact of NCLE. Each program has a different aim that hopes to help patients and families with NCLE. Butler and colleagues (2008) examined the role of cognitive remediation programs for children who received treatment to the CNS with the goal of reducing their neurocognitive sequelae. 161 children participated in the study, with 53 children in the control group and receiving no intervention and 108 children in the intervention group (Butler et al., 2008). All participants underwent baseline neuropsychological evaluation. Examiners assessed academic achievement, brief focused attention, working memory, memory recall, vigilance, learning strategies, self-esteem, parent and teacher ratings of cognitive problems, and inattention using standardized psychological measures (Butler et al., 2008). Participants in the intervention group received 20 two-hour weekly sessions that included cognitive-behavioral interventions designed to teach strategy acquisition and incorporate hierarchically graded massed practice (Butler et al., 2008). They also completed the Attention Process Training cognitive rehabilitation program (Sohlberg, Johnson, Paule, Raskin, & Mateer, 1999; Sohlberg & Mateer, 1999; Butler et al., 2008). Six months post-baseline, assessments of neuropsychological functioning were re-administered to the control and intervention groups to examine differences in neuropsychological variables. While parents of participants in the intervention reported better academic achievement and improved attention, there was no statistically significant difference between the control and the intervention group on measures of neurocognitive functioning. Academic achievement improved; however, it could not definitively be
associated with improvements in neuropsychological functioning (Butler et al., 2008).

Patel and colleagues (2014) drew attention to the unsustained effects of Butler and colleagues’ (2008) cognitive remediation study in their parent-directed behavioral intervention. While Butler and colleagues (2008) focused directly on the child’s neuropsychological and academic functioning, Patel and colleagues (2014) created an intervention focused on equipping parents with the skills necessary to help their child with NCLE perform well in school and examined parents’ ability to advocate for their child in school. Parents who took part in the intervention group received a baseline assessment (Time 1), participated in eight training sessions over three months, received a post-training assessment (Time 2), and then were assessed again after six months had passed after the initial baseline assessment (Time 3)(Patel et al., 2014). Training sessions targeted ways parents could facilitate effective learning strategies, learn ways to encourage their child in school participation, discover how to take advantage of resources, and learn how to provide emotional support in their child’s educational growth. Parents in the control group did not receive training sessions during the course of the initial study, but did receive a baseline assessment (Time 1), three-month assessment (Time 2), and six-month assessment (Time 3). The children received neuropsychological testing at baseline (Time 1) and at six months post-intervention (Time 3). Parents in the intervention group spent 30 minutes a day utilizing the skills they learned in their eight-session training. Parents reported their adherence to the program as well as the benefit they and their child received because of the training sessions. The therapists who trained the parents also tracked their adherence to the intervention (Patel et al., 2014).

Results showed that after the final six-month assessment, parents in the
intervention group were able to maintain the 30-minute daily regimen by utilizing the skills taught to them during the intervention (Patel et al., 2014). Parents’ knowledge, efficacy, and pro-learning behavior all increased in the intervention group when compared to the control group from Time 1 to Time 2. From Time 1 to Time 3 parents reported less stress when compared to the control group at Time 1 and Time 3. The children in the intervention group showed increased academic achievement, specifically in math, from Time 1 to Time 3 when compared to children in the control group; however, despite parents reporting better school performance, executive functioning did not statistically change from Time 1 to Time 3 in the intervention or control group. The researchers suggest that future studies should aim to be more inclusive of the child in learning these pro-learning skills, as well as integrating more support for parents to maintain their likelihood of practicing long term what they have learned (Patel et al., 2014).

Northman, Ross, Morris, and Tarquini (2005) examined a school liaison intervention in a pediatric hospital setting. This program helped parents and children with school deficits that occur throughout the course of many leukemia and CNS tumor patients’ lives. This program was a connection between the parents and the school, making communication between the two more effective. Patients who have CNS cancers are assigned a psychosocial provider who is a liaison between the parents and the schools; their goal is to provide psycho-education for the parents and the school the child will be attending in order to help them prepare for the deficits related to NCLE the child may experience (Northman et al., 2015). In addition to psycho-education, the School Liaison Program (SLP) provider worked as an advocate and ongoing consultant for the
child in their school, making sure they received the proper recommendations for classroom and curriculum and that they had what they needed to succeed in the classroom (Northman et al., 2015). In order to learn if the parents felt the services were effective and helpful with their child’s NCLE and educational needs, 57 out of 130 of the eligible families who participated in the program answered a survey asking how they perceived the services they received. Those who responded were satisfied with the care received and saw it as invaluable while they navigated the changes in their child’s cognitive functioning. While the sample size was small, the researchers suggest this model of care should be examined in other pediatric settings to see how effective it is in aiding families with the transition from treatment back to school (Northman et al., 2015).

Types of Qualitative Research

Creating interventions that help families prepare for NCLE is an important research aim and should continue to be explored in ongoing research. One specific way researchers can understand parents’ needs is through qualitative research methodology. Qualitative research seeks to answer questions that a population might have by examining the experience as a whole in a comprehensive manner, instead of breaking it down into discrete, quantifiable pieces (Walker, 1987). Using these methods researchers understand the meaning of an experience from the perspective of the person living the experience and not through that of an outside observer (Fiese & Bickham, 1998). This allows researchers to get an in-depth look at areas where information or support is lacking, where families would benefit most from interventions, and what interventions need to be created to address the unmet needs. There are several processes that researchers can use to collect qualitative data. Interviews, focus groups, questionnaires, observation, and
textual and document analysis are some of the methods used to collect qualitative data from subjects (Fiese & Bickham, 1998; Morgan, 1999; Walker, 1987; Woodgate, 2000).

According to Woodgate (2000), grounded theory, ethnography, phenomenology, and biography or illness narratives are specific veins of qualitative research that can be selected and used to drive the overall research aim of a qualitative study (Fiese & Bickham, 1998; Woodgate, 2000). Grounded theory looks at symbolic interactionism and the psychosocial process of the group, focusing on their actions and how they connect symbolic information and events. Ethnography examines the beliefs, values, and practices of a group to understand how they perceive and develop understanding of a situation. Use of phenomenology allows researchers to examine the experiences of a group and how they perceive the phenomenology they are experiencing. Illness narratives are biographical retellings of events that allow researchers to construct a timeline of events and when certain beliefs and attitudes began to emerge (Woodgate, 2000).

*Qualitative Research on Parent Information Needs*

Gibbins and colleagues (2012) conducted a systematic review of qualitative literature in pediatric cancer from 1998 to 2011 on the experience of parents whose child had been diagnosed and treated for cancer and found 28 articles that met their search criteria. These articles focused on parents’ experiences of their child’s cancer, treatment, and diagnosis. Once they had analyzed all the papers, 10 themes emerged and were prevalent enough to be discussed across all 28 papers. These themes are common in the qualitative literature and common in quantitative research on NCLE and parent information needs. The themes identified were: Facing the reality of their child’s cancer and what it meant for them; identifying information needs; acquiring control over
treatment and their child’s fate; maladaptive and adaptive coping styles that varied over time; negative and positive effects on life post-diagnosis; support from family, friends, and HCPs; and the differences between mothers and fathers in their reactions and coping with their child’s cancer based on their gender (Gibbins et al., 2012).

Kerr and colleagues (2007) used a mixed methods approach in their study assessing parent information and support needs. After families had completed their survey, follow-up phone calls were used to gather qualitative data to support the quantitative questionnaire data. They were able to identify themes for different needs such as information, support from HCPs, family, and coworkers, and financial needs (Kerr et al., 2007). Ringnér and colleagues (2011) used focus group methods and interview methods together and then analyzed the content to find themes on parent information needs in pediatric oncology. They found several overarching categories into which the themes they had discovered fit. The first category encompassed being viewed as an important person to HCPs. Inside that category were the themes related to being perceived as important to HCPs. The second category encompassed feeling unwanted or obtrusive to HCPs. Inside this category were themes related to feeling unwanted by HCPs (Ringnér et al., 2011).

Using qualitative research methods, this study will analyze qualitative responses to a survey on parent information needs. Using a phenomenological approach, qualitative content analysis will be used to code and analyze the data for common themes and areas where parents lack and desire more information.
Methods

Participants

Using social media and online support groups to recruit participants, 45 parents of childhood cancer survivors ages 6 to 18 were recruited for a study on parents’ needs related to their child’s NCLE. Participants self-selected into the online study. They completed an informed consent form, a demographics questionnaire, and a questionnaire assessing parent information needs. The questionnaire assessed what information parents themselves needed and what information they needed in relation to their relationship with their child.

Demographic characteristics are presented in Table 1. Participants ranged in age from 26 to over 55 (n=45), and 93.3% were female. A majority of participants were white (91.1%). Parents reported child demographics. Children’s ages ranged from 0-18 during time of diagnosis, with most children being diagnosed between ages 0-5 (60%). Twenty-six children were female (57.8%) and 19 were male (42.2%). Diagnoses ranged from 19 children with ALL (42.2%), 8 with brain tumors (BT; 17.8%), one with a CNS tumor (2.2%), three with other types of Leukemia (6.7%), and 14 with other types of cancer (31.1%). Ages of the children during the study ranged from 6 to 18 (m=10.0, sd=19.85). Children’s current grade in school ranged from Kindergarten to 5th grade (N=21, 46.7%) 8 children (17.7%) in 6th-8th grade, and 16 children (35.6%) in 9th-12th grade.

Procedure

The qualitative data for this study were used with permission from Dr. Catherine Peterson and used from a larger existing dataset obtained by the Pediatric Psychology
Lab at Eastern Michigan University. The Eastern Michigan University Human Subjects Review Committee granted exemption for the original study on May 27, 2014 (UHSRC: #40508). Using the Internet, participants were recruited through social media and online support groups. Participants completed an informed consent form online, a demographics questionnaire, and the Parental Information Needs measure. Upon completion of the study, participants were given the option to select a charity to which the research team would make a $1.00 donation. Data collection began on August 24, 2014, and concluded on December 13, 2015. Information collected was non-identifiable, stored on a secure server, and accessible only to research members of the Pediatric Psychology Lab with permission from Dr. Catherine Peterson.

Measures

Demographic Information

A demographics questionnaire was created for this study to collect information about their age, sex, relationship to child, race/ethnicity, how many people lived in the home, number of other children living in the home during their child’s treatment, current marital status, marital status during treatment, highest grade of school completed, and the highest grade of school their partner completed. Participants also reported demographics on their children such as their current age, sex, race/ethnicity, current grade in school, type of school attended by child, initial cancer diagnosis, age of diagnosis, if their child had surgery, chemotherapy, radiation, relapse, bone marrow/stem cell transplant, and when treatment was completed.
Parental Needs/Program Content

The principal investigator developed a three-item survey assessing parent information needs for the purpose of gathering quantitative and qualitative data to assess parent needs. The first item assessed what information parents desired and what information parents needed to hear more about when they reflected on the relationship they had with their child. Information needs covered a range of topics including behavioral issues, school issues, sleeping and eating problems, and psychological and emotional functioning. The second item assessed what information parents desired when they reflected on their own needs in relation to having a child with cancer, such as coping post treatment and psychological and emotional wellbeing. The third item assessed what other information parents desired or would benefit them that wasn’t addressed in the survey or that they wanted to elaborate on more. See Figure 1.

Data Analysis

Qualitative data were obtained from the third item on the Parent Needs/Program Content questionnaire and were examined verbatim. Using content analysis, after the text was read several times, common themes were identified. Codes were assigned to every content area found in the dataset. The primary reviewer went through the dataset and assigned codes to the content. To establish inter-rater reliability, three other reviewers also coded the data set. Any differences were agreed upon by consensus from the reviewers.

Results

From the qualitative data, 17 areas of parent information needs were identified and sorted into 4 main themes (see Table 2). These themes included the long-term impact
of survivor’s cancer treatment, specific concerns about the physical and mental functioning of the survivor, parent and family functioning, and accessing information and help. A majority of parents expressed a need for information in at least one area within each theme; however, the greatest need for information was found pertaining to the themes of accessing information and help, and the long-term impact of survivor’s cancer treatment.

Many parents discussed wanting certain guidelines, roadmaps, and clear instructions on whom to call for help. Parents had specific questions about their children’s different physical deficits and symptoms post treatment, but were unsure of what course of action to take, since resources were lacking or they were unable to find them. A lack of information about how to handle life post treatment led a few parents to express concerns that the situation would never improve for their child. Low-income families expressed concern that they wouldn’t be able to find affordable care or resources. One family didn’t know where to find children’s books about children with cancer to give to their survivor. More information on how to find the resources needed was desired by many parents in this study.

Families did not feel prepared or informed about NCLE after treatment and were unsure they would be able to identify them in their child. Parents didn’t know where to find the resources and the follow-up care needed for NCLE.

“The late effect list is endless. Parents have no idea what is coming or how to plan for making the child an independent adult. Early info would probably scare families but would be useful.”
“Most doctors we have come across are not aware that children who have undergone ALL treatment can develop late cognitive difficulties and hence do not certify that the child requires special support.”

HCPs were perceived to not know about late effects or to not understand that late effects are a common issue post treatment for many cancer survivors. Lack of information on NCLE from HCPs left parents with a feeling of uncertainty about what behavior to watch for in their child. This led to a sense of being unsupported by HCPs and uncertainty about how to care for the child post treatment. Some parents did not even know where to find HCPs who could help them with neuropsychological testing and NCLE. One survivor’s parents waited until they were struggling in school before they noticed and got testing for their child’s NCLE. One parent stated they were not accurately informed about the severity of treatment and how age of diagnosis mattered in predicting neurocognitive functioning post treatment.

“I have two survivors. One was diagnosed at 15 months and one at 10 years old. The issues surrounding each are VERY different. Treatment at a very young age (i.e. 15 months) seems to have had a much more profound effect on one child versus a diagnosis at 10 years old. Information on issues around age at diagnosis would be helpful.”
Not only are parents lacking information on specific people to call for help, where to gather the necessary resources for post treatment care, and information about NCLE, but also concerns about the survivors' emotional and psychological functioning are unmet. Mental health, emotions, confidence, attachment, and coping were areas where more information was desired. Parents wondered how to help their children cope with the side effects of treatment and how to help them feel confident after surgeries that left them physically unable to participate in activities. Enabling their children to cope and become functioning adults was important to this population of parents. Along with emotional and psychological concerns were behavioral concerns as well. A few parents desired information on how to handle survivors' behavior, regressive behaviors, avoiding taking medication or avoiding preferred activities, and behaviors related to sleep disorders.

Several families reported experiencing issues with school. Many didn’t know how to approach schools to seek help or accommodations. Many didn’t know how to communicate with the schools about the issues their child was facing post treatment, such as physical accommodations.

“We have struggled with getting our son to be physically active after treatment. From ages 3-6 he was on chemo and couldn't do much. Since then, he lacks confidence and is so far behind in skills and endurance compared to other children that he doesn't want to even try. Advice and resources on this would be helpful.”

Information about obtaining school accommodations for children with learning disabilities was desired. Other areas of need included how to handle absences from
school post treatment and managing children who couldn’t sit for extended periods of time, thus affecting their school performance.

Parents were unsure and desired more information on preparing their survivors to become independent adults, specifically how to help survivors with physical functioning problems and help with taking medications. One family wanted details about group home alternatives for younger adult cancer survivors. Others wanted information on support groups for cancer survivors who finished high school and were beginning college.

“Will she be able to conceive and become a mother?”

Fertility was mentioned as a fear from a few parents and not knowing whether the survivor could conceive offspring of their own due to the treatment for their cancer.

Children post treatment have a multitude of needs that parents need information about; however, parents themselves need information about their own supportive and emotional needs while caring for their child.

“Life after your child finishes treatment... Will it ever feel normal again?”

Post treatment parents struggled with knowing how to feel important to HCPs. One parent wanted to learn how to let go of their child and not be overly protective or too attached after treatment. Parents needed information on coping, mental health, and counseling for Post-Traumatic Stress Disorder. A few parents wanted information on how to maintain their family relationships, such as maintaining a healthy partner relationship.
where they felt supported and cared for, even with a recovering child, work responsibilities, and other children. Some parents were unsure of how to parent the siblings of survivors and help them cope with cancer. Others did not want to worry that the siblings would get sick as well. One parent worried about their children’s faith after the survivor’s cancer diagnosis.

Finally, parents struggled with knowing how to communicate with others about their child’s cancer. Information was desired on how to discuss the survivor’s cancer, diagnosis, treatment, and the parents’ hopes and fears. One parent indicated that some people they shared with didn’t know how to respond to their child’s cancer, making communication about the issue difficult.

“How to help friends and family feel more comfortable in how to communicate with families going through Cancer, we found some people didn’t know what to say so didn’t say anything, so would be helpful if they had guidelines in how they could help.”

Discussion

Parents of children with cancer are confronted with a large quantity of information as they learn about their child’s diagnosis, treatment, and post treatment symptoms. While HCPs try to inform parents adequately about the medical needs their child now has, parents are still left with information needs post treatment (Bradlyn et al., 2004; Kelly, 2005). Parents desire information to be presented to them multiple times, so they are able to absorb and understand the care needs of their child (Gibbins et al., 2012; Kerr et al., 2007; Ringnér et al., 2011; Trask et al., 2009). Several studies noted
information needs on the survivor's psychological and emotional functioning (Gibbins et al., 2012; Kerr et al., 2007; Trask et al., 2009; Wakefield et al., 2012). Post treatment, many parents underestimated their child's risk for NCLE and left with questions about what cognitive deficits their survivor might face (Askins & Moore, 2008; Gibbins et al., 2012; Patel et al., 2013; Ringnér et al., 2011; Shultz et al., 2017; Trask et al., 2009; Vetsch et al., 2015). Analyzing qualitative data from a questionnaire, this study examined areas where parents desired more information and identified where information is potentially lacking.

Results from the present study revealed key information about areas of information needs. Four information themes were identified: The long-term impact of the survivor's cancer treatment; concerns about the mental and physical functioning of the survivor; parent and family functioning; and accessing information and help. More need for information was found within the category of the long-term impact of the survivor's cancer treatment theme, specifically about NCLE and concerns about the survivor's behavior and behavior management, the survivor's psychological and emotional functioning, and the survivor's maturation to adulthood. This finding supports the existing literature on parent information needs. Bradlyn and colleagues (2004) illustrated how HCPs were more acutely focused on the physical symptoms of treatment and health changes in their patients and saw medical needs as superior to psychological needs. Over one-third of the parents in this study reported having needs for more information about their survivor's emotional and psychological functioning, suggesting HCPs should focus more on preparing families to handle the emotional and psychological effects of cancer on the children they are treating. Many parents were unsure how to cope with the mental
health of their child. Psychological and emotional function is vitally important to many parents, and information on these areas from HCPs would aid them in caring for the survivor.

NCLE were also discussed by 22% of the parents in the study. Many parents were unsure what exactly NCLE are and how to identify them in their child. Some parents believe that HCPs were not aware of NCLE, since they never informed the parents about them. This supports Trask and colleagues’ (2009) findings that parents whose children had CNS tumors or ALL were not satisfied with the information they received on NCLE. Many parents underestimated their child’s risk for NCLE, suggesting oncologists and HCPs are not adequately informing or discussing the implications of intrathecal chemotherapy and craniospinal irradiation (Shultz et al., 2017; Trask et al., 2009). Being unprepared for the long-term impact of a survivor’s treatment will impact families adversely. If parents are not informed about NCLE properly, they may not be prepared for the behavior of the survivor or the cognitive deficits they will face. Parents need to be adequately informed about NCLE so survivors can receive the proper school services and so unneeded stress for the parents and survivor is avoided (Patel et al., 2013). Around 15.3% of parents in the study reported concerns about school-related issues suggesting many parents are not receiving the resources they need. Researchers should continue to test interventions that will aid families to prepare their survivor for school post treatment and to help them succeed academically (Butler et al., 2008; Northman et al., 2015; Patel et al., 2014).

While many studies have examined parent information needs in cancer relating to NCLE, when they would prefer to receive information, and what kind of information they
felt they were lacking, parents in this study reported a general lack of knowledge about where to even find the resources they needed for themselves and their child post treatment. Over 33% of parents needed help locating resources on school-related issues, psychological function, NCLE, and how to handle their own emotional functioning. Parents need to be informed on where they can go for resources post treatment when they are not interacting with HCPs everyday. Guidelines are needed that direct parents to the services they need for their child and also for their own functioning. HCPs should make information easily and clearly accessible to parents so their survivor will not be impaired because parents were not adequately informed. HCPs and researchers should continue to examine how best to disseminate information about these information content areas to parents.

One limitation to this study was the method used to gather data. While the survey allowed participants to provide a qualitative response about their needs, some answers were unclear about to whom they were speaking or what exactly their information need was. Collecting data through interviews or focus groups allows researcher to ask clarifying questions so they are able to gather the most accurate data; however, that could not be done in this study since it was a survey. Having other reviewers assign codes to the data set was a strength of this study and allowed for greater reliability in how the data were analyzed by the primary researcher.

This study reiterated the importance of HCPs providing information to patients about, not only their physical health, but also about their psychological health. Integrative care is needed for pediatric cancer patients so the multiple issues they are facing may all be addressed instead of focusing on only a few key areas of relevance to HCPs. This
study has demonstrated that research is needed to examine how to disseminate information to parents about their needs, specifically about their information needs on resources, NCLE, and the psychological and emotional functioning of their survivor.
References:


APPENDIX:

Table 1

*Participant Characteristics (N=45)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n (%)</th>
</tr>
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<tbody>
<tr>
<td><strong>Parent Characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>Parent Sex</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>42 (93.3)</td>
</tr>
<tr>
<td>Male</td>
<td>3 (6.7)</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
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<tr>
<td>White</td>
<td>41 (91.1)</td>
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<tr>
<td>Other</td>
<td>4 (8.9)</td>
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<tr>
<td>Current Age</td>
<td></td>
</tr>
<tr>
<td>26-35</td>
<td>5 (11.1)</td>
</tr>
<tr>
<td>36-45</td>
<td>17 (37.8)</td>
</tr>
<tr>
<td>46-55</td>
<td>20 (44.4)</td>
</tr>
<tr>
<td>Over 55</td>
<td>3 (6.7)</td>
</tr>
<tr>
<td><strong>Child Characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>Child Sex</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>26 (57.8)</td>
</tr>
<tr>
<td>Male</td>
<td>19 (42.2)</td>
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<tr>
<td>Race/Ethnicity</td>
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<tr>
<td>White</td>
<td>40 (88.9)</td>
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<tr>
<td>Other</td>
<td>5 (11.1)</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td></td>
</tr>
<tr>
<td>0-5</td>
<td>27 (60.0)</td>
</tr>
<tr>
<td>6-11</td>
<td>10 (22.2)</td>
</tr>
<tr>
<td>12-18</td>
<td>8 (17.8)</td>
</tr>
<tr>
<td>Current Age</td>
<td></td>
</tr>
<tr>
<td>6-11</td>
<td>22 (48.9)</td>
</tr>
<tr>
<td>12-18</td>
<td>23 (51.1)</td>
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<tr>
<td>Diagnosis</td>
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<tr>
<td>ALL</td>
<td>19 (42.2)</td>
</tr>
<tr>
<td>BT</td>
<td>8 (17.8)</td>
</tr>
<tr>
<td>CNS</td>
<td>1 (2.2)</td>
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<tr>
<td>Other Leukemia</td>
<td>3 (6.7)</td>
</tr>
<tr>
<td>Other</td>
<td>14 (31.1)</td>
</tr>
<tr>
<td>Current Grade in School</td>
<td></td>
</tr>
<tr>
<td>Kindergarten-5th Grade</td>
<td>21 (46.7)</td>
</tr>
<tr>
<td>6th-8th Grade</td>
<td>8 (17.7)</td>
</tr>
<tr>
<td>9th-12th Grade</td>
<td>16 (35.6)</td>
</tr>
</tbody>
</table>
Table 2

*Themes Identified from Qualitative Data*

<table>
<thead>
<tr>
<th>Themes and Areas</th>
<th>Number of Parents Who Stated Need n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Long Term Impact of Survivor’s Cancer Treatment</strong></td>
<td></td>
</tr>
<tr>
<td>- Concerns About Survivor’s Behavior/Behavior Management</td>
<td>6 (13.3%)</td>
</tr>
<tr>
<td>- Concerns About Survivor’s Emotional/Psychological Functioning</td>
<td>14 (31.1%)</td>
</tr>
<tr>
<td>- Long Term Follow Up Care of the Survivor</td>
<td>4 (8.9%)</td>
</tr>
<tr>
<td>- Long Term Effects of Treatment/NCLE/Late Effects</td>
<td>10 (22.2%)</td>
</tr>
<tr>
<td>- Communication with HCP About Late Effects</td>
<td>3 (6.7%)</td>
</tr>
<tr>
<td>- Survivor Becoming an Adult</td>
<td>6 (13.3%)</td>
</tr>
<tr>
<td><strong>Concerns About Mental or Physical Functioning of the Survivor</strong></td>
<td></td>
</tr>
<tr>
<td>- School Related Issues</td>
<td>7 (15.6%)</td>
</tr>
<tr>
<td>- Learning Disabilities (LD)</td>
<td>2 (4.4%)</td>
</tr>
<tr>
<td>- Concerns about Physical Functioning and Quality of Life</td>
<td>4 (8.9%)</td>
</tr>
<tr>
<td>- Fertility Issues</td>
<td>2 (4.4%)</td>
</tr>
<tr>
<td><strong>Parent and Family Functioning</strong></td>
<td></td>
</tr>
<tr>
<td>- Parent Needs: Supportive/Emotional</td>
<td>9 (20%)</td>
</tr>
<tr>
<td>- Long Term Parent and Child Relationship</td>
<td>2 (4.4%)</td>
</tr>
<tr>
<td>- Faith</td>
<td>1 (2.2%)</td>
</tr>
<tr>
<td>- Siblings</td>
<td>3 (6.7%)</td>
</tr>
<tr>
<td>- How to Communicate with Friends/Family about Child’s Cancer</td>
<td>3 (6.7%)</td>
</tr>
<tr>
<td><strong>Accessing Information and Help</strong></td>
<td></td>
</tr>
<tr>
<td>- Resources</td>
<td>15 (33.3%)</td>
</tr>
<tr>
<td>- Low Income</td>
<td>2 (4.4%)</td>
</tr>
</tbody>
</table>
Parent Needs/Program Content

1. Thinking about your relationship with your child, please check all of the boxes next to the information area that you feel you would want to receive information about or that you feel would be helpful to have more information about.

✓ Noncompliance/Not following Directions/Not Listening
✓ The best ways to deliver praise
✓ Following through with consequences
✓ Following through with directions
✓ Setting limits
✓ Discipline
✓ My child’s attitude
✓ Arguing
✓ Homework (getting it done, turning it in, bringing it home, etc.)
✓ Getting assistance from your child’s school
✓ Poor School Performance
✓ IEP/504
✓ Inattention/Distractability
✓ Hyperactivity
✓ Sadness in your child
✓ Worrying in your child
✓ Anger/Frustration in your child
✓ Social Relationships
✓ Organization/planning
✓ Sleeping
✓ Eating
2. Thinking about yourself, please check all of the boxes next to the information area that you would want to receive information about or that you feel would be helpful to have more information about.

- ✓ Coping post treatment
- ✓ Time management
- ✓ My mental health
- ✓ Taking breaks
- ✓ My frustration tolerance
- ✓ Worrying/Anxiety
- ✓ Sadness
- ✓ Anger

3. Are there any other areas of information that you would feel would help you and/or your child? Please use this space to talk about any other area that you may need or want help with.