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Parents' Experiences of Camp for Siblings of Pediatric Oncology Patients

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**PARENTS' EXPERIENCES OF CAMP FOR SIBLINGS OF PEDIATRIC ONCOLOGY
PATIENTS**

A Master's Thesis

Presented to

The Graduate College of
Missouri State University

In Partial Fulfillment

Of the Requirements for the Degree

Master of Science, Early Childhood and Family Development

By

Kristen Krueger

May 2020

PARENTS' EXPERIENCES OF CAMP FOR SIBLINGS OF PEDIATRIC ONCOLOGY PATIENTS

Childhood Education and Family Studies

Missouri State University, May 2020

Master of Science

Kristen Krueger

ABSTRACT

The diagnosis and treatment of childhood cancer is oftentimes a stressful experience for individuals other than the patient, such as parents and siblings of pediatric oncology patients. Parents and siblings may be impacted in many ways, but there are interventions to help. The purpose of this qualitative study was to understand parents' lived experiences of having a child who has attended a camp designed for siblings of pediatric oncology patients. Parents ($n=5$) of siblings that have attended camp for siblings were interviewed with open-ended questions. Data was analyzed using phenomenology procedures. Results from this study indicated that mothers and fathers of siblings saw camp as a positive experience. Parents described the reasons for sending their child to camp, how they perceived their child to experience camp, and how they viewed camp to affect their child. The results of this study can be used by helping professionals, parents, and camp staff.

KEYWORDS: siblings, camp, pediatrics, cancer, oncology, parents

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In the interest of academic freedom and the principle of free speech, approval of this thesis indicates the format is acceptable and meets the academic criteria for the discipline as determined by the faculty that constitute the thesis committee. The content and views expressed in this thesis are those of the student-scholar and are not endorsed by Missouri State University, its Graduate College, or its employees.

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INTRODUCTION

The diagnosis and treatment of childhood cancer is oftentimes a stressful experience for individuals other than the patient, such as siblings of pediatric oncology patients (Prchal & Landolt, 2009). Siblings are greatly impacted in various ways. Research has shown that siblings of children actively receiving treatment for childhood cancer exemplify damaged psycho-health and health-related quality of life (Buchbinder, et al., 2010). In almost every area of life, siblings of oncology patients experience hardship. Siblings experience many potential negative changes to their emotions, relationships, family, home, school, and psychosocial state. However, there are interventions, such as a sibling camp that can decrease the negative impact towards a sibling.

Statement of the Problem

While the attention of family members and caregivers is aimed towards a child diagnosed with cancer (Prchal & Landolt, 2009), it is important to consider how siblings of pediatric oncology patients are reacting or are impacted. Family members, close friends, and caregivers of pediatric patients are involved in the cancer journey (Buchbinder, et al., 2010). The population of siblings of pediatric oncology patients is growing quickly (Buchbinder, et al., 2010). However, little is known about these siblings and siblings are at risk for many negative consequences. Siblings are at risk for emotional, behavioral, and social problems due to the diagnosis and treatment of cancer (Prchal, Graf, Bergstraesser, & Landolt, 2012). Siblings of pediatric oncology patients experience intensified emotional/behavioral problems, lower perceived quality of health, and mental health issues (Prchal & Landolt, 2009). Attention should be paid to siblings because they are involved in the treatment experience, the population is growing, and they are at

risk for many negative impacts (Buchbinder, et al., 2010). Therefore, there is a need for psychosocial interventions. Sibling interventions focus on enhancing coping abilities, recognizing needs, involving siblings in the treatment and/or hospital stay, sharing medical information/knowledge with siblings, being a resource to siblings, and giving social support to siblings (O'Shea, Shea, & Robert, 2012; Prchal & Landolt, 2009). Most interventions are aimed at improving a sibling's depression symptoms, psychosocial well-being, medical knowledge, social support, and quality of life and decrease negative psychosocial impacts (Prchal, Graf, Bergstraesser, & Landolt, 2012; Prchal & Landolt, 2009). Siblings and parents experience satisfaction as a result of the positive changes siblings of pediatric oncology patient's experience, such as decreased depression symptoms and improved well-being (Prchal & Landolt, 2009).

Siblings experience psychosocial impacts as a result of the patient's medical diagnosis and treatment. Most siblings experience less time participating in social experiences (Weiner & Woodley, 2018). Siblings are also at risk for social problems, such low amounts of social support (Prchal, Graf, Bergstraesser, & Landolt, 2012). Siblings experience changes amongst their social relationships, often times leaving siblings searching for relationships if the change is negative. Siblings may also experience changes in their extracurricular activities (Yang, Mu, Sheng, Chen, & Hung, 2016). Siblings of pediatric oncology patients experience less participation in extracurricular activities once the patient is diagnosed with cancer due to having less time for activities, decreased performance levels, lack of interest, and decreased parental availability and involvement (Weiner & Woodley, 2018). Siblings of pediatric oncology patients become socially isolated and are likely to experience adjustment issues (Wellisch, Crater, Wiley, Belin, & Weinstein, 2005). Siblings will likely experience psychosocial issues shortly after the diagnosis

that last through remission (Houtzager, Grootenhuis, Caron, & Last, 2004). Therefore, there is a need for a psychosocial intervention.

Summer camps targeted at siblings of pediatric oncology patients can serve as an intervention. Summer camps are provided separately for patients and siblings. These camps benefit siblings and patients differently (Wellish, Crater, Wiley, Belin, & Weinstein, 2005). Camping interventions promote positive peer interactions, allow siblings to express feelings, relate to others, and participate in fun activities (Hancock, 2011; Packman, et al., 2010; Prchal & Landolt, 2009; Prchal, Graf, Bergstraesser, & Landolt, 2012; Ranita, Passmore & Baker 2005). Camping can provide siblings with an idea that they are not alone and others are experiencing similar reactions, which can lead to positive psychosocial adjustment (Prchal & Landolt, 2009). Although the effects on siblings have been described in a variety of articles and interventions, few studies specifically examine the effects a camp intervention has on a sibling psychosocially. However, researchers have pointed out that it is evident that siblings are impacted and that parents experiences of having children that have attended camp have been positive. Parents have stated that camp is positive because it provides their children with peer support, improvements to their behavior and level of independence, and it provides respite for the parents themselves (Wu, Prout, Roberts, Parikshak, & Amylon, 2011). Parents have shared that their children gained skills in adventure, independence, making friends, positive identity, and peer relationships due to their child attending camp (Henderson, Whitaker, Bialeschki, Scanlin, & Thurber, 2007).

Purpose of the Study

The purpose of this study was to understand parents' lived experiences of having a child who has attended a camp designed for siblings of pediatric oncology patients. This was executed

utilizing in depth interviews amongst parents of siblings that have attended an oncology sibling camp. Open ended, qualitative and demographic questions were asked to gather data.

Research Questions

The purpose of this study was to understand parents' lived experiences of having a child who has attended a camp designed for siblings of pediatric oncology patients. Research questions were developed with the purpose in mind. Parents were interviewed through a variety of questions (see appendix A) to answer the following research questions.

Unfolded research questions:

1. What encourages a parent to send their child to a camp specifically designed for their population?
2. What do parents notice within their children after their child attends a camp designed for siblings of pediatric cancer patients?
3. Is a summer camp experience designed for siblings of pediatric cancer patients a beneficial intervention?

Research Hypothesis

Qualitative studies are not always driven by the need to test a hypothesis and do not typically involve statistical hypothesis testing. However, it was hypothesized that summer camps designed and targeted at siblings of pediatric cancer patients positively impact these siblings. It was hypothesized that there is a need for siblings to attend similar camps in order to relate to others, socialize, and have time designated for themselves with others who experience similar situations.

Research Design

The study was completed through phenomenology and thematic coding (Creswell, 2007). Data was collected through in depth interviews with parents through open-ended interview questions regarding the summer camp experience and demographics. Participants involved in this study were recruited via snowball sampling.

Significance of the Study

This study has the potential to allow helping professionals to recognize the impact a cancer diagnosis has on a sibling of a pediatric patient and to understand the need for an intervention. This study will emphasize a parent's perception of their child attending a sibling camp. This study will allow helping professionals to pay attention to siblings, point out to parents a sibling's needs, and provide intervention ideas. More helping and medical professionals may refer families to camps that are designed for siblings of pediatric oncology patients, which will lead to psychosocially healthier siblings to pediatric cancer patients. In addition, this study has the potential to reach parents who are considering sending their child that is a sibling of a pediatric cancer patient to a summer camp intervention. This study can encourage parents to send their children to a camp intervention, as they will understand the benefits a camp designed for them can offer. More parents may send children to these interventions upon reading this article.

Assumptions

1. It was assumed that parents would be excited and motivated to participate in this study, as they are passionate about the camp their children attend.
2. It was assumed that questions would be answered honestly by parents, as they want

others to see why their children should attend sibling camp if applicable.

3. It was assumed that there were parents willing to share their experiences regarding the summer camp.

Limitations

There were anticipated limitations of this qualitative study. The researcher did not have control over how the parents respond. Information reported in interviews had the potential to be an accurate or inaccurate memory of how the parents actually experienced the event, which can serve as a limitation if the information reported is not an accurate description of the lived experience of camp.

Definition of Terms

1. Intervention – the act of interfering with the outcome or course especially of a condition or process (as to prevent harm or improve functioning).
2. Oncology – a branch of medicine concerned with the prevention, diagnosis, treatment, and study of cancer.
3. Sibling – one of two or more individuals having one common parent to include: step children and adopted children.

LITERATURE REVIEW

Siblings of pediatric oncology patients experience many potential negative changes to their emotions, relationships, family, home, school, and psychosocial state. However, there are interventions in place that can improve a sibling's depression symptoms, psychosocial well-being, medical knowledge, social support, and quality of life and decrease negative psychosocial impact (Prchal, Graf, Bergstraesser, & Landolt, 2012). Parents have the choice on what interventions their children utilize. Therefore, there is a need to understand parent's lived experiences of an intervention due to how siblings are impacted, interventions for siblings, camp interventions for siblings, and parent perceptions.

Cancer & Siblings

We know siblings of pediatric cancer patients are impacted in a variety of ways. Siblings experienced emotions, such as fear, worry, anger, depression, anxiety, stress, isolation, jealousy, shock, guilt, and/or uncertainty when their ill sibling was diagnosed/receiving treatment for cancer (Weiner & Woodley, 2018). Siblings fear death of the patient, uncertainty, disruption of normalcy, and that they may contract the disease (Hamama, Ronen, & Rahav, 2008; Long, et al., 2018). Siblings may feel worry often because they have observed their brother or sister receiving treatment that induces emotional and physical pain for the patient (Prchal & Landolt, 2009). These siblings may also experience anger due to the patient receiving all of the attention and being constantly sick (Weiner & Woodley, 2018). Siblings are likely to experience jealousy and isolation as treatment continues because the ill child is receiving more parental attention, toys, gifts, food, and more care in general (Prchal & Landolt, 2009; Weiner & Woodley, 2018). Internalizing issues, such as depression can be experienced by siblings (Prchal & Landolt, 2009).

Siblings of male survivors are at a greater risk for developing depression for unknown reasons compared to female survivors (Buchbinder, et al., 2010). About 33% of teenage siblings experience internalizing problems, such as depression (Houtzager, Grootenhuis, Caron, & Last, 2004). Anxiety and uncertainty are experienced by siblings due to a family not having an accurate diagnosis, not knowing the outcome of a sibling's treatment or journey, threats created by cancer, and fear that the sibling may become diagnosed (Hamama, Ronen, & Rahav, 2008; Weiner & Woodley, 2018). Stress is also a common feeling felt by siblings of patients due to the cancer journey. In addition, stressors connected to the diagnosis of childhood cancer affect everyone in the family, including siblings (Long, et al., 2018). Guilt is often felt by siblings due to the patient not being able to participate in typical childhood activities, such as sports or swimming, while they can participate in these activities (Weiner & Woodley, 2018). Guilt may also be experienced when a healthy sibling is able to go home from the hospital or feel better (Weiner & Woodley, 2018).

Emotional distress is present in siblings of pediatric oncology patients (Houtzager, Grootenhuis, Caron, & Last, 2004; Sharpiro & Brack, 1994). Multiple risk factors are associated with sibling distress, such as lower family income, nonwhite race, female gender, parental unmarried relationship status, young sibling age at time of diagnosis, shorter time since patient diagnosis, and death of sibling with cancer (Buchbinder, et al., 2010; Long, Marsland, & Alderfer, 2013). Sibling distress is also linked to lower parental acceptance of the cancer diagnosis (Long, Marsland, & Alderfer, 2013). In addition, siblings of pediatric oncology survivors display greater psychological distress compared to siblings of children without a cancer diagnosis (Weiner & Woodley, 2018). Siblings younger than patients have a greater risk to experience distress because of less parenting time and attention during the cancer journey

(Buchbinder, et al., 2010). Sibling distress may be due to changes in family routine and roles (Hamama, Ronen, & Rahav, 2008). In a recent research study, 25% of siblings met criteria for PTSD, while 62% met criteria for moderate/ severe PTSS (Long, Marsland, & Alderfer, 2013).

Healthy siblings are impacted within their family system and their home life. When a child is diagnosed with a chronic illness, such as cancer, a parent's attention may become focused on the ill child (Prchal & Landolt, 2009). This has the potential to leave a healthy sibling feeling neglected and isolated (Weiner & Woodley, 2018). Siblings of pediatric oncology patients will likely experience change in ways their parents parent. Siblings may experience a shortage of time spent with both of their parents and spend extended periods of time with parental substitutes (Shapiro & Brack, 1994). Therefore, the family dynamic changes. Parents of the healthy sibling and ill siblings are attempting to cope with the chronic diagnosis, therefore, they may have higher expectations for their healthy children and may tolerate less, which leads to emotional deprivation in healthy siblings (Shapiro & Brack, 1994). In addition, siblings will likely experience sibling rivalry as they compete for the attention of their parents. As parents focus their attention on their ill child, healthy siblings may feel negative emotions towards their parents (Yang, Mu, Sheng, Chen & Hung, 2016). Likewise, siblings may feel neglected and then learn to resent their ill sibling and their parents (Fainsilber Katz, et al., 2018). When a sibling of an oncology patient receives less parental attention, a sibling is more likely to develop behavior problems (Fainsilber Katz, et al., 2018) However, it is common for siblings to build a stronger relationship with their father during the patient's treatment and use their father as an emotional support, while their mother is often times at the hospital or clinic with the ill sibling (Weiner & Woodley, 2018).

In addition, siblings feel as if they need to grow up quickly and take on more responsibilities (Weiner & Woodley, 2018). Routines are often broken and normalcy is diminished (Long, et al., 2018). Some roles that siblings picked up at home included doing chores and taking care of younger siblings (Weiner & Woodley, 2018). For example, parents are oftentimes stressed or unavailable for healthy siblings, which may lead to other siblings caring for children at home (Long, et al., 2018). In addition, healthy siblings began to create new roles for themselves within their family of origin to maintain normalcy within their family (Weiner & Woodley, 2018).

Siblings of oncology patients can experience role overload. Role overload occurs when there is a disparity between the role stresses placed on the sibling and the resources they have to meet those demands (Hamama, Ronen, & Rahav, 2008). Greater role overload is correlated to higher levels of anxiety and psychosomatic symptoms and lower role overload is correlated with greater self-control (Hamama, Ronen, & Rahav, 2008). Therefore, when siblings take on too many roles (student, sibling, daughter, caregiver, cleaner, etc.) and do not have the time or other resources needed to complete these roles they have the potential to experience role overload, which can lead to other negatives (Hamama, Ronen & Rahav, 2008).

While siblings are affected within their family and home lives, they are also impacted within the school system. Siblings experience disruption and changes within their schooling due to the cancer diagnosis (Yang, Mu, Sheng, Chen, & Hung, 2016). For example, siblings can have poorer academic performance compared to their peers (Long, et al., 2018). Specifically, siblings of new patients with a pediatric oncology diagnosis experience lower academic performance (French, et al., 2013). However, it is unknown if a sibling's academic performance returns to its normal state once the patient has completed treatment (French, et al., 2013). School age siblings

show poorer academic functioning and all siblings note school difficulties (Long, et al., 2018). Some siblings may dive into schoolwork to avoid the diagnosis or to control a part of the life (Shapiro & Brack, 1994). In addition, some siblings note they are doing well in school and do not experience negative changes to their school functioning (Shapiro & Brack, 1994). Siblings are at risk for emotional and behavioral problems, post-traumatic stress, low quality of healthy, and many internalizing problems, all of which can impact their academic performance (French, et al., 2013).

Survivors and siblings are absent from school more often than children and siblings not affected by childhood cancer (French, et al., 2013). Siblings of childhood cancer survivors are absent twice as many times as the general population at school (French, et al., 2013) Siblings are reported to miss near 7% of the school year each year due to poor physical quality of health in the oncology patient (French, et al., 2013). Reasons for siblings missing school are unclear, but are potentially due to an acceptance by parents of missing school or persistent psychosocial difficulties experienced by siblings of childhood cancer patients (French, et al., 2013).

Siblings note that peer relationships are an important resource for them (Prchal & Landolt, 2012). Siblings are also at risk for social problems, such as social functioning and low amounts of social support (Prchal, Graf, Bergstraesser, & Landolt, 2012). Siblings older than the ill child had a greater chance to search and locate support systems, such as peers or adults, compared to siblings younger than ill sibling (Buchbinder, et al., 2010). In addition, younger siblings also experience significant psychosocial problems compared to adolescent siblings and these problems continued after their ill sibling's treatment was over (Houtzager, Grootenhuis, Caron, & Last, 2004).

Siblings experience changes amongst their social relationship, which can impact their social functioning leaving siblings searching for relationships and experiencing changes in their extracurricular activities (Yang, Mu, Sheng, Chen, & Hung, 2016). Siblings of pediatric oncology patients experience becoming socially isolated and will likely experience adjustment issues (Wellisch, Crater, Wiley, Belin, & Weinstein, 2005).

Siblings of pediatric oncology patients' relationships with peers have changed due to the diagnosis. Siblings lost and gained friendships along the way (Weiner & Woodley, 2018). The friendships healthy siblings had served as a distraction from the cancer journey, however oftentimes the amount of time a healthy sibling could spend with friends was diminished because of less availability due to parental obligations and other family responsibilities (Weiner & Woodley, 2018). Some siblings experienced an increase in the time they spent with friends because their friend's parent became a substitute caregiver for the sibling (Weiner & Woodley, 2018). Decreased time spent with friends and engaging in social events affects a sibling's idea of friendships (Long, et al., 2018). It is noted that siblings' peers knew about the illness, but that only some discussed the illness with their friends (Shapiro & Brack, 1994). In addition, siblings stressed the importance that they do not want their friends to tease or make fun of their ill sibling (Shapiro & Brack, 1994). Some siblings noted being irritated when peers would speak or question their sibling's diagnosis too much (Weiner & Woodley, 2018).

Interventions

Siblings of pediatric oncology patients are at risk to develop emotional, behavioral, and social problems (Prchal, Graf, Bergstraesser, & Landolt, 2012); therefore, there is a need for psychological interventions. Interventions for siblings focus on enhancing a sibling's coping

abilities, recognizing unique needs, involving the sibling in the treatment and/or hospital stay, sharing medical information/knowledge, being a resource to siblings, and giving social support to siblings (O'Shea, Shea, & Robert, 2012; Prchal & Landolt, 2009). Most interventions are known to improve a sibling's depression symptoms, psychological well-being, medical knowledge, social support, and quality of life and decrease negative psychological impacts (Prchal, Graf, Bergstraesser, & Landolt, 2012; Prchal & Landolt, 2009). Siblings and parents report satisfaction as a result of the positive changes siblings of pediatric oncology patients experience, such as decreased depression symptoms and improved well-being due to the interventions (Prchal & Landolt, 2009). Interventions yield positive results.

There are multiple types of interventions, such as interventions that focus on medical knowledge, interventions that focus on family communication, and camping experience interventions (Prchal & Landolt, 2009). There are multiple interventions that focus on the increase of medical knowledge amongst siblings. In these interventions, siblings are provided with information that will improve their knowledge regarding pediatric cancer (Prchal & Landolt, 2009). When siblings are provided with accurate medical information, they feel less anxious and more secure (Prchal & Landolt, 2009). Interventions that focus on family communication involve encouraging and implementing family communication between siblings, patients, and the parents (Prchal & Landolt, 2009). There are also childhood camping experiences aimed at siblings of pediatric cancer patients. This form of intervention focuses on recreational activities and peer support (Prchal & Landolt, 2009). While summer camps are provided for patients and siblings, these camps benefit siblings and patients differently (Wellish, Crater, Wiley, Belin, & Weinstein, 2005). More research should be done on sibling experience at

camp, as changes in affective symptoms are present for patients, but not siblings (Wellish, Crater, Wiley, Belin, & Weinstein, 2005).

In addition to the different types of interventions, there are interventions in general that are individual or group interventions. Individual interventions are rare (Prchal & Landolt, 2009). Interventions should be designed for specific siblings based on developmental stages, age, personal concerns, and specific cancer information (Prchal & Landolt, 2009). In order to address these issues, it is best to address them individually so the needs of a specific sibling can be fully met (Prchal & Landolt, 2009). However, a group format also has benefits. A group intervention can provide siblings with an idea that they are not alone and others are experiencing similar reactions, which can lead to positive psychosocial adjustment (Prchal & Landolt, 2009). In addition, two-session interventions are known to improve sibling adjustment, psychosocial well-being, social support, and medical knowledge (Prchal, Graf, Bergstraesser, & Landolt, 2012).

Camping Interventions

A summer camp is an effective and beneficial intervention for siblings of pediatric oncology patients due to the activities the children participate in and peer interactions (Hancock, 2011; Packman, et al., 2010). Camping interventions focus on recreational activities and peer support and are created to aid with psychosocial and behavioral issues of siblings (Packman, et al., 2010; Prchal & Landolt, 2009). Camp provides siblings with peer interaction as a way to validate feelings through discussion groups, opportunities to create peer relationships through archery, swimming, sports, boating, and arts and crafts, and chances to express emotions through discussion with camp counselors/adult mentoring, trust building activities, and recreations activities (Packman, et al., 2010). Camp implements discussions between peers through

encouraging participation in camp activities that are meant to increase medical knowledge, perceptions of social acceptance, and self-esteem, which positively impacts a child (Hancock, 2011).

A need for a camping intervention exists because siblings of pediatric oncology patients experience becoming socially isolated and will likely experience adjustment issues (Wellisch, Carter, Wiley, Belin & Weinstein, 2005). Group interventions, such as camping, have the potential to provide siblings with an idea that they are not alone and others are experiencing similar reactions (Prchal & Landolt, 2009). Ranita, Passmore, and Baker (2005) found siblings that attended camp showed improved mental health. According to Ranita, Passmore, and Baker, before attending camp almost half of the siblings' experienced high levels of emotional distress, however, after the camp siblings reported a decreased level of emotional distress. They also stated the siblings reported they experienced improved social competence and an increased perception of social acceptance.

Parent Perceptions

Parents believe the most important interventions are those that help their healthy children work through emotions and provide information on their ill siblings (Murray, 2001). Parents reported that the most common interventions provided to their healthy children are meant to support the children emotional, provide information, and assessed what their child needed (Murray, 2001).

Parents have stated that camp is positive due to their child receiving support from peers, an increase in positive behavior and sense of independence, and a break for the parents (Wu, Prout, Roberts, Parikshak, & Amylon, 2011). Parents have noted that their children gained

positive social skills while at camp (Henderson, Whitaker, Bialeschki, Scanlin, & Thurber, 2007). Along with the campers, parents reported they were very satisfied with the camp experiences (Wu, Prout, Roberts, Parikshak, & Amylon, 2011). In addition, parents noted that what they understood happened at camp and what their children learned at camp was a positive experience (Henderson, Whitaker, Bialeschki, Scanlin, & Thurber, 2007). This research and the future study are important because parents determine the type of interventions their children who are siblings participate in. Therefore, by having a parent perception of an intervention, we are able to understand what types of interventions appeal to parents.

Conclusions

By looking at research of siblings of pediatric cancer patients, we know that siblings are impacted negatively in a variety of ways. In summary, pediatric cancer has a mostly negative impact on siblings that include: emotions, family/home life, school, and psychosocially. Siblings of pediatric oncology patients experience many negative emotions, such as emotional distress, fear, worry, anger, depression, anxiety, stress, isolation, jealousy, shock, guilt, and/or uncertainty. A parent has limited attention and availability for a sibling of a cancer patient and this may leave a sibling feeling isolated and neglected. In addition, siblings take on new and different roles at home. Siblings may experience changes in their school life, such as absenteeism and poor academic functioning. It is likely that siblings will experience less time in social experiences and are at risk for poor social functioning.

Since we know siblings are at an increased risk for many adverse effects, we know siblings could benefit from interventions. By reading relevant research, we know interventions allow siblings to improve depressive symptoms, well-being, medical knowledge, social support,

and quality of life. We know that group interventions provide siblings with the idea that they are not alone and social support. Camp interventions align with a group intervention because camp provides siblings with peer interaction as a way to validate feelings through discussion groups, opportunities to create peer relationships through archery, swimming, sports, boating, and arts and crafts, and chances to express emotions through discussion with camp counselors/adult mentoring, trust building activities, and recreations activities. Therefore, we know camp has the potential to be a positive impact.

We know little about how a parent views the camp experience from previous research. However, we do know that parents believe programs that support their siblings emotionally are beneficial. Therefore, the future study seeks to understand how parents perceive the camp experience for their healthy siblings because it is evident siblings are at risk for adverse effects and camping interventions can be beneficial.

METHODS

The purpose of this study is to understand parents' lived experiences of having a child who has attended a camp designed for siblings of pediatric oncology patients. Phenomenology served as the research design for the study with snowball sampling as a recruitment tool of parent participants. Data was collected in an interview process and thematic coding was utilized for data analysis.

Research Design

Qualitative research is a type of research utilized when a researcher collects and interprets non-numerical data (Corbin & Strauss, 2015). Phenomenology, a type of qualitative research, was best utilized in this study due to its rich philosophical presuppositions and its ability to describe in detail an experience/phenomenon. Moustaka's transcendental phenomenology procedures were utilized in this study. Briefly, it includes: identifying a phenomenon, participating in epoche or setting aside one's own personal experiences, collecting data, and data analysis (Moustaka, 1994). In depth parent interviews of a parent with a child who has attended a camp designed for siblings of pediatric oncology patients were conducted in this phenomenological study.

Sampling Strategy

The researcher utilized the snowball sampling strategy. According to Elfil and Negida (2017) snowball sampling is utilized when the population is difficult to locate. Parents of siblings of pediatric oncology patients that have attended a summer camp specifically designed for the siblings are difficult to locate as there are only a few of these camps throughout the nation. Elfil

and Negida also state that with the snowball sampling method, the researcher will ask each participant to utilize his or her knowledge of others within the same population to participate in the study.

In order to recruit participants, the researcher contacted parents of siblings who have attended a camp designed for siblings of pediatric oncology patients and presented information regarding the study. The researcher started by contacting two parents already known to the researcher who have children that have attended a regional oncology sibling camp. These parents lead to the recruitment of other parents with children who have attended oncology sibling camp. This study included 5 participants.

Data Collection Procedures

Participants were contacted with information about the study as well as an invitation to participate in an interview. The researcher started the data collection process by calling two parents the researcher had already identified. The researcher held a discussion asking if they had interest in participating in the study. The researcher then set up a time to meet with the participants individually. At the meeting, the researcher shared more information about the study. In addition, the researcher gained informed consent from the participant. The participant was offered the informed consent form to read over and then sign it if they agreed to participate (see appendix B). The interview then started. The semi-structured interview involved open-ended questions that were recorded. Upon completion of the interview, the participant provided the researcher with a contact of another potential participant. The collection of data took place at the place of choice of the participant: house, office, etc. Data was stored on a password-protected computer and in a locked room.

Before the interview, the researcher participated in epoche and pushed aside her own experiences to gain a fresh perspective (Moustaka, 1994). Demographic and open-ended questions were asked in the interview process. Some demographic questions were asked at the beginning of the interview and some were asked at the end to allow the participant to ease into the interview (see appendix A). The interview was conducted as a conversation and the interview questions were asked as needed with discussion. Moustaka's two guiding questions were asked along with other open-ended and demographic questions. Moustaka's two guiding questions in this study included:

1. What have you experienced due to your children attending a sibling week at a summer camp?
2. What situations or contexts have influenced or affected your experiences of your child attending sibling week?

The interview was dependent on what the participants shared and what they felt comfortable sharing. Questions were created in advance, but follow up questions were asked in the interview to gain a greater sense of the lived experience. Through the interview, the researcher anticipated the following questions to be answered:

3. What did you hope your child would gain from this summer camp experience?
4. Do you believe summer camp has the potential to benefit your child as an intervention?
How so?
5. Why is camp special to you and your family?

Other questions were anticipated to be answered (see appendix A).

Instrumentation. Instrumentation in this study included the survey and research questions (see appendix A) implemented and constructed by the researcher. The researcher

developed the interview questions through careful thought after considering the purpose of the study and the research questions. The researcher considered her own experiences, what would a parent feel comfortable sharing, and the purpose of the study when developing interview questions.

Role of the Researcher. The researcher was the instrument. The researcher was responsible for implementing and applying all procedures discussed. The researcher had completed a review of previous literature, thought in depth regarding the research design, created instruments to be utilized with data collection and data analysis, actively participated in data analysis through thematic coding. By interacting personally with the participants, the researcher was able to understand their lives and personal beliefs, which lead to a better understanding of the participants.

Ethical Considerations

The researcher filed an IRB application (see appendix C) to help reinforce the principles of research ethics and to communicate to others that the researcher understands the IRB requirements. In addition, the researcher has completed human subjects training (see appendix D). The rights of participants were protected in this study. The thoughts and actions of this study give full respect to individual human dignity. Information regarding the study was shared with participants prior to their participation . Their signature was acquired prior to the start of data collection through informed consent letters (see appendix B).

Names of participants were not shared in the results of the study. In addition, participants were assigned a unique code and letter. This code was used on forms instead of their name. Each interview was recorded, transcribed, analyzed, and then themes with quotes were sent back for

approval from each participant upon data analysis. Data was stored on a password-protected computer and in a locked room. The interview process had the potential to bring up emotions due to the topic of pediatric cancer being sensitive to many families. The researcher respected the participant's wishes and emotions during the interview process. The participants could have chosen not to answer specific questions if they felt uncomfortable.

Analysis of Qualitative Data

Establishing Reliability & Validity. To establish reliability and validity of the study, multiple procedures were used in the planning process of the research, data collection processes, and data analysis. Creswell (1998) states that qualitative research studies should utilize at least two different procedures to establish reliability and validity. Creswell shares these procedures can include: prolonged engagement, triangulation, peer reviewing, negative case analysis, clarifying research bias, member checks, rich thick description, and external audits. Clarifying researcher bias and member checking were used in this study.

Clarifying research bias is full written statement by the researcher that details her past history, biases, prejudices, and orientations that initially shaped the study. It was integral for the researcher in this qualitative study to be clear on her past experiences and biases in order for the readers to understand the potential impact on the results (Merriam, 1998). Member checking is the most important technique for establishing credibility (Lincoln & Guba, 1985). Member checking involves gathering data, analyses, interpretations, and conclusions and sending them back to the participant to decide if they are accurate and credible (Creswell, 2007). Recording the data and sending the transcriptions with connected themes back for approval ensured validity due to limiting room for the researchers interpretation.

The researcher participated in clarifying research bias by removing herself and participating in epoche (Moustaka, 1994). The researcher achieved this by writing out her own experiences, views, and biases with an oncology sibling camp before beginning the interview process. The researcher participated in member checking by recording and transcribing the interviews. The data analysis themes were sent back to each participant for approval. Lastly, reliability and validity were ensured by the researcher taking notes of responses during the interview.

Data Analysis. The researcher followed Moustaka's (1994) phenomenological research approach:

Horizontalization The researcher highlighted significant statements from the interview transcriptions. Each statement will have equal worth.

Clusters of Meaning The researcher grouped the highlighted statements into themes.

Textural Description The researcher will write a description of what happened.

Structural Description The researcher will write a description of how the phenomenon was experienced by the participants.

Essence The researcher will write a description that details the common experiences of the participants and will detail what it is like to experience the phenomenon.

The interviews were transcribed and printed. The researcher then participated in horizontalization and read through the interview transcriptions. The researcher made notes of significant statements by highlighting. According to Moustaka's (1994) procedures a list of significant statements were created. Moustaka states the researcher will develop clusters of

meaning or themes from these significant statements. This was achieved by placing statements from interviews on note cards and dividing them into themes.

These statements and themes were used to write the textual description, which will detail what the parent experienced. In addition, Moustaka's (1994) procedure calls for the structural description to be written upon analysis to describe how the lived experience occurred. In addition, Moustaka states upon completion of the textual and structural description, an essence of the experience will be written that will demonstrate the how and what of the phenomenon.

Participants

Five participants ($n=5$) were involved in this study. Three of the five participants were female/mothers and two of the five participants were male/fathers. The participants were all white, middle-aged, and married. All of their children whom were cancer patients have been cancer free and survivors for multiple years. Their children whom are siblings have been attending sibling camp for multiple years. All siblings involved in the study attended the same sibling camp.

Participant 1 (P1): Participant 1 is a married, stay at home, white mother with three sons. Participant 1 is married to participant 2. Her eldest son is a survivor of acute lymphoblastic leukemia (ALL). He was diagnosed at four years old and is now 16. Only one of her other sons was alive at the time. Her middle son was two at the time of the diagnosis and is now 14 years old. Her youngest son was born a month after her eldest finished his three and a half year treatment and is now 8 years old. Her sons are now involved in many sports and after school activities. Both of her sons who are siblings attend sibling camp.

Participant 2 (P2): Participant 2 is a married, white father of three sons. Participant 2 is married to participant 1. This participant has been married for twenty years. His eldest son was diagnosed with ALL at four years old and is now 16. Their cancer journey included many adverse, dramatic side effects. His middle son was alive at the time of the diagnosis and is now 14 years old. His youngest son was born shortly after treatment ended and is now 8 years old. Both of his sons who are siblings attend sibling camp. His sons are very involved in sports and are very active.

Participant 3 (P3): Participant 3 is a married, part-time working, white mother. Participant 3 is married to participant 4. She is a mother to two adolescent daughters. Her daughters are involved in dance and cheerleading. They travel often and love spending time as a family. Her oldest daughter was diagnosed with cancer shortly after she was born. She was diagnosed with neuroblastoma at four months old and her treatment lasted until she was a little over one years old. She has now been cancer free for over 10 years and is now 16 years old. Her other daughter who is a sibling was not alive during the cancer diagnosis and treatment and is 13 years old now. Her sibling daughter still attends sibling camp today.

Participant 4 (P4): Participant 4 is married, white father. He is a father to two adolescent daughters and married to participant 3. His eldest daughter is 16 years old and his youngest daughter is 13 years old. They travel often and attend their daughters' dance recitals and competitions. His cancer journey started when his eldest daughter was a baby and was showing cancer-like symptoms at birth. She was diagnosed with neuroblastoma cancer as she grew close to one years old and took an aggressive form of treatment that lasted close to a year. His youngest daughter was born about three years after the diagnosis and treatment. She attends sibling camp today.

Participant 5 (P5): Participant 5 is a married, full-time working, white mother of three children. She has been married for 21 years to her husband. Her eldest is a 18 year old son, her middle child is a 16 year old daughter, and her youngest is a 6 year old son. She is constantly busy attending sporting events and activities for her children. Her daughter was diagnosed with medulloblastoma, a brain tumor, when she was three years old and started a 13-month treatment outside of their hometown due to needing specialized doctors. Her eldest son was alive during the diagnosis and treatment, but her youngest son was not. They both attend sibling camp. Her eldest just attended his last week as a camper as he turned 18, but plans to be a counselor in the coming summers.

Bias Statement

In February 2008, my cousin was diagnosed with acute lymphoblastic leukemia (ALL) at four years old. I was in middle school at the time and was present for all of the ups and downs treatment brought. During treatment, my cousin attended a week long, overnight camp for oncology patients. While his parents were hesitant on sending their six-year-old son with cancer to an overnight camp more than an hour away, he went to camp. When he returned from camp, there weren't enough positive things to share. Therefore, they looked into more camps related to pediatric cancer. They came across a family camp and a sibling camp organized by the same

organization that held camp for patients. They attended a family camp together and shortly after decided to send their other son to sibling camp. I wrote letters to each of my cousins while they were away at camp and when they returned they told me all about how much fun they had. Ten years later and my cousins are still attending sibling camp as teenagers. They have voiced to me recently that this is the one summer event they will not miss no matter what. They even want to go back and want to be counselors once they age out.

I view sibling camp as an extraordinary place where siblings are able to feel at ease and are able to relate to others. I see sibling camp as a magical place that allows kids to be kids and to simply have fun. In my opinion, every sibling of a pediatric oncology patient should attend sibling camp. I have not heard anything negative about sibling camp. Therefore, in my eyes camp is amazing and has the potential to benefit so many children.

RESULTS

Sibling camp may be a beneficial resource for siblings of pediatric oncology patients. Results from this study indicated that both mothers and fathers of siblings of a pediatric oncology patient who have attended a sibling camp specifically designed for them see camp as a positive experience.

The Reason for Camp

Parents described feelings that they perceived their sibling of a pediatric oncology patient was experiencing due to the cancer diagnosis or journey. They sensed their child feeling emotions, such as jealousy, isolation/neglect, and worry. The parents detailed these feelings as reasons they sent their children to sibling camp. Each parent also noted expectations they hoped their child would gain from attending sibling camp. Parents hoped camp would allow their child to have all of the attention on them for the week, to relate to other kids whom are siblings, and to gain knowledge about the cancer diagnosis/treatment and understand that they are not alone.

Three out of five parents stated that their child whom is a sibling to a pediatric cancer patient experienced jealousy. These parents perceived the siblings to feel jealous of the attention their sibling was getting or the special treatment they received.

(P2):Our son became very jealous of our sick child because he was getting gifts and you know imagine when people come to your house, what do they do they ask about the sick child and so we started to make stuff up like these gifts are for you guys.

(P3):A younger sister already sometimes has issues with being in their big sister's shadow and so there's just all of these things that started happening and well during that time our daughter was starting to notice like 'oh my sister gets a medal at this fundraiser, my sister gets this attention at this event when we go', she hears everybody talking about her sister when her sister gets sick everybody is like, 'She's sick what is going on like is she okay'. She was able to start verbalizing like 'I don't want to be sick, but like I want like I want a

medal too'. As a little person, she was able to say I want a medal, I want to get recognized too... Our daughter was getting all of this attention and extra gifts and extra love and extra like people checking on her and our other daughter was like 'I want that too. I don't want to my sister to be sick, but I want to feel special and important and valued'.

(P4): She also wants attention too so it has always made her feel like she was on the sidelines all the time. It was kind of like the mindset 'what about me, my sister is always glorified. I want my sister heard, I feel sad, I worry about her, but at the same time how come I don't get the special things she gets'.

In addition, three of five parents stated that their child whom is a sibling to a pediatric cancer patient experienced feelings of isolation or neglect. These parents perceived siblings to feel neglected when their parents were taking care of the patient or they had to spend time with others outside of their immediate family.

(P1): Our son had just turned two and so when our other son was diagnosed, I don't know if this happens with every sibling, but I mean especially being two well you know he's going to have to take a little bit of a back seat. Not intentionally. We you know you focus a lot of your attention on the sick child and you know we did our best, but we're only two people. We had to find other places for him to be and he was used to being with me because I stayed home and so it was really hard for him and I'll just never forget. He started distancing himself from me, didn't want to spend time with me, which was really hurtful. But then you realize that he's doing that for a reason.

(P2): It had a real effect on him and had a real effect on his relationship with my wife, you know, when a little boy is sick they go to their mom and that's what my wife did, who wouldn't and that meant our son spending more time with me and feeling maybe a little shunned and not that my wife ever shunned him, she certainly didn't she's a great mom... The counselor came to my wife and she said you know I want you to get down on your knees and look at him in the eyes at his level and tell him how sad it made you feel when you had to leave him at Grandma's or whoever else to go to the hospital and without saying the word he hugged her for a minute.

(P5): We reacted to get our son to someplace where we know he's going to be well taken care of so we can focus on our daughter and for a couple of weeks our focus was solely on our daughter and that was really hard really hard on our son. Really hard on him and he would act out sometimes.

Three out of five parents stated that their child whom is a sibling to a pediatric cancer patient experienced feelings of worry. Parents perceived siblings to feel worried about their sick

siblings during different treatment aspects or their well-being.

(P1): They're worrying and I know that there were a lot of things that our son worried about, but he didn't need to worry about, but when you don't know, you don't know.

(P3): There's still talk all the time when our daughter is super sick and her sister even said 'you know I was worried she was going to end up in the hospital'. Like she knows that that's what could happen to her sister. Siblings also have these extra worries like if their sibling like something happening to them you know or them being in the hospital.

(P4): She's a great worrier of her sister.

Four of five parents stated that they hoped camp would allow their child to have all of the attention on them for the week. They wanted the focus to be on the sibling who has felt neglected or jealous. Parents were hoping their child would feel valued and worthy through receiving extra attention.

(P2): We knew it was to spoil him and it was about him.

(P3): I was hoping that it was just really special because also even people are like 'Oh you're so and so's sister, Oh your sister, your sister, your sister.' and so I kind of asked them can this like let this be her week not about her sister. She was just showing me signs of just like exactly what sibling camp is about like just giving attention and support to the sibling.

(P4): We knew that the special treatment her sister got, this was an opportunity to mirror that for her and make her feel special.

(P5): Their sibling is getting a lot of attention... So that was our hope for him at camp was to be able to just be around these other kids and have a fun week that was just for him that was only focused on him.

Three out of five parents stated that they hoped camp would allow their child to relate to other kids. Parents hoped they would be able to make connections and realize they are not alone in their feelings during the cancer journey.

(P2): We knew he would go be with other kids that were dealing with the same stuff he was and the emotions that go around having parents that cry often, not cry often, but they're emotional.

(P3): I was really hoping that it would you know like not answer all of her issues, but I

just thought if she could go to camp and be around other kids that totally understood how she felt and even be a support.

(P5): I think a lot of it was a chance to have this time with other kids who knew exactly what he was going through. They can't articulate the fact that 'oh my sister has cancer' when they're that little, but they really can, but they don't know what it means, but they know something is different. Their sibling is getting a lot of attention. There's a lot of doctor appointments. My sibling is sick. I have to be here like these things that they start to experience and other kids knowing kind of what's happening at the same time, even though they might not at that age really get the full gravity of the situation. So that was our hope for him at camp was to be able to just be around these other kids.

Two of five parents stated they hoped camp would allow their child to gain knowledge about the cancer diagnosis/treatment and understand that they are not alone. Parents were hopeful that camp would allow their child to learn more about the diagnosis and understand other kids feel the way they do.

(P1): We just heard it was great and it's great for the kids and I am truly someone that like you talk about stuff you don't hide it because it does lead to fear.

(P2): If there was things that could help him understand that at a kid level they're explaining and they're talking about and so he's starting to get you know he doesn't get it, but he might have a little bit of understanding of listening to kids.

These themes and quotes share reasons why parents decided to send their child to sibling camp and what they hoped their children would gain from attending a sibling camp. Parents have chosen to send their child to camp due to perceiving feelings of jealousy, isolation/neglect, and worry. Parents hoped their children would relate to other kids, gain knowledge, and have all of the attention on them for the week of camp. Therefore, one can gather that parents are able to recognize that their siblings are impacted by the cancer diagnosis negatively. With this information, parents can consider more deeply how their sibling is impacted by the diagnosis and can consider what they want for their child. With this information, helping professionals could encourage parents to look into interventions for their siblings or can encourage parents to put some focus on the siblings, as well.

The Camp Experience

Parents described how they perceived their child to experience the week at sibling camp. They held perceptions of what occurred at camp and how it related to siblings. Parents sensed camp to be a place where their children shared a common bond with the other campers, to be place where their children had fun through participating in recreational activities, to be place where the siblings feel valued and all of the attention is on them, and to be one of their child's favorite things about summer that they look forward to it each year.

All five parents stated that they perceived camp as a place where their children whom are siblings to a pediatric cancer survivor share a common bond. They perceived all of the campers to relate to one another due to having similar experiences.

(P1): They also talk at wish night, they can talk, people talk about it with people that get it. I mean they could talk to their friends about it, but I really don't think they do. I really don't think our son probably talked to his friends about the cancer. It's just a real place of real acceptance. The best part about camp is you have the chance to take a break from your every day like and just be with people that have the common bond.

(P2): It's natural to them and there's some beauty to that and when they go to camp those kids aren't typically the kids necessarily that for example, our son would hang out with and but he loves those kids. They love him and he loves the counselors. There's this bond that I can't explain. I just don't know how to explain it.

(P3): I think it's definitely the friendships that she's created there and she looks forward to going back and seeing those same friends. There's something so unique about camp. It's just different because everyone is being brought there for the exact common reason of being on the journey of either having fought cancer or currently fighting cancer like everybody there is being pulled together for this common bond.

(P4): She was fulfilled with the experience being around kids that were like her realizing that she wasn't alone. She wasn't alone feeling like her sister what she went through with her sister. I think her connecting to the other children with the same experiences that she's gone through someone that can relate to her and she can relate to them.

(P5): He had just had such a fun time and he had already connected with some new little buddies.

Four out of five parents stated that they perceived camp as a place where their child has

fun through simply participating in recreational activities and playing with the other children at camp.

(P1): The smile on his face, the light in his eyes, the bright happy like pure joy, but it's really valuable. I mean when you see your kids so happy if you haven't and you realize you haven't seen that in so long. It just made it all worth it. He just lit up and the stories he talked.

(P2): I think what they do, there is they just make sure those kids are having a wonderful experience if it's songs and dancing and skits, the pool, the Rockwall, the zip line, horseback ride. I don't know, I mean they make this experience something that's really special and I don't know what it is.

(P3): When we picked her up at the end of the week, she was just as fired up and happy as her sister always is, singing all the camp songs, and just like had all of these new friends, hugging her counselors, and wanting to stay in touch with everybody.

(P5): He was just happy, he'd had so much fun...he had just had such a fun time... They have fun. I mean it's camp.

Three out of five parents stated they perceived camp as a place where it is all about the siblings and that the siblings feel valued through receiving extra love, attention, and support.

Parents detailed the ways they thought their child received extra attention.

(P1): This little character that comes at night and brings gifts and they do get gifts. They get gifts every day. It's a little overboard, but it's great they absolutely loved it.

(P3): They are treated like royalty I mean they are just treated like gold.... I mean the whole time they are there it's just like special, they're just spoiled.

(P4): The way that camp treats these kids is like they're on top of the world and do whatever they want. They get all of these gifts. They're the center of attention.

Three of five parents stated that they perceive camp as the best part of their child's summer plans. They sensed that their child looks forward to attending sibling camp every year.

(P1): I mean every year when we pick them up they are probably the happiest of the whole year. I would say the best week of their year for sure. They say it every year.

(P2): So our schedules are so busy one summer with all the activities and sports and trips and things we wanted to do. We said to him like, alright this summer we're going to try to cut it back. Like let's go through all the things that we did last year. What do you not

want or what? What should we cut out? And the number one thing that they had to do was go to camp and so it was number one priority for them. Camp is super important to them.

(P5): Our child always calls it, it's his home away from home and kind of like to them it's the happiest place on earth.

These themes and quotes share how parents perceived campers experience camp. Parents saw camp as a place where the kids shared a common bond, had fun, received extra love, attention, and support, and where the kids experienced the best part of their summer. With this information, parents can see what camp is like when they are considering how to help their siblings and can make a decision on an intervention like camp if this is what they are looking for. In addition, helping professionals can take this information and share with parents what interventions like camp include.

Life After Camp

Parents described how they perceived camp affecting their child whom is a sibling to a pediatric cancer survivor after attending camp. They believed there to be life-lasting effects from sibling camp. Parents sensed that camp created a community and a connection for their child to relate to after and outside of camp, was a healing experience and stress outlet for the siblings, and that their children gained knowledge while at camp.

All parents perceived camp as an opportunity that led their child to having a community or a connection they can relate to at all times. They perceived their child to rely on this community while not at camp.

(P1): It's a safe place. It is definitely such a comfortable place for him where he knows no matter what these people will be there for him and he does have people that he sees every year. I will say the acceptance piece just a such, it's almost hard to get it because you're not apart of it, but it's just like there's no cliques, there's no boundaries on what can be. I know that they know that support is there for them if we need it.

(P2): I think the biggest benefit is that their personal understanding that they're not alone. That other kids are going through what they're going through. And I think it helps them communicate and talk with their friends about what they're experiencing and what they're feeling and because it's hard to do that your parents.

(P3): I feel like it was just her having that community of people that were in the same shoes to feel like she wasn't alone. Her closest friend that she snap chats all day long is a friend from camp. On a daily basis or every other day our daughter is supporting her emotionally with what she's going through.... and honestly it is so amazing.

(P4): It's both an escape and a connection. It relieves the issues and anxieties and things we can't touch on just by them immersing themselves with other kids like them.

(P5): It's the people and it's the friends that we probably wouldn't have made otherwise had our paths not crossed this way and I think our son has the same experience where he always knows there's this other group of people that just get him on a different level and there are kids that he met when he was five that he is best friends with now and that connection will never ever end and they talk outside of camp, they get together outside of camp. I think it equipped him to talk about things that he maybe wouldn't normally talk about with my husband and I and gave him this group of people that he knew that he could talk about certain emotions and feelings with than outside of camp and it was better obviously as he got older and you know kids have phones and all that stuff. He leans on them a lot now just for like normal everyday teenage stuff like now he's got this really good group of friends that he talks to just as much as he talks to his friends from high school.

All parents perceived camp to be healing and a stress outlet for their children whom are siblings. They sensed that camp was a place for the siblings to deal with their emotions outside of every day life.

(P1): Camp gives you a different perspective on what you're family's gone through but it's always good to have different perspectives on what people go through.

(P2): I think that's a real benefit that to help them emotionally get through some of their feelings.

(P3): I really do like sincerely feel like it's been better, which is weird to say, but it has been like I don't hear her as much saying 'Oh it's all about my sister'. I don't hear her say that stuff as much anymore... At camp, they literally have a stick or they write the wish and then they throw it into the fire so then it would be symbolic and I think it's a really meaningful, powerful experience for all the kids that are there. I think it was healing.

(P4): I would describe it for her as a stress outlet. It's both an escape and a connection. It

relieves the issues and anxieties and things we can't touch on just by them immersing themselves with other kids like them is really beneficial just to their mental state I think.

(P5): I don't know what other outlet he would have.

Two out of five parents perceived camp as a place where their child gained knowledge that lead to them asking questions about the diagnosis after camp or lead to them having a greater understanding of what they have been through.

(P1): Just for him to come away and ask questions was wonderful. You know randomly he'd kind of say 'so what's this? What's that?' I'd say I'd explain it and it was just able to give him some clarity on things. A lot of things go unanswered and that was able to give him a platform to say 'Hey I am curious about this. What's is this?' and so that helped us. I think every year he learns more lately. I think that it just continually keeps his eyes open and he learns more. It's giving him a real insight as to what cancer is and what it can do and how it affects people.

(P2): I just think he has a better depth and understanding of what's happened to him. And what happened to our son and us as a family.

These themes and quotes share how parents perceived camp to leave a lasting impact on their children. Parents saw their to be long lasting effects of camp, such as the siblings having a community/connection to rely on, they gained long-lasting knowledge, and that camp was healing and a stress outlet for the siblings. With this information, parents can understand the benefits of camp and why they should send their child to a similar camp and camp directors can share this information with potential campers' families to encourage them to attend camp.

DISCUSSION

Connections between the different themes within the current study can be made when looking at the themes across the board. Throughout the study parents pointed out why they sent their child to camp, what they wanted their child to gain, what happened at camp, and how they are effected in the long run. Many parents perceived their child to feel jealous and neglect and hoped that at camp the attention would be put on the their child. At camp, the parents then perceived their child to have the attention on them and feel valued, which allowed them to heal after camp. In addition, some parents perceived their child to worry about the diagnosis and treatment of cancer and hoped they would gain knowledge at camp. These parents then reported that the children did gain knowledge after camp and that it was helpful from them all. Also, parents perceived their children to have negative feelings upon the diagnosis and treatment of cancer and they hoped that their children would have the opportunity to connect to other children who have gone through similar things at camp. These parents then reported that there was a common bond at camp and after camp these siblings now have a community and connections they can rely on after camp. Therefore, it is clear that camp is a positive experience with positive outcomes. In general, when considering camp, the reason for camp, the camp experience, and life after camp are all interconnected.

The results indicated that camp is a positive experience for siblings of pediatric oncology patients and survivors. With the information from past literature and results from this study, implications can involve healthcare professionals, camps across the nation, and parents. Health care professionals can begin to take a family-centered care approach, can include siblings, realize when siblings are struggling, and encourage parents to give the siblings support and

assistance when needed, as well. It is important to allow helping and healthcare professionals to understand that siblings of pediatric patients are also in need of support. It is also important to allow these helping professionals to recognize a way in which siblings are at risk and how they can be supported. This study allows helping professionals to understand siblings need support and how to support them through recommending a sibling camp. Sibling camp directors and staff can take the information presented in this study and share it with potential campers, their guardians, and other helping professionals to detail that camp can be beneficial. The current study promotes the need for more sibling camps. There are few sibling camps across the United States and this study emphasizes the need for camp and the benefits it offers to siblings. This study has the potential to increase funding and awareness to develop more camps. This study also has the potential to encourage parents to send their children to sibling camp. Many parents may struggle with sending their children to overnight camp. This study will allow parents to understand the benefits of sending your child to a sibling camp. In general, this study will increase awareness that siblings need and should be supported, as well in these situations.

From this study, we can gather that parents are able to pinpoint that their children demonstrate a need for an intervention, such as sibling camp. We can gather that siblings need support too. Siblings experience adverse effects like their brother or sister who is fighting cancer, however it looks different. While siblings are not fighting for their life, receiving chemo, or losing their hair involuntarily, their emotions, routines, and social interactions are being impacted negatively. Therefore, they need support in form of an intervention, as well.

Once parents recognize their child that is a sibling demonstrates a need for an intervention, they are able to create hopes for their children through utilizing sibling camp. After attending camp, parents recognize that something special is happening for the siblings at

camp that is making a lasting impact. It seems as most parents view sibling camp as a positive experience that benefited their child. This means that sibling camp can be viewed as a beneficial intervention for siblings of pediatric oncology patients. Every sibling of a childhood cancer patient should be presented with the opportunity to attend a sibling camp. From parent perceptions, it is clear that is such a special week for these children and truly creates a long lasting impact on their life. We should be advocating for every child to have this opportunity to attend camp.

Results from this study indicated that camp is a positive intervention for siblings of pediatric cancer patient from a parent's perceptions. Parents were able to recognize reasons they sent their children to camp. These reasons included parents perceiving feelings of jealousy, isolation/neglect, and worry within their children that are siblings to pediatric cancer patients. The parents were able to explain what they hoped their children would gain from attending sibling camp. Participants in the study hoped camp would allow their child to relate to other siblings, gain knowledge, and have all of the attention on them for the week. After the sibling attending sibling camp, parents were able to detail what the camp experience entailed. From a parent's perception camp entailed the campers/siblings sharing a common bond, having fun, feeling valued and worthy through receiving extra attention, and experiencing the best part of their summer. After camp, parents were also able to notice long lasting effects of camp, such as the siblings having a community/connection to rely on, they gained knowledge, and that camp was healing and a stress outlet for the siblings. Helping professionals, camp staff, and parents can take the information detailed in this study and apply it to many facets of daily interactions and decisions.

Future research should look into other parts of a summer camp intervention. We have

established that sibling camp is a positive intervention for siblings in a variety of ways. Therefore, future research should look into how different siblings are affected from a summer camp intervention. Specific factors can include: age at diagnosis, age while at camp, gender, younger or older siblings, and type of cancer/treatment. In addition, further research from a child's perception could gain a greater perception of what sibling camp is truly like and could allow parents and others to see the true difference sibling camp is making in the life of a sibling. Lastly, future research could include parents and/or siblings that have attended different sibling camps to conclude that all siblings have this lasting impact. Only a few sibling camps exist in the country, therefore, more work needs to be done to show why more camps should exist.

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APPENDICES

Appendix A: Anticipated Interview Questions

The following open-ended and demographic questions were anticipated to be answered based on the experience the participant was willing to share.

1. Do you have a child that has or has had a cancer diagnosis? If yes, what is the cancer diagnosis?
2. How many children do you have (including step children and adopted children)?
3. How many of these children are siblings to children whom have or have had a pediatric cancer diagnosis?
4. What are the current ages of the siblings?
5. What is the gender of the sibling?
6. What have you experienced in regards to your children who have attended sibling week at camp?
7. What situations or contexts have typically influenced or affected your experiences of your child attending sibling week?
8. How did the siblings of your child diagnosed with cancer react at the time of the diagnosis?
9. What social supports or resources did the sibling have after the diagnosis?
10. How would you describe your child's (sibling) interactions with peers after the diagnosis? Ex: Were friendships gained or lost? Was more time spent with peers? Did the child isolate themselves? Were they hesitant with peer interactions? Did they discuss the diagnosis?
11. How did you learn about the summer camp opportunity?

12. How did you decide to send the siblings to summer camp? How did you feel about sending your child to camp?
13. What did you hope your child would gain from this experience?
14. What social expectations did you have for your child when attending this camp?
15. What changes did you notice in your child after attending summer camp?
16. Why is camp special to you and your family?
17. If you could describe camp in a couple of words, how would you describe camp?
18. What keeps your child coming back to camp?
19. After having your child attend camp, what are your feelings toward camp?
20. Do you believe summer camp has the potential to benefit your child as a intervention?
How so?
21. What is your gender?
22. What is your age?
23. What is your racial/cultural/ethnic origin?
24. What is your current relationship status?
25. What is the highest level of education that you have completed?
26. What is your religious preference?
27. What is your employment status?
28. What socioeconomic status does your family hold? (low, middle, high)

Appendix B: Informed Consent Form

PROJECT TITLE: Parent's Experiences of Camp for Siblings of Pediatric Oncology Patients

INVESTIGATORS: Kristen Krueger & Dr. Cemore Brigden

This is a research study. Please take your time in deciding if you would like to participate. Please feel free to ask questions at any time.

INTRODUCTION:

The purpose of this study is to understand parents' lived experiences of having a child who has attended a camp designed for siblings of pediatric oncology patients. Specific questions will be asked regarding demographics of the parent, how the siblings were impacted at the time of diagnosis, how the parents made the decision to send their child to this sibling summer camp, and the effects the summer camp had on their children.

The researcher anticipates this project will fulfill requirements for the degree of Masters of Science in Early Childhood & Family Development at Missouri State University and be published in an academic peer-reviewed journal based on research data.

You are being invited to participate in this study because you have a child who is a sibling of a current or a past pediatric cancer patient who has attended sibling camp.

PROCEDURES OR METHODS TO BE USED:

If you agree to participate in this study, your participation will consist of an in-person interview that will last approximately one hour and later a review of the transcript from your interview. You will be asked questions regarding your child who attended sibling week and their experiences and demographic questions. You may skip any question that you do not wish to answer or that makes you feel uncomfortable. Lastly, your interview will be recorded and transcribed. After transcription is complete, you will be asked to approve the transcription. The data will be erased/shredded upon completion of the project. Your participation (time from interview to review) will last for approximately 3 months.

LENGTH OF STUDY: 1 hour for interview; 1 hour review of interview

RISKS ANTICIPATED:

There are no anticipated risks from participating in this study.

BENEFITS ANTICIPATED:

There are no anticipated direct benefits other than the opportunity to share your experience.

COSTS AND COMPENSATION:

You will not have any monetary costs for participating in this study. You will not be compensated for participating in this study.

PARTICIPANT RIGHTS:

Your participation in this study is completely voluntary and you may refuse to participate or leave the study at any time. If you decide to not participate in this study or leave the study early, it will not result in any penalty or loss of benefits to which you are otherwise entitled.

EXTENT OF CONFIDENTIALTY:

Records identifying participants will be kept confidential to the extent permitted by applicable laws and regulations and will not be made publicly available. However, federal government regulatory agencies and the Institutional Review Board (a committee that reviews and approves human subject research studies) may inspect and/or copy your records for quality assurance and data analysis. These records may contain private information.

To ensure confidentiality to the extent permitted by law, the following measures will be taken: subjects will be assigned a unique code and letter and will be used on forms instead of their name. All printed records and audio recordings of interviews will be kept on a secure computer with access only by the researcher. All identifying information will be omitted from online data and interview transcripts. In the publication that results from this study (peer-reviewed academic journal), all participants' names and any other identifying information was omitted and replaced by pseudonyms to maintain confidentiality. All data will be kept in a locked room and on a password protected computer.

TERMS OF PARTICIPATION:

I understand this project is research, and that my participation is completely voluntary. I also understand that if I decide to participate in this study, I may withdraw my consent at any time, and stop participating at any time without explanation, penalty, or loss of benefits, or academic standing to which I may otherwise be entitled.

QUESTIONS OR PROBLEMS

You are encouraged to ask questions at any time during this study. For further information about the study contact, Kristen Krueger at 515-333-6058 or Krueger322@live.MissouriState.edu or Dr. Cemore Brigden at 417-836-8403 or JoannaCemore@missouristate.edu. If you have any questions about the rights of research subjects or research-related injury, please contact the Office of Sponsored Research and Programs, 407 Carrington Hall, (417) 386-5972.

SUBJECT SIGNATURE

Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document and that your questions have been satisfactorily answered. You will receive a copy of the signed and dated written informed consent prior to your participation in the study.

Subject's Name (printed) _____

(Subject's Signature)

(Date)

INVESTIGATOR STATEMENT

I certify that the participant has been given adequate time to read and learn about the study and all of their questions have been answered. It is my opinion that the participant understands the purpose, risks, benefits and the procedures that will be followed in this study and has voluntarily agreed to participate.

(Signature of Person Obtaining
Informed Consent)

(Date)

Appendix C: Approved IRB

Date: 11-10-2019

IRB #: IRB-FY2020-353

Title: Parents' Experiences of Camp for Siblings of Pediatric Oncology Patients

Creation Date: 10-27-2019

End Date:

Status: **Approved**

Principal Investigator: Joanna Cemore Brigden

Review Board: MSU

Sponsor:

Appendix D: Human Subjects Training

