

Social Work Leadership and the Needs of Pediatric Cancer Patients in Schools: Providing  
Education and Support to Teachers and Administration on the Front Line

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## Abstract

This study explored the perceptions of teacher preparedness from educators' and administrators' points of view, and the value of social work assistance during the learning process when educating a child who has survived cancer. Social work leadership and advocacy in the school setting can assist professional school staff in feeling confident to provide services to children with unique needs, such as learning differences experienced among pediatric cancer survivors. The Pediatric Cancer Survivor Educator Survey was developed by the researcher and distributed to all professional staff members in the participating school district. The final sample of quantitative data includes 63 participants ( $N = 63$ ). Of the six presented hypotheses, three were found to be significant. The findings highlight the lack of knowledge by educators on the unique learning needs of pediatric cancer survivors in the school setting. Results indicate that knowledge is positively associated with feelings of confidence and preparedness in meeting the needs of pediatric cancer survivors in the school setting. Results also found that previous experience working with cancer survivors showed improvement in preparedness and confidence when meeting the needs of pediatric cancer survivors in an educational setting. In addition, it was found that educators were accurate in their self-ratings of knowledge on the topic, when comparing to the actual score of the base knowledge quiz. The mean score of this portion of the measure was approximately 50%, indicating an overall lack of knowledge in the sample. The current study demonstrates the need for school social work leadership in the development of trainings and programs, as well as systems navigation, all which are vital to support educators when providing services to this student population.

## **Dedication**

This work is dedicated to all cancer survivors, but especially our littles. Never give up on your dreams. It is also dedicated to my daughter Sophie. Everything I do, I do for you my love.

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## **Chapter One: Introduction and Relevance for Social Work**

More children are living with and surviving cancer diagnoses due to advances in cancer care and treatment. These children are likely to be enrolled in school with the same hopes and aspirations as their peers. Unfortunately, teacher and administrator education, training, and support may not be sufficient to respond to the unique needs of pediatric cancer survivors. School social workers have an opportunity to provide leadership in schools by providing curriculum supports to professional school staff. Current research indicates a need for extended neuropsychological support during the treatment process and into survivorship (Nabors, et al., 2008). This includes support through special education services in the school setting.

Evaluating learning needs and providing appropriate learning interventions for students with cancer early on in the educational process will increase students' chances of success throughout their lifetimes. Unfortunately, many teachers reported a lack of education and training to meet the unique learning needs of children with cancer (Dubowy, et al., 2006; Hay et al., 2015). The increase in survival of pediatric cancer patients supports the need for research regarding how best to support survivors during their educational career. To gain a better understanding of the supports provided in the schools for these students, it is important to first understand the education and support offered to teaching staff and administration on this topic.

### **Purpose**

This study explored perceptions of teacher confidence and preparedness from educators' and administrators' points of view, and the value of social work assistance during the learning process when educating a child who has survived cancer. When an educator has a student in their classroom with a significant medical need, education regarding the diagnosis and treatment of the student is typically limited (Dubowy, et al., 2006; Hay et al.). Past research often focused on

prior knowledge of the topic in professional school staff and interest in obtaining additional knowledge. The relationship between experience levels and knowledge, preparedness, and confidence levels, when working with the targeted population, were also considered. Exploring the current knowledge and confidence levels of professional staff encountering a student in their school with a pediatric cancer diagnosis will be useful for identifying the need for development of educational offerings, procedures, and policy by school social workers. Additionally, the need for social work involvement, when educating a pediatric cancer survivor will be discussed. The role of the school social worker not only includes supporting students and families, but often supporting professional school staff by providing trainings, education, policy development and navigation of services for students.

## **Background**

### **Problem**

Receiving a diagnosis of cancer is a life-changing event for any family. It is particularly devastating when the person receiving that diagnosis is a child. The diagnosis and treatment of a pediatric cancer patient disrupts the lives of the family in many ways. One necessary consideration, while treating school-aged children with a cancer diagnosis, is their ability to participate in educational opportunities. Educational accommodations, such as cyber schooling and homebound instruction, can be made so the child is able to continue participating during treatment. When a student/patient returns to the school setting, they are often thrust back into their regular classroom, with celebration of their cancer victory, but without the appropriate supports to address the impact of cancer treatment on the ability to learn.

Almost a quarter of pediatric cancer survivors will develop significant mental health diagnoses such as depression, anxiety, or posttraumatic stress disorder (Coughtrey, et al., 2018).

These diagnoses can negatively impact learning in the form of memory issues, decreased motivation, and missed instruction time. Additional studies support the concern for other long-term mental and/or cognitive effects, identifying risk of development as high as 67% for attention deficit disorders and as high as 28% for other cognitive side effects (decreased memory, learning disabilities, etc.) (Marusak, et al., 2017).

### **Population**

Pediatric cancer as a whole is considered a rare disease; however, every year over 15,000 children in the United States receive this diagnosis, and cancer continues to be the leading cause of death by disease in children (National Cancer Institute, 2018). Pediatric cancer survival rates have shown a large improvement over the past 50 years (Marusak, et al., 2017). Patients have seen survival rates soar from approximately 50% in the 1970's to a current average of 85%, due in large part to the improvements of research and treatments of this disease (Marusak, et al., 2017). By 2020, there were approximately 500,000 pediatric cancer survivors living in the United States (Marusak, et al., 2017). With so many now surviving this disease, many practitioners, patients, and families find themselves questioning how best to support children into adulthood.

### **Public Education**

Public schooling in America is one of the largest institutions created in modern history (Barger, 2004). The move to formalize the education of children in America began with the appointment of the first Secretary of Education, followed by the establishment of the first public school in America in 1839 (Chen, 2021). The promotion of education was thought to be an equalizer of wealth and success for lower socio-economic classes of the nation (Barger, 2004). However, the initial creation and promotion of education excluded individuals with disabilities,

females, and many non-whites (Bezliudnyi, 2019; LaNear, & Frattura, 2007). In addition, formalized schooling was optional and children from impoverished backgrounds typically were not enrolled (LaNear, & Frattura, 2007).

Inequalities were addressed by the Massachusetts's Compulsory Attendance Act of 1852 which mandated children between the ages of eight and fourteen to be enrolled in an educational program (Chen, 2021). However, the act allowed attendance exceptions for students who suffered from physical or mental “handicaps,” thus excluding these individuals from the right to receive education and enabling states and communities to avoid responsibility for educating children who may not be the typical learner. Other states soon followed suit in passing similar legislation focused on the education of children, yet continued to exclude those with disabilities (Barger, 2004).

### **Modern Public Educational System**

The modern public educational system is now a more inclusive environment designed to provide equal education to all students, regardless of disability, race, gender, and socioeconomic status. Section 504 of the Rehabilitation Act of 1973 highlighted the importance of free and appropriate public education (FAPE) for all children (LaNear & Frattura, 2007). Under Section 504, children with disabilities were provided the right to disability accommodations in an educational setting, requiring public schools to provide individualized education for those who qualify (United States Department of Education (USDE), 2010). In addition, FAPE identified the importance of non-segregated educational settings for those with disabilities, as well as the right to evaluation and appropriate placement of students based on educational needs (USDE, 2010).

The move toward educational rights for special education students began in 1975 with the passing of the Individuals with Disabilities Education Act (IDEA), the first organized effort to

provide free and appropriate education to students with disabilities in America (IDEA, 2004).

This law was intended to protect the rights of children with disabilities, provide federal funding to support these educational efforts, and monitor the success of special education programs (IDEA, 2004).

### **Social Work in the School Setting**

The developmental trajectory of educational reform was paralleled by the changing roles of social workers in educational settings. Social workers were initially recruited by schools to address compliance with attendance and child labor reform laws (Sherman, 2016; Teasley, 2018). School social workers continue to serve as the link between home and community settings, and similar to pioneers in the field such as Bertalanffy, Durkeim, Germain, and Marx, incorporate a systems or ecological perspective into their practice (Lemert, 2013; Robbins, et al., 2012). In addition, social workers were expected to function as advocates, starting with the implementation of special education laws in the 1970's. Social workers, due to their problem-solving and advocacy skills, provided consultation to the schools in an effort to adequately meet the needs of special education students entering the public school system (Sherman, 2016).

### **Underutilization of Social Workers**

Across settings, present-day social workers continue to assess students' and families' needs, advocate for students, and serve as liaisons between schools and the community. Openshaw (2008) identifies training and professional staff development as an essential role of the school social worker. The educational setting, however, social workers are often underutilized and understaffed, with unclear roles (Sherman, 2016; Stalneck, 2020). In addition, social workers are not recognized as formal leaders in the educational setting (Sherman, 2016). As a result, the full potential of social workers as leaders, specifically for policy and professional staff



training, are underutilized in this setting. According to Sherman (2016) school social workers should be considered an invaluable resource in the development of programs and policies that focus on bridging the gap between educational and psychosocial needs.

The role of the school social worker not only includes supporting students and families, but often supporting professional school staff, as well. Openshaw (2008) identifies training and professional staff development as an essential role of the school social worker. The National Association of Social Workers (2012) also identifies leadership as an essential function of the school social worker, stating:

School social workers shall also serve as leaders and consultants to facilitate an understanding of factors in the home, school and community that affect students' educational experiences. School social workers shall provide training and engage parents, school personnel, other professionals and community members in the removal of barriers to learning (p. 13).

The inclusion of social workers in the training of professional school staff, specifically on disability topics such as pediatric cancer, should be considered fundamental in ensuring the academic success of at-risk student populations. Needs assessment and policy development are also identified as essential tasks for school social workers, underscoring the importance of social work leadership when educating children with disabilities is vital (NASW, 2012). Despite the need for involvement of social workers in professional education, needs assessment, and policy development in the educational setting, research has continued to identify the lack of inclusion and involvement of school social workers in these areas (Berzin et al., 2011). Social workers are highly qualified to provide training sessions for professional school staff, with the goal of increasing knowledge of various disability topics, while assisting teachers to meet the unique

needs of every learner (Balli, 2016).

### **School Social Work Leadership**

Within the educational system, social workers assist in system navigation, provide assessments and interventions, advocate for meeting the needs of students and professional staff, and are capable of serving in leadership roles within their institution by providing consultation and trainings in the school setting. Specifically, school social workers provide leadership which is vital to providing appropriate education and support to both pediatric cancer survivors and the educators who serve them.

Leadership from school social work staff can provide increased awareness among administrators and educators regarding the needs of students post-cancer treatment. Social workers in a school setting can also lead by advocating for services that meet the educational needs of the pediatric cancer survivor population (Teasley, 2018). Social workers are experienced in navigating interagency communication, services, and education across all levels of systems that serve medically fragile children in the community and school setting. Social workers are also able to collaborate in the reduction of barriers and the development of interventions to promote a successful educational experience for children, regardless of their unique medical needs.

Social workers apply leadership skills in the school setting and are often tasked with providing support to teachers and administration, as well as a positive influence on school culture and climate (Sherman, 2016). School social workers are often viewed as a resource for teachers who are concerned about students, but unaware how to help them. They are also the source for student support for social, medical, mental health, or family related concerns. Teachers will often consult with social workers to learn more about a student's home situation.

The social worker's role in the school setting includes working with a child and their family to address needs at home, in the community, and at school, that may affect the child's adjustment in school (Kontak, 2003). The school social worker serves as a resource to school personnel by providing professional staff with essential information to better understand a student's situation (in the current context, to better understand the cancer diagnosis) and how this affects a student's school performance and behavior (Kontak, 2003). Social workers can assist teachers by assessing and addressing behaviors in the classroom and providing direct support, such as emotional support, to teachers and administrators (Kontak, 2003).

School social workers develop in-service trainings, provide fundamental instruction to teachers on topics ranging from mental health to disability rights for students, and offer consultation to teachers throughout the school year on similar topics (Teasley, 2018). Bye, et al. (2009) found that trainings and consultation services provided by the school social worker were identified by both teaching staff and administrators as essential functions of the role. Social workers provide teaching staff with both awareness and confidence in addressing non-traditional issues in the classroom setting (Kontak, 2003). Leadership and advocacy in the school setting assist professional school staff in feeling confident to provide services to children with atypical needs, such as learning differences experienced among pediatric cancer survivors. Many teachers reported feeling ill-equipped to provide educational services to children who have survived cancer, reporting minimal knowledge on the impact of the cancer diagnosis on learning (Dubowy, et al., 2006; Hay et al., 2015; Nabors, et al., 2008).

Research has also shown that trainings on the neuropsychological and psychosocial impact of a cancer diagnosis on young learners provide meaningful education to teachers and increases their confidence levels in their work with pediatric cancer survivors (Dubowy, et al.,

2006). Neuropsychological deficits and mental health challenges are among the most common side effects from childhood cancer treatment; teachers must be prepared to address these challenges when affected students return to the school setting. This study contributes to educator preparation by exploring teachers' and administrators' views on their current level of skill.

### **Theoretical Perspectives**

Systems and ecological social work perspectives assist in the conceptualization of the atypical learning needs of pediatric cancer survivors and suggest how social workers might assist in the successful reintegration of survivors into the classroom setting (Lemert, 2013; Robbins, et al., 2012). Both theoretical perspectives highlight the importance of cross-system, contextual, reciprocal collaboration in enabling professionals and families to intervene effectively on behalf of students. Social workers have training that allows them to assess the students' needs and functioning across various settings.

Empowerment theory provides an informative viewpoint on the educational requirements of pediatric cancer survivors and the professionals who teach them. This perspective highlights the need for, and function of, a positive, reciprocal relationship between student and educator. The empowerment approach also falls under the umbrella of the ecological paradigm of social work by examining the impact of empowerment on the organizational level (Cui, et al., 2018).

### **System-Based Theories**

System-based theories are concentrates on societal constructs, environment, and human behavior. These theories suggest that human behavior is often fueled by the interrelatedness of society. Historically, system-based theories were promoted by social theorists such as Marx, Durkeim, and Tonnias, Parsons, and Merton, and focused largely on the societal class system (Lemert, 2013; Robbins, et al., 2012). As these theories became more well known, those in

similar fields began to expand the perspective and apply system concepts to many different aspects of social life and behavior.

General systems theory and ecological perspective, are contemporary renditions of system-based theories. Today, social workers utilize numerous system-based theories to observe how factors such as education level, socioeconomic status, and family relationships affect the lives of clients. Adjustment and assistance can be provided to strengthen specific areas and, theoretically, improve the overall quality of life of the individual.

### ***General Systems Theory***

General systems theory was first presented by Bertalanffy who, unlike his predecessors, attempted to humanize systems theories by examining relationships among subjects, for example, a family system (Robbins, et al., 2012). Each subject in the system is individualized, however intrasubject reciprocity is requisite for survival. Family systems and relationships are integral components of the bigger ecological system, which includes school and community settings.

**Application of General Systems Theory.** General systems theorists examine the relationships of the child with their family, physicians, nurses, teachers, and other professional school staff when examining the needs of the child in the classroom setting. For example, the classroom teacher may be aware that establishing trust between themselves and the student will increase the student's comfort, facilitating learning. Professional school employees may prepare classmates for the child's return by fielding questions and allaying fears, so that peers can welcome the child back to the classroom while maintaining some normality. General systems would also be useful in determining if a child is having a difficult time socially at school and referrals to a trusted adult, such as the social worker or counselor, could be made to provide

additional support (Robbins, et al., 2012).

### ***Ecological Perspective***

Ecological perspective was first applied to the field of social work by theorist Caryl Germain in 1973 (Robbins, et al., 2012). This perspective focuses on the interaction and transactions of humans with their environments. A key concept of this perspective is “goodness of fit,” which can be used to assess the influence of the environment on needs, focusing on the adaption of the person to their environment (Robbins, et al., 2012).

**Application of Ecological Perspective.** Pediatric cancer survivors who are reintegrating into the school setting during or after treatment are likely faced with a variety of environmental challenges that could serve as a disruption to their learning. The ecological perspective can be used to analyze disruptions in the school setting, raising educators’ awareness of disruptions, so they may shape the environment to meet the child’s needs (including learning-related needs or social difficulties due to the effects of cancer treatment) in the classroom (Harris, 2009). Responses would include referrals for counseling or flexibility regarding absences and assignments due to physician appointments, among others.

This perspective may also inform the child’s functioning and solutions to address the systems of care needed for a child with a cancer diagnosis (Harris, 2009). When a pediatric survivor returns to school, assistance is needed to support the child’s reintegration. Social workers navigate home, school, and hospital ecosystems while supporting both the child and their family. Having a process for communication with the interdisciplinary team, for example an assigned liaison (typically the school social worker) to discuss environmental learning needs; help the family navigate the system for reintegration to school; and discuss the child’s mental health would be consistent with the ecological perspective (Sheilds, et al., 1995).

Examining the relationships of these systems, either environmental or relational, and the child's functioning within systems offers a proactive approach to address various behavioral and educational needs when these students return to the school setting (Harris, 2009). The ability of social workers to work collaboratively, among several subsystems encompassing several disciplines, aids in the ability of the school to be sensitive to the needs and concerns of individual students (Sheilds, et al., 1995).

### **Empowerment Theory**

Empowerment is a guiding principle and core value in the field of social work that helps to influence the implementation of services (Cui, et al., 2018). Empowerment focuses on one's own beliefs of competency, strengths, and mastery of concepts as a way to achieve desired outcomes (Cui, et al., 2018; Rothman, et al., 2019). The development of empowerment theory in the field of social work grew from early social reform efforts and is associated with names such as Jane Addams and Bertha Reynolds (Robbins, et al., 2012). Clients can be empowered when social workers provide them with education and information they need to become their own advocates, creating increased access to resources. Utilizing empowerment theory includes providing education for clients that allows them to learn the skills to advocate for needed resources and take control of their lives (Reynolds, 1942).

### ***Application of Empowerment Theory***

Children with cancer are a vulnerable population with atypical needs that may be difficult to meet in a school setting. Social workers are educated to be strengths-based; social work practice involves client empowerment, particularly when clients face difficult life circumstances. School social workers can offer encouragement and empowerment to both the students and educators, giving a voice to those considered the most vulnerable (Lynch, 2018). In addition,

meeting the student where they are, educationally, and applying appropriate interventions can help the student through difficulties, empowering them in their educational experience (Lynch, 2018). Empowering the student by offering appropriate interventions may also improve student self-determination and achievement (Cui, et al., 2018; Rothman, et al., 2019).

### ***Organizational Empowerment***

Rothman, et al. (2019) describes organizational empowerment as providing encouragement and building confidence of individual professional staff members within an organization in relation to effectiveness and goal achievement. This approach could also be used to work with teaching staff and administration, by offering encouragement and training related to educating the cancer survivor. Social work leadership in the school setting can positively impact organizational empowerment by providing education to administrators and professional staff on supporting cancer survivors in the school setting. Educational processes can be influenced by the empowerment of individuals in the organization, thus creating policy and social change within an organization and increasing the ability to meet the overall mission (Rothman, et al., 2019).

Full consideration of social work skills and relevant theoretical perspectives points to the cost of marginalizing social workers in school settings. In addition, values and ethics of the profession encourage advocacy and protection for the most vulnerable populations, including students with learning differences. The failure to embrace and integrate the full capacity of social workers in the educational setting shows the need for advocacy and policy change. The opportunities to utilize the expertise of social workers in the school setting, especially when supporting some of the most vulnerable children in the school system, are limitless. From the beginning of social work involvement in schools, social work professionals were tasked with advocating for students with unique needs and abilities. The ability to collaborate effectively



across multiple systems has also, historically, been a strength of social work professionals.

Collaboration between school social workers and educators is vital for the successful education of pediatric cancer survivors.

## Chapter 2: Literature Review

History has demonstrated the importance of policies that support children with specific learning needs. Specifically, school social work advocacy and support during the adoption of IDEA and FAPE began the leadership movement in this field (IDEA, 2004). It is important to consider the value that social workers bring to an educational leadership team and how to improve services offered in the educational setting by school social workers and special education teams. Social workers are often responsible to provide training of professional school staff, specifically on disability topics such as pediatric cancer. School social workers are often tasked with the education of professional staff members when managing complex cases.

Social workers in school settings must understand how cancer diagnoses and treatment can interrupt the learning of school-aged children, as they are primarily responsible for providing cross-system coordination and support for the child and their family. The academic success of at-risk student populations relies on the involvement of social worker services in the school setting. For this reason, it is vital for school social workers to understand the neuroscience and subsequent support needed by students and professional staff when addressing learning differences in the pediatric cancer population. A comprehensive review of literature was conducted and focused on the cognitive side effects experienced by pediatric cancer survivors as a result of their diagnosis, treatment, and associated trauma. This information also aided in the development of the Pediatric Cancer Survivor Educator Survey, which was included in the methodology of the research study.

It is also important to consider what specific challenges educators identify when attempting to meet the needs of these students in the classroom. The goal of this research study was to gain additional understanding of the education and support offered to teaching staff and

administration on this topic. Exploring the current knowledge and confidence levels of professional staff encountering a student in their school with a pediatric cancer diagnosis was useful for identifying need for future development of educational offerings, procedures, and policy by school social workers. Organizational empowerment theory was considered as a justification for improvement in training and policies in the school setting. Literature specific to providing training to professional educators in regards to supporting pediatric cancer survivors in the school setting was also included in the literature review.

### **Mental Health in Pediatric Cancer Survivors**

In the United States, pediatric cancer affects 15,000 children, ages newborn to age 18, every year (National Cancer Institute, 2018). From diagnosis to the survivorship phase as adults, pediatric cancer patients experience a wide variety of symptoms associated with the diagnosis and treatment of this disease. One of the more common implications of this disease is the neuro and psychological trauma that is experienced by children and their families (Cordova, et al., 2017). Pediatric oncology patients experience a variety of emotional responses after receiving a cancer diagnosis. These responses can include acute reactions such as anxiety, depression, fear, and adjustment issues (Cordova, et al., 2017).

Research identifying percentages of PTSD in childhood cancer survivors appears limited. Cordova, et al. (2017) reported statistically significant results when using PTSD symptom scales with pediatric cancer survivors (Cordova, et al., 2017). Further, Koutna, et al. (2017) reported pediatric-specific PTSD outcomes, based on meta-analysis, ranging from 2-20%. An additional study reported rates of PTSD in pediatric cancer survivors ranging from 0-35% (Kosir, et al., 2019). Kosir, et al. (2019) also identified differences in rates of depression and anxiety in the adolescent cancer population, identifying significance in increased depressive symptoms

compared to those in the general adolescent population.

Lown, et al. (2015) not only reported a higher rate of PTSD among pediatric cancer survivors, but also reported a greater risk for emotional and behavioral disorders, neurocognitive effects, higher rates of suicidal ideation, and greater use of mental health services. The prevalence of psychosocial distress among pediatric oncology patients and families is high, with research identifying anywhere from one third to half of cancer patients expressing emotional distress (Hamilton & Kroska, 2019; Mehnert et al., 2018). In addition, a subset of pediatric cancer survivors were found to have increased rates of suicidal ideation, anxiety, and global distress, indicating the need for distress screening for the continuum of oncology care (Bitsko, et al., 2016).

Almost a quarter of pediatric cancer survivors will develop significant mental health diagnoses such as depression, anxiety, or posttraumatic stress disorder (Coughtrey, et al., 2018). These diagnoses can negatively impact learning in the form of memory issues, motivation factors, and missed instruction time. In their review of the literature, McDonnel, et al. (2015) and Allen, et al. (2018) reported increased anxiety and depression and decreased self-esteem among pediatric cancer survivors, in comparison to their healthy peers. Other research, however, report no significant differences in mental health and quality of life, when compared to peers (Allen, et al., 2018; Bitsko, et al., 2016; Mertens, & Marchak, 2015).

Additional studies also supported findings for other long-term mental and/or cognitive effects, identifying risk of development as high as 67% for attention deficit disorders and as high as 28% for other cognitive side effects (memory problems, learning disabilities, etc.) (Marusak, et al., 2017). Further, isolation from peers during and after treatment due to physical separation from the school setting is known to increase self-esteem issues, depression, difficulties

integrating with peers, and difficulties with academic achievement (Marusak, et al., 2017).

In addition to mental and emotional challenges and learning concerns, psychosocial challenges are commonly identified in the pediatric survivor population. After diagnosis, pediatric patients are often abruptly removed from their established life routines, including school and social settings, and spend a large amount of time in isolation. Families face an abrupt change in routine that can impact finances, family functioning, and the mental health of parents and siblings, all of which can influence the overall adjustment and functioning of the identified child (Christ, et al., 2015).

### **Social Consequences of a Cancer Diagnosis**

An important consideration for children who have been diagnosed with cancer is the impact the illness and its treatment on the social functioning of the child. A cancer diagnosis is generally considered to be a socially traumatic experience (Oh, et al., 2019). Children typically miss substantial amounts of school time after a diagnosis, have altered social roles, and experience limited opportunities for socialization during treatment (Husson, et al., 2017).

Reintegrating into the social structure of school can be challenging for the student. Survivors often experience difficulties connecting with peers, developing friendships, and re-establishing friendships that may have been interrupted during treatment. They also struggle to meet developmentally appropriate social milestones (Oh, et al., 2019). Park et al. (2018) reported 22% of survivors experienced a lack of friends, 30% of survivors reported bullying, and up to 25% of survivors experienced peer-related difficulties when returning to school after cancer treatment. Park et al. (2018) also found a relationship between learning difficulties and peer relationships, with research showing that children who experience minimal peer issues experienced less difficulty learning and higher academic performance.

### **Family Systems Interruption**

Studies have shown significance in the effect of family distress on the patient's adjustment to their illness across systems, both during treatment and into survivorship (Zwahlen, et al., 2011). The emotional impact of cancer and treatment on the survivor's family, both parents and siblings, is an important consideration as it often disturbs the functioning of the child in social and school settings. Among pediatric cancer survivors and their family systems, distress is an expected occurrence during all phases of cancer treatment and survivorship (Zwahlen, et al., 2011).

The diagnosis and treatment of a pediatric cancer patient disrupts the lives of the family. For example, parents often require a leave of absence from employment, causing great financial strain on the family (Zwahlen, et al., 2011). Siblings also experience a disruption in routine, including the absence of their parent during the treatment process (Wiener, et al., 2015). In addition, specialty children's hospitals are not available in rural areas, with families traveling far distances for treatment, essentially becoming temporarily displaced from their home. Wiener, et al. (2015) emphasized the importance of recognizing parental distress, identifying the relationship between parental distress and child distress in the pediatric oncology setting. Patients may be at higher risk of developing emotional side-effects if the parents have increased distress, poor coping, or a history of psychiatric concerns.

Parental distress may also lead to communication problems between the distressed parent and medical providers, the parent's spouse, and/or their child/children (Berg, et al., 2019). A traumatic event within the family system is disruptive and can shape long-term adaptation for the family (Berger & Weiss, 2009). The disruption of adaptation within the family system can include poor leadership, alliance between parents, poor communication, and inability to identify

and address emotions (Berger & Weiss, 2009). Parental factors will also influence the child's adaptation to the school setting post-treatment. Studies reported that there is a direct relationship between parental psychosocial distress and academic functioning (Gargano, et al., 2017). Berg, et al. (2019) reported that parental distress was associated with lower grades, low math scores, and a decrease in academic performance among pediatric cancer survivors.

### **Neurocognitive Effects of Cancer Treatment**

Neurocognitive effects related to pediatric cancer and treatment are an important consideration in the education setting. Children who have had intrathecal chemotherapy are at an additional risk of neurocognitive effects, when compared to those who have had traditional IV treatments (Bisen-Hersch, et al., 2013). These effects are profound and yet not well-understood by those providing support to students who have undergone chemotherapy and/or radiation (Marusak, et al., 2017). A substantial number of patients receive intravenous (IV) medications, including chemotherapy, during the treatment process. Some medications are known to cause more harm than others when examining neurocognitive effects and other late-term effects after treatment. In addition, some patients may receive intrathecal chemotherapy, which is infused directly into the spinal fluid. Depending on diagnosis, patients may also receive radiation treatments to the affected area. This is particularly harmful if the treated area involves the brain or spine (Bisen-Hersch, et al., 2013).

A decrease of white matter volume in the brain is positively associated with lower scores in intelligence, attention, and academic performance among pediatric survivors (Reddick, et al., 2014). It is also important to consider that many of these deficits may not be seen for several years after treatment and can last for months, years, or indefinitely (Marusak, et al., 2017; Bisen-Hersch, et al., 2013).

The lack of research in the neuropsychological effects of cancer treatment has led to a limited understanding of why survivors experience cognitive deficits after treatment. Bisen-Hersch, et al. (2013) found that children who experience treatment that directly impacts the central nervous system, such as intrathecal chemotherapy and brain radiation, are at higher risk of experiencing cognitive side effects. Specifically, patients treated at a younger age, during prime brain development stages, are at a high risk of a decrease in white matter volume (Reddick, et al., 2014). Neuroplasticity effects are commonly associated with lower retention rates, slower learning, and deficits in both short-term and long-term memory (Bisen-Hersch, et al., 2013).

Marusak et al. (2017) reported cognitive effects, such as attention difficulties, difficulty reintegrating in school and social settings, and decrease in academic functioning are common occurrences in the pediatric survivor population. In addition, cognitive dysfunction is as high as 67% for attention and up to 28% for deficits in executive functioning, IQ, memory, and processing speed (Marusak, et al., 2017). Despite obvious trauma to brain development via treatment mechanisms, studies have also identified harmful white matter changes in pediatric cancer survivors who have not received treatments specific to the central nervous system.

### **Trauma and Learning**

Adverse childhood experiences can negatively impact brain development (Kerker, et al., 2015). According to Marusak, et al (2017), childhood trauma, such as abuse, domestic violence, and other life-threatening events, have significant impacts on brain development. The biological changes in the brain that result from trauma may be related to learning issues among children with a trauma history. Researchers reported that trauma alters the development of brain structures (Davis, et al., 2018). Brain changes can include disruption of the limbic system, which



then causes the child to have a heightened flight or fight response, disruption in memory formation, and alterations to the brain structure in the parts of the brain that regulate emotions and stress (Davis, et al., 2018). The trauma and subsequent damage to the brain have a negative impact on the child's ability to learn and adapt in the classroom setting. This leads to learning deficits, performance problems, and sometimes, problematic behavior, all of which serve as barriers to academic success and achievement (Davis, et al., 2018).

The diagnosis of cancer in a child is a significant life-threatening and traumatic event. Cancer is traumatic for both the child and caregivers. The impact of trauma on a child can result in disruptions in learning, behavior, and overall functioning in home and educational environments. In a meta-analysis of childhood trauma and impact on learning, Larson, et al. (2017) found that children exposed to trauma are more likely to have decreased academic performance and poorer academic outcomes when compared to peers who have not experienced a traumatic event. This was especially apparent with students who have been diagnosed with a mental health condition such as post-traumatic stress disorder, depression, or anxiety (Larson, et al., 2017). Explanations for poorer academic achievement among children who experience trauma include the development of mental health disorders, which may impact behavior in the education setting, motivation, concentration, organization, and sleep (Davis, et al., 2018).

### **Chronic Illness and Learning**

It is estimated that approximately 20% of children in an education setting have been diagnosed with a chronic medical condition (West, et al., 2013). Pediatric cancer is also considered a chronic, lifelong illness due to the increase in survival, prognoses, and number of long-term effects that result from cancer treatments (Nabors, et al., 2008). Children with special health care needs often experience learning disruption due to missed instruction time and do not

perform at grade level (Perfect & Moore, 2019).

Parents of children diagnosed with cancer also reported difficulty with academics in regard to work completion, attention, and retention that was significant when compared to typical children (Perfect & Moore, 2019). Disruption in learning, when not met with proper accommodations, appears to follow children with chronic illnesses through adulthood. Maslow, et al. (2011) reported lower educational and vocational outcomes, including lower college graduation rates, among young adults with childhood onset chronic medical needs. Pinquart (2014) also reported lower rates of completion of advanced education for those with childhood-onset chronic diseases, in addition to impairment in achieving developmental milestones specific to psychological maturity.

The role of mental health in learning, especially for children with specialized medical needs, should also be noted. Perfect and Moore (2019) found emotional-social well-being and self confidence levels were approximately five times lower in children with chronic medical issues, when compared to their grade level peers. Negative impacts on self-image can also spill over to the classroom, resulting in insecurities in the child's ability to learn (Jackson, 2013).

### **Educational Needs for Pediatric Oncology Patients**

Around the same time FAPE and IDEA were adopted, childhood cancer incident rates were under increasing investigation by the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results Program (SEER). In 1975, NCI identified a pediatric cancer rates of 1.3 out of 10,000 children (Hewitt, et al., 2003), with a 5-year survival rate of approximately 50% due to the implementation of pediatric chemotherapy protocols (Hewitt, et al., 2003; Jessop, 2015). Improvements in treatments began to save more lives of pediatric cancer patients. The treatments, however, were harsh and intense, resulting in challenges to children

who were expected to return to their “normal” lives, including attending school (Hewitt, et al., 2003).

Over the next several years, cancer researchers began to identify late-term side effects of cancer treatment as a cause for various learning and emotional disabilities among childhood cancer survivors (Jessop, 2015). High-functioning survivors were usually placed in regular education classrooms with minimal accommodations or understanding by the teaching staff related to the experience of the cancer diagnosis. At the time, the impact of treatment on cognitive functioning had not been explored, thus no services were offered in an educational setting (Hewitt, et al., 2003).

### **Educational Statistics**

According to the research completed by Marusak et al. (2017), approximately 67% of cancer survivors would likely qualify for special education services based on the risk of development of attention deficit disorders and other cognitive side effects alone. Many survivors who qualify for these services are overlooked, likely due to educators’ unfamiliarity of pediatric cancer diagnoses, treatment, and the impact on learning. Studies indicate that approximately 23% of pediatric cancer survivors utilize special education services in a school setting (Mitby, et al., 2003). In comparison, the National Center for Education Statistics (2019) reported 14% of students in a public-school setting (2017-2018 school year) were provided services under the Individuals with Disabilities Education Act. The above percentages show a vast difference in the educational needs among cancer survivors, compared with the overall student population in a public-school setting.

### **Long-Term Educational Attainment**

Poorer educational achievement and decrease in cognitive functioning are regularly

identified as outcomes for survivors of childhood cancer (Mitby, et al., 2003). Boman, et al. (2010) attribute poor academic achievement among cancer survivors to a decrease in cognitive functioning. Saatci, et al. (2019) reported significantly poorer educational outcomes of pediatric cancer survivors, when compared to peers, with cancer survivors being significantly less likely to progress from a primary to secondary level of education. In addition, research shows that patients who have had treatment directly related to the central nervous system have poorer long-term outcomes related to education, employment, and salary throughout their lifespan (Boman, et al., 2010). These specific patients have also been found to underperform on achievement testing at all educational levels (Saatci, et al., 2019).

### **Special Education and Accommodations for Students with Cancer**

Studies have identified that as high as 23% of pediatric cancer survivors utilize special education services in a school setting (Mitby, et al., 2003). Specifically, there was a higher utilization among students diagnosed prior to age 6 and in those who experienced harsher treatments known to alter white matter volume in the brain (Mitby, et al., 2003). The study also reported that younger age at diagnosis, regardless of cancer type and treatment, was consistent with a higher, long-term need of special education services (Mitby, et al., 2003). This is likely due to the interruption of early brain development by various cancer drugs and treatments. The Children's Oncology Group (n.d.) recommends that children who have received a diagnosis of cancer be monitored and evaluated for learning disabilities, allowing for early intervention if learning problems are identified. Benefits to involving special education services, both during and after cancer treatment, include an increase in graduation rates among survivors who utilize special education services (Mitby, et al., 2003).

During the 45 years since the passage of FAPE and IDEA, pediatric cancer survivors

have continued to struggle to be recognized as having disabilities--physical, learning, or otherwise-- that interfere with their ability to access protections under these laws (Hay, et al., 2015). This highlights the need for additional education for school employees specific to the learning needs of pediatric cancer survivors, as well as additional advocacy in the educational setting for this population. Hay, et al. (2015) provided basic recommendations for providing educational services to pediatric cancer survivors, identifying the individualized educational plan (IEP) and 504 plan as options to address the student's needs.

IEP's are identified through school psychological testing, which is meant to determine if a child has a disability that is interfering with their ability to learn, thus qualifying them for special education services (Grandinette, 2014). If the student is identified as having a disability, special education services are provided and accommodations can be made in the school setting with the objective of reducing barriers to learning. Examples of these may include adjusting length of times to complete assignments or exams; providing occupational, physical, and/or speech therapy services in the school setting; and providing behavior support in the classroom (Losinski, & Ennis, 2018). All accommodations, along with a treatment plan and goals, are outlined in the IEP and reviewed by the key stakeholders in the child's education.

If a child is found to have a disability that does not require special education services, the child may still qualify for reasonable accommodations in the school setting under section 504 of the Rehabilitation Act of 1973 (Losinski, & Ennis, 2018). The need for these accommodations is also documented in a learning plan and reviewed by key stakeholders, including parents/guardians, teacher, psychologist, social worker, and other specialists that provide services to the student in the educational setting. The key difference between the IEP and 504 plans is that the IEP provides special education services, while the 504 plan provides reasonable

accommodations in a regular education setting (Grandinette, 2014). Hay, et al. (2015) also reported that neither of these documents address specific challenges experienced by pediatric cancer survivors, as many of the terms and goals included in these plans are generic and more relevant to students with typical special education needs.

### **Educating Children with Cancer in the School System**

Teachers are tasked with the responsibility of ensuring equal education for students living with or recovered from cancer, regardless of missed academic time and absences, cognitive deficits, or accommodations needed for classroom activities (National Center on Safe Supportive Learning Environments, 2011). While teachers are now starting to receive education and training on traumatic experiences and their impact on learning, trainings are typically generic so that they have wide applicability and can address varied traumatic experiences. There is minimal training for educators related to chronic diseases, and specifically pediatric cancer, and how they impact learning in the school environment.

### **Preparation for Teachers Educating Childhood Cancer Survivors**

Despite the commonality of chronic diseases in children, more than half of teachers reported feeling unprepared to meet the needs of these students in the classroom and more than three quarters of teachers reported a need for additional education on the topic (Nabors, et al., 2008). Specific to childhood cancer, most teachers have had no formal education and minimal first-hand experience working with these students (Dubowy, et al., 2006). Dubowy, et al. (2006) also found that literature on teacher training concerning the needs of pediatric cancer survivors and learning is limited.

Hay et al. (2015) reported a lack of training to prepare teachers to meet the unique needs of pediatric cancer survivors, also noting the emotional impact and grief of the teacher, and the

lack of school policies to address the needs of pediatric cancer survivors. Teachers often may need additional support such as consultations with the school social worker, medical team, or counseling to provide the appropriate accommodations to these students. Research indicates that educators often do not feel equipped to provide the appropriate support to students with significant health issues, and often feel a need for guidance from medical professionals (Hay, et al., 2015). Teacher training on this topic has been identified as a positive way to increase confidence in teachers and empower them to address the challenges and unique needs of students with a cancer history (Dubowy, et al., 2006).

Current trainings offered to teachers that are loosely relevant to educating children with pediatric cancer histories focus on generic trauma and trauma-informed classrooms and social-emotional health (National Center on Safe Supportive Learning Environments, 2011). The trainings typically reflect an ecological perspective, as they focus on preparing teachers to build relationships with students and their families and develop partnerships among school, family, and community members. In these circumstances it is especially important to include social workers as advocates and system experts, when providing assistance to the teaching staff and students in this population.

Implementation of trauma-sensitive school training assists teachers and administrators in understanding, recognizing, and addressing trauma in a sensitive way in the classroom (National Center on Safe Supportive Learning Environments, 2018). Without appropriate support, students who have experienced trauma may experience learning difficulties, social-emotional development delays, and disruption in executive functioning skills (National Center on Safe Supportive Learning Environments, 2018). Teachers are in a unique position in the classroom to identify and intervene in trauma-related learning difficulties. There is not, however, any

inclusion of medical related trauma in most trainings.

Trainings on social-emotional learning, although broadly related to the issue at hand, offer skill development for teachers to address self-awareness, self-management, and social skills in their classrooms (National Center on Safe Supportive Learning Environments, 2011). There is also an emphasis on communication between school and family. Despite offering loosely related trainings on general trauma topics, the information received in trauma trainings is not sufficient when considering the learning and support needs of students with a pediatric cancer history.

Very limited information specific the teacher's role and training on this topic was found during the literature review process. Despite the lack of information, research findings indicate a need for more training and support of professional educational staff members when accommodate a pediatric cancer patient in the school setting. Dubowy, et al. (2006) found that providing training modules for teachers on brain anatomy, late effects, and psychosocial aspects of cancer treatment, and how to incorporate special education to accommodate the needs of cancer survivors, increased preparedness and confidence of teachers, especially those working with a child undergoing cancer treatment. Both Losinski and Ennis (2018) and Spinelli (2004) identified several topics for teachers to be aware of in a classroom setting, such as emotional and physical ramifications of cancer treatment, learning and attention issues, memory and retainment challenges, and social implications. It is also important to consider the emotional effects of the cancer diagnosis on a student's peers. Teachers should also be aware of preparing other students for the child's return to the classroom and become familiar enough with the diagnosis to answer age appropriate questions, and address peer anxieties associated with a pediatric cancer diagnosis (Losinski, & Ennis, 2018; Spinelli, 2004).

Children's Oncology Group (n.d.) also emphasizes that teachers must understand learning



problems after cancer treatment, comprehend psychological testing that identifies and addresses learning needs, and be able to identify accommodations that may be beneficial for pediatric cancer survivors. Teachers can become familiar with simple techniques to address learning differences, such as seating placement in the classroom, use of audio books, modifications to testing arrangements, or use of a calculator for math problems (Children's Oncology Group, n.d.). Children's Oncology Group (n.d.) also identified the importance of teachers becoming familiar with recognizing simple medical issues related to cancer and/or its treatment that may occur in the classroom, such as fevers, increased bleeding risk, and exposure to viral illnesses.

### **Gaps and Limitations in the Literature**

The dearth of literature on the needs of pediatric cancer survivors is a barrier to the effective preparation of teachers who may work with such students in their classrooms. Similarly, the lack of research on the role and potential contributions of social workers who interact with students and their families may prohibit social workers from working effectively in leadership positions. Social workers—shaped by their familiarity with systems perspectives, accustomed to working ecologically, and dedicated to the empowerment of clients—are uniquely qualified to lead school systems in the development of programs that prepare teachers and facilitate partnerships across complex systems and speak to the unique and layered needs of pediatric cancer survivors and their families.

A review of the literature also indicates that there is a lack of rigorous research on the assessment and training needed or valued by educators, related to the educational needs of the pediatric oncology population. In addition, because there are minimal options and measures designed to assess these needs, it is unclear as to which type of trainings would be beneficial for educators to receive when tasked with the responsibility of teaching a pediatric cancer survivor

in the school system. The literature also fails to identify the extent to which relevant trainings are available to teachers and administrators; whether training material that is available is implemented; and potential implementation barriers.

Despite the high incidence of neuropsychological effects in pediatric cancer patients, there has been limited research in this area, as evidenced by the small number of peer-reviewed articles that were identified in this review of the literature. Marusak, et al. (2017) and Bisen-Hersch, et al. (2013) also identify limitations on available research on this topic. Reddick, et al. (2014) discuss the lack of understanding of the mechanisms of neurotoxicity from cancer treatment in the brain. The lack of research in educational considerations, teacher trainings, and social work leadership related to meeting the needs of the pediatric oncology population points to a dire need for additional research and social work support for teachers educating children with a cancer diagnosis (Mitby, et al., 2003).

### **Chapter Three: Methodology**

Programs that support educators who teach pediatric cancer survivors align with the spirit of inclusive education. The development of such programs will contribute greatly to the improvement of services offered to children and families who have endured traumatic, chronic illness. In addition, the leadership of social workers is imperative in the creation of policies, trainings, and overall improvement of services offered to this population in the educational setting. A first step is a better understanding of the kind of support that educators need.

#### **Research Design and Methods**

This study utilized an original survey to explore educators' and teachers' perceptions of teacher preparedness and confidence for teaching a child who has survived cancer. The literature review indicates that exploring the current knowledge, preparedness, and confidence levels of teachers who may encounter a student in their classroom with a pediatric cancer diagnosis will enable school social workers to develop future trainings, procedures, and policies in the school setting for students with a pediatric cancer diagnosis. The study is a quantitative research design utilizing survey methods.

#### **Research Questions**

The development of additional educational programs for professional school staff may be a relatively simple task, but would provide a great service to key stakeholders invested in educating children who have survived cancer. Prerequisite knowledge includes understanding current knowledge of, how it was developed, and what additional education or information on the topic is desired. The research presented here responds to these research gaps. The survey examined confidence and preparedness levels of the teachers and administrators when tasked with providing education and addressing the needs of the pediatric cancer survivor in the

classroom setting. Research questions included:

- Does knowledge of the topic affect preparedness and confidence levels of educators when tasked with meeting the needs of pediatric cancer survivors in the school setting?
- Does previous experience working with a pediatric cancer survivor affect preparedness and confidence of educators when serving this student population?
- Does experience working in the field impact preparedness and confidence in educators when working with this population?
- Does experience working in the field affect scores on base knowledge section of the Pediatric Cancer Survivor Educator Survey?
- Does previous experience working with cancer survivors affect scores on base knowledge section?
- Is self-rated prior knowledge of the topic associated with actual score on the base knowledge survey?

### **Setting**

The participating school district is a medium-sized, public-school system in central Pennsylvania. The district educates approximately 3,600 students each school year and employs 228 full time teachers (National Center for Education Statistics (NCES), n.d.). It comprises a total of six schools: a high school, a middle school, and four elementary schools. The district is known for its exemplary special education program and provides autism support, emotional support, learning support, life-skills, and gifted education to students with learning differences. About six percent of students receive special education services, such as individualized education plans (IEPs), gifted IEPs, and 504 plans (NCES, n.d.). In addition to special education

services, the elementary and middle school divisions offer regular social-emotional learning modules, taught by school counselors, for all elementary students.

### ***Social Work Support***

The school staffs two full-time social workers with responsibility for the elementary and secondary student populations. Social workers provide resources for families in need of referral to community resources, provide consultation for students experiencing mental health challenges, participate in the IEP process, and assist in the teaching of specialized topics in the classroom (such as grief and loss, high-risk activities, and emotional health). Social workers also provide crisis intervention services and liaise among community agencies, school teams, and families. The most common consultation for the social worker is mental health and behavioral challenges in the classroom.

### **Participants**

Data were collected as a convenience sample of the Pediatric Cancer Survivor Educator Survey completed by teachers and administration. Following Dillman's Principles, the Pediatric Cancer Survivor Educator Survey was sent to the school email of all professional staff in the district welcoming participation in the survey, with reminder email sent prior to closure. Those who were interested in participating were invited to click the link to the survey, which was available in the district's secure, teacher Google account via a Google Form. The participants were asked to complete the survey within one week from the time it was sent, with a goal of receiving 60 respondents.

Participants were required to hold a valid teaching certificate or license in their field (such as a registered school nurse, licensed social worker, licensed speech pathologist, etc.) for the state of Pennsylvania and be employed or contracted by the selected district. Employees who

do not hold a valid teaching certificate (for example instructional aids or other support staff) or license, or those who are not employed by the district were excluded from participation.

Administrators were also invited to participate in the survey, as policy development and professional staff training are developed by the administrative leadership team. Administrative professionals, such as school principals, superintendents, and/or those on the administrative leadership team were also invited to participate. Participants were required to be age 18 and above.

### ***Demographics***

The district population is approximately 92% white, 4% Hispanic or Latino, 2% Asian, 1% black, and 1% mixed race (NCES, n.d.). Families have a median household income of \$65,000 per year (NCES, n.d.). Approximately 10% of families have an income below the poverty level (NCES, n.d.). Lower poverty levels are more prevalent in one elementary school. In addition, 32% of families in the district rent their homes (NCES, n.d.).

### ***Respondents***

Quantitative data were collected over a 3-week period. The final sample of quantitative data included 63 participants ( $N = 63$ ). Respondents were 79.4% female ( $n = 50$ ) and 20.6% ( $n = 13$ ) male. Respondents, based on educational assignment, were 84.13% teachers ( $n = 53$ ), 7.94% administration ( $n = 5$ ), and 7.94% special education professional staff ( $n = 5$ ). Participants had a mean experience level of 14.16 years ( $M = 14.16$ ) in their professional field. Participants were also asked to utilize a 7- point Likert scale to identify their previous professional experience working with pediatric cancer survivors in the educational setting ( $M = 2.79$ ).

### **Institutional Review Board**

The Institutional Review Board (IRB) at Millersville University reviews all studies involving human subject research for compliance with federal regulations. A copy of the IRB application and approval is located in appendix D. This study was identified as low risk and approved. A signed informed consent was obtained from participants and they were informed of the risks associated with participation. The informed consent is located in appendix E. An optional debriefing was offered by the social worker and contact information was provided for the researcher. Respondents' names and email addresses were removed from data and all respondents were assigned a unique identifying number. All data were password-protected and kept on a computer to which only this researcher had access. Data collected will be kept for three years after study completion. Data files will continue to be stored securely and password protected.

### **Scale Development**

Research questions were used to create a quantitative survey to gather data from educators related to working with a student who has experienced a pediatric cancer diagnosis. The literature review (detailed in Chapter 2) and focus group session were completed prior to scale development. After creation of the Pediatric Cancer Survivor Educator Survey, an expert review of the scale and a pilot study were completed before finalizing the measure. Procedures leading up to and including development of the Pediatric Cancer Survivor Educator Survey are outlined below.

### **Focus Group**

During the research and literature review portion of the scale development, this researcher conducted a focus group regarding meeting the educational needs of pediatric cancer

survivors. The focus group was completed via a Zoom conference session due to the COVID-19 pandemic, and was recorded (with the participants' permission). There was a great amount of interest in the project and 13 colleagues responded volunteering to participate. Due to scheduling, seven people were able to participate in the focus group. Participants included a school social worker, an elementary principal/childhood cancer survivor, two elementary-level teachers (one who is the parent of a child with a history of cancer), a PhD-level educator at a private elementary and secondary school, an Intermediate Unit13 (IU13) school teacher who is assigned to the local children's hospital to provide learning support, and a school nurse.

The literature review was provided to participants a week prior to the focus group for review. All participants reported that they were able to review the information prior to attending the session. The focus group provided insightful discussion that was guided by both previously-composed questions and the participants feedback on the information that was provided to them. Discussion questions included: (a) Have you ever had a pediatric cancer survivor in your classroom?; (b) Have you had any trainings specific to this topic?; (c) Or any trainings that could be loosely applied?; (d) What questions would you have when welcoming a pediatric cancer survivor back into the classroom?; (e) What information would you want/need? This researcher provided prompts related to prior training and experience related to the research topic, anticipated questions about educating students with a pediatric cancer history, agency/district protocols, and interest in the topic.

### ***Key Findings of Focus Group***

Participants expressed an overall lack of knowledge of the pediatric oncology population, including educational needs. Several agreed that they felt they were just "thrown" into teaching these students in the past, with no clear organizational trainings, procedures, or policies. The



participants also reported a desire for increased preparedness to teach these students, suggesting organizational trainings, better procedures, and clearer policies should be incorporated into their professional setting. The inclusion of trainings, policies, and additional social work involvement would help in the process of reintegrating students into the classroom by providing clear steps to take when preparing for students of this population. Several participants also reported relying heavily on the parents of the student to guide them through school reintegration, learning concerns, and medical updates. While information from parents was appreciated, many participants identified this as problematic in that they did not want to “bother” families for information or had difficulty getting more detailed scientific information regarding learning barriers in the student.

All participants agreed that having a liaison to help them meet the needs of such students would be helpful. They also discussed the importance of feeling comfortable managing their own emotions as well as answering questions and calming fears of a cancer patient’s classmates. The participants also raised and engaged topics not introduced by the researcher, such as encouraging ongoing communication among teachers on the child’s status, planning for support of siblings, preparation for the student’s return by being proactive with trainings, discussions with classmates, and getting appropriate accommodations in place.

One participant shared her experience with sibling support, as both an educator and mother of a pediatric cancer survivor. The participant stated, “*Our preschool came to me regarding some minor behavioral changes in our son, during the beginning of my daughter’s treatment. What they didn’t understand was that my husband was essentially functioning as a single parent during that time. He missed his momma because I was basically living at the hospital with his sister.*” This comment led to a discussion of the importance of the sibling’s

educator being informed of the disruption to the family system and the need for increased support when a sibling is diagnosed with this disease.

All participants of the focus group verbally expressed unfamiliarity with the cognitive impact and neuropsychological effects of a pediatric cancer diagnosis. Educators participating in the focus group verbally reported feeling unprepared to meet the needs of this student population. Focus group participants were also in agreement that they needed and wanted additional training on this topic in order to feel prepared to meet the needs of pediatric cancer survivors in the school setting. When asked if participants would be interested in a training on the research topic, all participants answered “yes.”

### **Pediatric Cancer Survivor Educator Survey**

As there were no previously identified measurement scales on this topic, the researcher was tasked with creating a survey that would result in a detailed assessment of the nature and depth of knowledge currently possessed by teachers and administrators; sources where their knowledge was acquired; and gaps in knowledge and topics with which they would like to become more familiar (Musser, 2020). Utilizing the information from the literature review and focus group session, the Pediatric Cancer Survivor Educator Survey was developed by the author and is included as appendix A. The goal of creating this survey was to measure educators’ understanding of childhood cancer and their level of comfort in addressing needs of children with cancer in school.

The Pediatric Cancer Survivor Educator Survey, developed by this researcher, collects general survey data and includes questions related to teachers’ and administrators’ base of knowledge (Musser, 2020). The Pediatric Cancer Survivor Educator Survey includes questions to ensure that participants met the requirements for the study (i.e. Do you have a current teaching

certification for the state of Pennsylvania?). Questions include demographics, such as the teacher and administrator's experience level, and if they have had the experience of working with a cancer survivor.

The survey comprises of two parts: the educator section (based on opinions) and the base knowledge section (based on scientific fact). The educator section includes contextual and demographic data, as well as questions related to confidence level of teaching the targeted population, support required to meet the needs of these students, and feelings of preparedness concerning welcoming a student with this diagnosis back into the classroom. Participants rated each statement on a seven-point Likert scale, with 1 being strongly disagree and 7 being strongly agree.

The survey also includes questions designed to collect information from teachers and administration on the neuropsychological side effects of cancer treatment on children. The base knowledge section is a facts-based quiz on general pediatric oncology information, neuropsychological side effects of cancer treatment on children, and special accommodations in the educational setting. This provided insight into the base knowledge of the topic for both teachers and administrators currently employed by the school.

### ***Expert Review***

To gain additional insight into the developed measure, two colleagues, who are experts in the field of education, were asked to review the measure with the researcher via cognitive interview. Cognitive interview is a long-standing practice in survey methodology that is designed to identify question design problems in survey (Ridolfo & Schoua-Glusberg, 2011). The Pediatric Cancer Survivor Educator Survey was taken by the experts, followed by a discussion

on the measure, question by question, with the researcher. As a result of the cognitive interviews, feedback regarding the survey were discussed and necessary changes were made to the measure.

**Key Findings of Expert Review.** Both participants were females and had approximately 15 years' experience in the field of education. Participant #1 is a school social worker, who has regularly served as a liaison for children with medical conditions within the district. She has also been involved in school fundraising for a local pediatric cancer advocacy group. Participant #2 is an elementary school principal. She has experience in individualized education and 504 planning for elementary age students, as well as experience within special education services in the school setting.

Participant #1 provided feedback related to the wording of instructions, length, overall organization of the survey, and how educators may interpret questions specific to their school district. For example, if the educator previously worked in a school district that did have specific policies in place for this population, and the current school district does not, the researcher should advise the participant to answer the question based on any employment experience, not just their current school district. There was also a concern related to the way a question on implementation of IEP and 504 plans was worded. Participant #1 suggested that some participants may conclude that they are being advised to put a plan in place, when the intent of the question was to simply gather information. Their concern was that a question regarding appropriate services might unintentionally imply that every child who had a history of cancer and treatment should have an IEP. It was that Participant #1's overall assessment was that the survey was well-worded and would be easily understood by participants, even those who had minimal experience with pediatric oncology topics. As a result, there were minimal changes made to the survey questions.

Participant #2 suggested that some educators may feel overwhelmed when they begin the survey and are immediately faced with unfamiliar questions related to base knowledge of the medical condition. Her concern was that those with a minimal amount of time may see the number of questions, become overwhelmed with their inability to answer questions correctly, and thus close the survey without completion. Participant #2 suggested providing the educator section (Likert scale) first, followed by the base knowledge section. This researcher also added a note that participants are not expected to know the correct answers since the goal of the research was to gather information. Participants are advised to “take their best educated guess” for this section. Participants again expressed unfamiliarity with the cognitive impact and neuropsychological effects of a pediatric cancer diagnosis and both participants shared that they were surprised with how many questions on the base knowledge section for which they did not know the answers. Consistent with the feedback from the focus group, expert participants verbally reported feeling unprepared to meet the needs of this student population.

### ***Pilot Survey***

Ten volunteers were provided with the Pediatric Cancer Survivor Educator Survey and a feedback form. The participants included a preschool teacher, five elementary level teachers (kindergarten and first grade), a fifth grade English as a second language teacher, two principals, a Director of Elementary Education, and a Director of Pupil Services. All are employed in the local area by schools of similar size and comparable populations to the population targeted in this study. Participants were asked to complete the measure and then email the feedback form back to the researcher with constructive criticism. Of the 10 surveys sent out, 10 surveys were completed, however only six feedback forms were returned. The survey was distributed online

via the Google Forms format. The feedback form was attached to the initial email, along with the survey link, after each participant expressed interest in helping with the project.

**Key Findings of Pilot Survey.** All participants agreed that the survey length was appropriate, with no suggestions to remove or reword any of the questions. One participant included the comment, *“Survey length was just right! Enough questions to generate meaningful thought, but not too many that I overthought my answers.”* Participants also reported satisfaction in the area of survey format, commenting on easy to read questions and clear organization of the survey as a whole. All participants were able to easily identify the purpose of the Pediatric Cancer Survivor Educator Survey, which one participant described as *“to determine the educator’s understanding of childhood cancer and their level of comfort in addressing needs of children with cancer in school.”*

### **Finalized Measure**

After completion of the focus group, expert review, and pilot study, feedback was utilized to complete final revisions to the survey. The final version of the Pediatric Cancer Survivor Educator Survey is included as appendix A. The informed consent and survey were also formatted on the Google Forms platform to prepare for distribution during the dissertation research process. The final measure, as well as the Google Form link, are located in appendix A.

### **Data Collection and Analysis**

Collection of data was completed during the fall 2020 semester. All outlined procedures were followed. The results of the Pediatric Cancer Survivor Educator Survey provided understanding of the need for additional support in the school setting when educating pediatric cancer survivors. Upon completion of the surveys, data were cleaned and organized to avoid potential errors in calculations. The data were also reviewed to identify any extraneous variables

that may exist. Quantitative data were then analyzed, utilizing Statistical Package for the Social Sciences (SPSS) Version 1.0.0.1508. Cronbach's Alpha was completed first to assess reliability of the survey. The confidence and preparedness subscale consisted of 8 items from the educator section of the survey and was found to be highly reliable ( $\alpha = .730$ ). The base knowledge section of the survey was facts based and did not require additional reliability testing, thus all questions from this section were included as a base knowledge measurement. Details on this scale and subscale(s) are included in Table 3.1. Detailed information on analysis and results is discussed in chapter 4.

**Table 3.1**

*Subscale and Survey Item Justification*

Subscale	Relevant section	Applicable survey questions	Justification
Confidence and preparedness	Educator section	1, 2, 4, 5, 7, 9, 10, 14	The identified questions on the educator section are focused on confidence and preparedness when meeting the needs of a cancer survivor in an educational setting. This was supported by the Cronbach's Alpha.
	Base knowledge section	All questions	The base knowledge section is designed to understand the educator's current knowledge of this topic. This will be determined by the percent score of the knowledge quiz.

## Variables

Data analysis includes testing for six hypotheses, with a total of five variables. The variables were utilized as two dependent variables and four independent variables (with one of the variables used as both an independent and dependent variable). Additional information on all variables are located on the hypothesis and analysis plan in Table 3.2.

**Table 3.2**

*Hypothesis and Measurement Plan*

Hypothesis	IV (X)	DV (Y)	Analysis
1. $H_a$ : Current knowledge, as evidenced by score on the base knowledge quiz, is positively associated with preparedness and confidence of meeting the needs of pediatric cancer survivors in the school setting.	Base knowledge	Preparedness and confidence	Correlation
2. $H_a$ : Groups based on previous experience working with a pediatric cancer survivor will have a difference in mean scores of preparedness and confidence when meeting the needs of pediatric cancer survivors in the school setting.	Experience working with selected population	Preparedness and confidence	Analysis of Variance (ANOVA)
3. $H_a$ : Groups based on years' experience working in the field will have a difference in mean scores of preparedness and confidence when meeting the needs of	Number of years in the field	Preparedness and confidence	Analysis of Variance (ANOVA)



Hypothesis	IV (X)	DV (Y)	Analysis
pediatric cancer survivors in the school setting			
4. $H_a$ : Groups based on years' experience working in the field will have a difference in mean scores on base knowledge survey.	Number of years in the field	Base knowledge	Analysis of Variance (ANOVA)
5. $H_a$ : Groups based on previous experience will have a difference in mean scores on the base knowledge survey.	Experience working with selected population	Base knowledge	Analysis of Variance (ANOVA)
6. $H_a$ : Self-rated prior knowledge of the topic is positively associated with score on the base knowledge section.	Self-rating of prior knowledge	Base knowledge	Correlation

### ***Base Knowledge***

The variable base knowledge, was defined by using the percent score of correct answers in the base knowledge section of the Pediatric Cancer Survivor Educator Survey. The raw score was then divided by the maximum score of 15 to determine percentage of correct items for this variable. The base knowledge section was designed to identify if there is a need for additional education in this area based on unfamiliarity with the topic

### ***Confidence and Preparedness***

Confidence and preparedness to meet the needs of pediatric cancer survivors in the school setting, was defined by utilizing the mean score of the confidence and preparedness subscale, which included items 1, 2, 4, 5, 7, 9, 10, and 14 on the educator section of the survey. Items were selected based on the previously referenced Cronbach's Alpha analysis for validity.

The identified questions on the educator section were self-ratings focused on how confident and prepared an educator would feel when transitioning a pediatric cancer survivor back into the classroom. Questions also inquired about the participants' comfort levels, emotional impact, and desire for continuing education on the topic.

### ***Experience working with Pediatric Cancer Survivor(s)***

Experience working with a pediatric cancer survivor in the educational setting, was defined by assigning each participant to a group based on the rating of question 3 on the educator section. Participants were asked to rate their level of experience, using a Likert scale to score their responses on this item:

*I have experience working with a child/children with this diagnosis in the past.*

Item responses range from 1 (strongly disagree) to 7 (strongly agree). Minimal experience was categorized as a rating of 1-2, moderate experience was categorized as a rating of 3-5, and high experience was categorized as a rating of 6-7. Chyung et al. (2017) referenced numerous articles supporting the use of a midpoint as a way to categorize and group Likert scale data and the results of this literature review supported the groupings in the current study.

### ***Experience in the Field***

Experience working in the educational field, was defined by number of years working in the field of education and was collected from participants during the survey process. Independent categories were grouped as 1-5 years, 6-10 years, 11-15 years, 16-20 years, and 21 years or more experience in the field. Consideration of similar studies as well as the commonality of these experience groups during the pay scale evaluation processes supported grouping of this manner (Aftab, & Khatoon, 2012; Athanassios, & Komis, 2007).

### ***Self-rated Knowledge***

Self-rated knowledge, was defined by participants' responses to question 15 in the educator section of the Pediatric Cancer Survivor Educator Survey. Participants were asked to rate their knowledge level of the topic, by use of Likert scale, stating:

*I feel confident that I have some base knowledge of the topic.*

Item responses range from 1 (strongly disagree) to 7 (strongly agree).

### **Statistical Analyses**

The variables' level of measure and research question aided in the selection of two types of statistical tests during the data analysis. Details of hypotheses, variables, and selected test are referenced in Table 3.2. A summary of the statistical tests is provided below.

### ***Correlation***

Pearson's correlation was used to explore the relationship of confidence and preparedness with other variables. Hypotheses 1 and 6 utilized correlation during data analysis. The statistical test was chosen based on the type of variable, hypothesis, and meeting overall assumptions during preliminary examination. Assumptions (linearity, outliers, homoscedasticity, normal distribution, and level of measurement) were confirmed to ensure that this statistical test was the appropriate analysis (Field, 2018). In addition, the raw data was converted into mean scores or mean percent for analysis.

### ***Analysis of Variance***

The analysis of variance (ANOVA) was used to identify relationships and compare means between variables. Hypotheses 2, 3, 4, and 5 utilized an ANOVA during data analysis. The statistical test was chosen based on the type of variable and hypothesis. Assumptions (linearity, independence, distribution, homogeneity, outliers, and types of variables) were

confirmed to ensure that that this statistical test was the appropriate analysis (Field, 2018). In addition, the raw data was converted into mean scores or mean percent for analysis.

### **Next Steps**

There were several hypotheses tested, related to the outlined research questions. These include investigation of relationships between feeling prepared and confident in meeting the needs of pediatric cancer survivors in the educational setting. A detailed chart of hypotheses and variables can be found in Table 3.2. Chapter 4 will also outline specific details of variables.

### Chapter 4: Research Findings

Data analysis includes testing for six hypotheses, with two dependent variables and four independent variables. Analysis includes various items of the Pediatric Cancer Survivor Educator Survey, including both the educator and base knowledge sections. The Statistical Package for the Social Sciences (SPSS) Version 1.0.0.1508 was used to analyze the data. The statistical analyses and measurement plan, including confirming assumptions, are discussed in Chapter 3. Table 3.2 also provides information on the hypothesis, variables, level of measure, and statistical analysis completed for this hypothesis. Table 4.1 details the descriptive statistics for the presented variables.

**Table 4.1**

*Descriptive Statistics for Variables (N = 63)*

Variable	Minimum <sup>a</sup>	Maximum <sup>a</sup>	Mean	Median	Mode	SD
Overall base knowledge	0.0	15.0	7.6	8.0	7.0	1.9
Neuro-specific base knowledge	0.0	6.0	3.3	3.0	4.0	1.0
Overall preparedness	7.0	49.0	39.3	39.0	24.0	5.9
Overall confidence	9.0	63.0	29.9	31.0	28.0	4.8
Confidence in special education topics	5.0	35.0	24.4	24.0	22.0	4.0
Experience in educational field	1.0	34.0	14.2	13.0	12.0	8.5
Experience working with population	1.0	7.0	2.8	2.0	1.0	2.0
Self-rated prior knowledge score	1.0	7.0	4.4	5.0	5.0	1.6
Desire for social work Involvement	7.0	28.0	19.5	20.0	18.0	2.7

<sup>a</sup> Minimum and maximum values identified in this table reflect the allowable range of total scores.

Of six tested hypotheses, three were found to be significant. Other hypotheses suggested patterns that bear closer examination.

### **Hypothesis 1: Overall Base Knowledge and Preparedness/Confidence Scores**

The initial hypothesis states current knowledge is positively associated with preparedness and confidence of meeting the needs of pediatric cancer survivors in the school setting. Pearson's correlation was completed to explore the data.

### **Variables**

The independent variable, base knowledge, is defined by using the percent score of correct answers in the base knowledge section of the Pediatric Cancer Survivor Educator Survey. The level of measurement for this item was categorized as ratio/quantitative. The base knowledge section was designed to identify if there is a need for additional education in this area based on unfamiliarity with the topic. The dependent variable, confidence and preparedness to meet the needs of pediatric cancer survivors in the school setting, was defined by utilizing the mean score-of the confidence and preparedness subscale. The level of measurement for this variable was determined to be interval for the purpose of examining the differences in scores among survey participants.

### **Results**

Confirming that all assumptions referenced in Chapter 3 were met, the Pearson's correlation was performed to explore the relationship between overall base and confidence and preparedness of educators to meet the needs of pediatric cancer survivors in the school setting. Results determined that the relationship between overall base knowledge and confidence and preparedness to meet the needs of pediatric cancer survivors in the school setting was significant, with a slight positive correlation between the variables ( $r = .27, p = .03$ ).

**Hypothesis 2: Experience Working with Population and Preparedness and Confidence**

According to hypothesis 2, groups based on previous experience working with a pediatric cancer survivor will have a difference in mean scores of preparedness and confidence when meeting the needs of pediatric cancer survivors in the school setting. The one-way analysis of variance (ANOVA) was completed to determine if there were any statistical differences of means of preparedness and confidence between several independent groups, based on the amount of experience working with the targeted population. The analysis includes Levine's test for homogeneity of variances, Tukey's HSD post-hoc test, and details on between-subject effects.

**Variables**

The independent variable, experience working with a pediatric cancer survivor in the educational setting, is defined by assigning each participant to a group based on the rating of question 3 on the educator section. Participants were asked to rate their level of experience. Minimal experience was categorized as a rating of 1-2, moderate experience was categorized as a rating of 3-5, and high experience was categorized as a rating of 6-7. The level of measurement for this variable is categorical. The dependent variable, confidence and preparedness to meet the needs of pediatric cancer survivors in the school setting, was defined by utilizing the mean score of the confidence and preparedness subscale. This variable was previously defined in hypothesis 1 and used identically for the current analysis. The level of measurement for this variable is interval.

**Results**

Confirming that all assumptions referenced in Chapter 3 were met, a one-way analysis of variance (ANOVA) test was used to determine if experience working with the targeted population was associated with preparedness and confidence in meeting the needs of pediatric

cancer survivors in the school setting. The results showed a statistically significant difference between groups for preparedness and confidence ( $F(2,60) = 6.47, p = .003$ ).

A pairwise comparison, utilizing the Tukey post hoc test, revealed two significant relationships, considered the main effect, for confidence and preparedness levels. Significance included confidence and preparedness scores between those with high experience ( $M = 5.64, SD = .59, p = .002$ ) and those with minimal experience ( $M = 4.42, SD = .002$ ) working with pediatric cancer survivors in an educational setting. The Tukey post hoc test also revealed a significant relationship between those with high experience ( $M = 5.64, SD = .59, p = .013$ ) and moderate experience ( $M = 4.53, SD = .75, p = .013$ ) working with pediatric cancer survivors in an educational setting.

### **Hypothesis 3: Years of Experience and Preparedness and Confidence**

Another hypothesis investigated if groups based on years' experience working in the field will have a difference in mean scores of preparedness and confidence when meeting the needs of pediatric cancer survivors in the school setting. The one-way analysis of variance (ANOVA) was completed to determine if there were any statistical differences of mean scores in preparedness and confidence between several independent groups, based on the amount of experience working in the field of education.

### **Variables**

The independent variable, experience working in the educational field, is defined by number of years working in the field of education and was collected from participants during the survey process. Independent categories were grouped as 1-5 years, 6-10 years, 11-15 years, 16-20 years, and 21 years or more experience in the field (Aftab, & Khatoon, 2012; Athanassios, & Komis, 2007). The level of measurement for this variable is categorical. The dependent variable,



confidence and preparedness to meet the needs of pediatric cancer survivors in the school setting, was defined by utilizing the mean score of the confidence and preparedness subscale. This variable was previously defined in hypothesis 1 and 2 and used identically for the current analysis. The level of measurement for this variable is interval.

## **Results**

Confirming that all assumptions referenced in Chapter 3 were met, a one-way analysis of variance (ANOVA) test was used to determine if experience working in the educational field was associated with confidence and preparedness of meeting the needs of pediatric cancer survivors in the school setting. The results were not statistically significant among groups for confidence and preparedness ( $F(4,58) = 2.03, p = .10$ ).

### **Hypothesis 4: Years in Field and Base Knowledge Score**

Hypothesis 5 states that groups based on years' experience working in the field will have a difference in mean scores on base knowledge survey. The one-way analysis of variance (ANOVA) was completed to determine if there were any statistical differences of means in the total base knowledge section between several independent groups, based on the amount of experience working in the educational field. The analysis includes Levine's test for homogeneity of variances-

## **Variables**

The independent variable, experience working in the educational field, is defined by number of years working in the field of education. Independent categories were grouped as 1-5 years, 6-10 years, 11-15 years, 16-20 years, and 21 years or more experience in the field. The level of measurement for this variable is determined to be categorical. This variable is also referenced in hypothesis 2. The dependent variable, base knowledge, was defined by using the

percent score of correct answers in the base knowledge section of the Pediatric Cancer Survivor Educator Survey. The level of measurement for this item was categorized as ratio/quantitative.

This variable is also used as the independent variable for hypothesis 1.

## **Results**

Confirming that all assumptions referenced in Chapter 3 were met, a one-way analysis of variance (ANOVA) test was used to determine if experience working in the educational field was associated with a difference of scores on the base knowledge section. The results did not show a statistically significant difference between groups ( $F(4,58) = 1.88, p = .13$ ) in the overall survey score.

### **Hypothesis 5: Experience Working with Population and Base Knowledge Score**

It was hypothesized that groups based on previous experience will have a difference in mean scores on the base knowledge survey. The one-way analysis of variance (ANOVA) was completed to determine if there were any statistical differences of means in the total score of the base knowledge section between several independent groups. Groups were again based on the amount of experience working with the population.

## **Variables**

The independent variable, experience working with a pediatric cancer survivor in the educational setting, is defined by assigned categories based on the rating of question 3 on the educator section. Minimal experience was categorized as a rating of 1-2, moderate experience was categorized as a rating of 3-5, and high experience was categorized as a rating of 6-7 (Chyung et al., 2017). This variable is referenced previously in hypothesis 2. The level of measurement for this variable is categorical. The dependent variable, base knowledge, was defined by using the percent score of correct answers in the base knowledge section of the

Pediatric Cancer Survivor Educator Survey. The level of measurement for this item was categorized as ratio/quantitative. This variable is also the independent variable for hypothesis 1 and dependent variable in hypothesis 4. The level of measurement for this item is categorized as ratio/quantitative.

## **Results**

Confirming that all assumptions referenced in Chapter 3 were met, a one-way analysis of variance (ANOVA) was used to determine if experience working with pediatric cancer survivors in the educational setting was associated with a difference of scores in the base knowledge section. There was not a statistically significant difference among groups for overall score on the base knowledge section ( $F(2,60) = .70, p = .50$ ).

### **Hypothesis 6: Self-Rated Knowledge and Score on the Base Knowledge Section**

Finally, the researcher explored if self-rated prior knowledge of the topic was positively associated with score on the base knowledge survey. Pearson's correlation was completed and also included the use of descriptive statistics to further explore the data.

## **Variables**

The independent variable, self-rated knowledge, is defined by participants' responses to question 15 in the educator section of the Pediatric Cancer Survivor Educator Survey. The level of measurement for this variable is determined to be interval. The dependent variable, base knowledge, was defined by using the percent score of correct answers in the base knowledge section of the Pediatric Cancer Survivor Educator Survey. This variable is also referenced as the independent variable for hypothesis 1 and dependent variable in hypotheses 4 and 5. The level of measurement for this item was categorized as ratio/quantitative.

## Results

Confirming that all assumptions in Chapter 3 were met, Pearson's correlation was performed to explore the relationship between self-rated knowledge and overall score of the base knowledge section. The results of the correlation indicated that the model was significant with a slight positive relationship between self-rated knowledge and actual base knowledge ( $r = .25, p = .05$ ).

### Summary of Results

The study included 63 participants ( $N = 63$ ) and six hypotheses. A detailed chart of hypotheses and variables can be found in Table 3.2. Descriptive statistics for all variables are referenced in Table 4. 1. ANOVA results are referenced in Tables 4.2 and 4.3.

**Table 4.2**

*Summary of Analysis of Variance (ANOVA) for Experience Groups and Preparedness and Confidence Scores*

Predictor	Sum of Squares	df	Mean Square	F	Sig.
Years' Experience					
Between Groups	6.22	4	1.55	2.03	.10
Within Groups	44.41	58	.77		
Total	50.63	62			
Experience with Population					
Between Groups	8.95	2	4.49	6.47	.003*
Within Groups	41.64	60	.69		
Total	50.63	62			

\* $p < .05$

**Table 4.3***Summary of Analysis of Variance (ANOVA) for Experience Groups and Base Knowledge Scores*

Predictor	Sum of Squares	df	Mean Square	F	Sig.
<b>Years' Experience</b>					
Between Groups	.12	4	.03	1.88	.13
Within Groups	.91	58	.02		
Total	1.02	62			
<b>Experience with Population</b>					
Between Groups	.02	2	.01	.70	.50
Within Groups	1.0	60	.02		
Total	1.02	62			

\* $p < .05$ 

Of the presented hypotheses, three were found to be significant (hypotheses 1, 2, and 6). The remaining hypotheses, which were not significant, yielded interesting data that merit tentative discussion and interpretation. The overall focus of the interpretation of results (Chapter 5) will highlight the importance of social work leadership in the context of school settings. Data suggest that social workers can contribute significantly to the training and support of school professionals who work with pediatric cancer survivors.

## **Chapter Five: Summary of Findings, Research Limitations, and Conclusions**

This exploratory study utilized an original survey instrument designed by the researcher to assess knowledge related to professional staff members' experience, knowledge of pediatric cancer survivors' learning needs, and feelings of preparedness and confidence in meeting the needs of these students. The results point to the importance of school social work involvement with professionals, students, and families who are shaped by the experience of pediatric cancer. All hypotheses are listed in Table 3.2, descriptive statistics in Table 4.1, and ANOVA results can be referenced in Tables 4.2 and 4.3.

### **Relationships**

#### **Experience with Population and Confidence and Preparedness**

There was a significant difference among mean scores between experience working with pediatric cancer survivor and preparedness and confidence levels in participant groups. This finding is consistent with hypothesis 2, as described in Table 3.2. Those in group 3, the most experience working with this population, showed a significantly higher score of confidence and preparedness levels when compared to those in the lower experience level groups 1 and 2. Two conclusions may be derived from these findings. First, professional school staff members in the highest experience group felt both prepared and confident in their ability to educate a pediatric cancer survivor, likely having successfully educated a student with similar needs previously. Second, inconsistency with prior research on confidence levels based on years' experience in the field may have been due to the addition of the pediatric cancer specific survey questions. Again, the data supports the theoretical discussion of empowerment. In theory, educators likely feel more prepared and confident based on previous experiences.

### **Years' Experience and Confidence and Preparedness**

The relationships between years' experience level confidence and preparedness were not significant. This result was interesting due to the inconsistencies with previously published research, which indicated that overall confidence among educators tends to increase over time (Kim & Klassen, 2018). The current study found that both preparedness and confidence levels remained the same despite years of experience in the field when working with cancer survivors. It may be that the significant impact of this disease and professional school staffs' unfamiliarity with the topic, as shown by the overall low scores on the base knowledge quiz, neutralized the effect of experience in the field. This underscores the need for additional education and training related to meeting the needs of students who have survived cancer.

### **Overall Knowledge of Sample**

The outcome delivered interesting data related to the knowledge of pediatric cancer topics in professional school staff. This information was useful in further analysis of the importance of professional staff training in meeting the educational needs of pediatric cancer survivors. The average score of the base knowledge section utilizing data from all participants was approximately 50%. Outcomes show that while some non-significant differences were seen across groups, the overall base knowledge of professional school staff, on this topic, is generally lacking. Furthermore, the sample identified the lack of knowledge in this area during self-assessment, as evidenced by significant results when examining the participant's self-rating score and correlation of score on the base knowledge section.

### **Current Knowledge and Confidence and Preparedness**

There was also a significant relationship, with a positive correlation, when looking at current knowledge and preparedness and confidence levels, which is consistent with hypothesis

1. Those who had higher base knowledge scores indicated that they would feel more prepared and confident when assisting a child with a cancer diagnosis or history in the educational setting. This is not surprising, as this idea is also consistent with empowerment theory. These results also show the importance and need for additional support and trainings on the topic among professional school staff members.

### **Self-Rating and Actual Knowledge Score**

When examining knowledge relationships, the participants' self-rating of base knowledge and actual score on the survey was found to be significant. This was consistent with hypothesis 6, as described in Table 3.2. Again, with a low average of survey scores across the board, participants appeared to be transparent in their admission that knowledge of the topic was limited, and self-rating scores appeared to be honest. Based on the accuracy of this prediction, the researcher assumes that participants were engaged and truthful when answering survey questions.

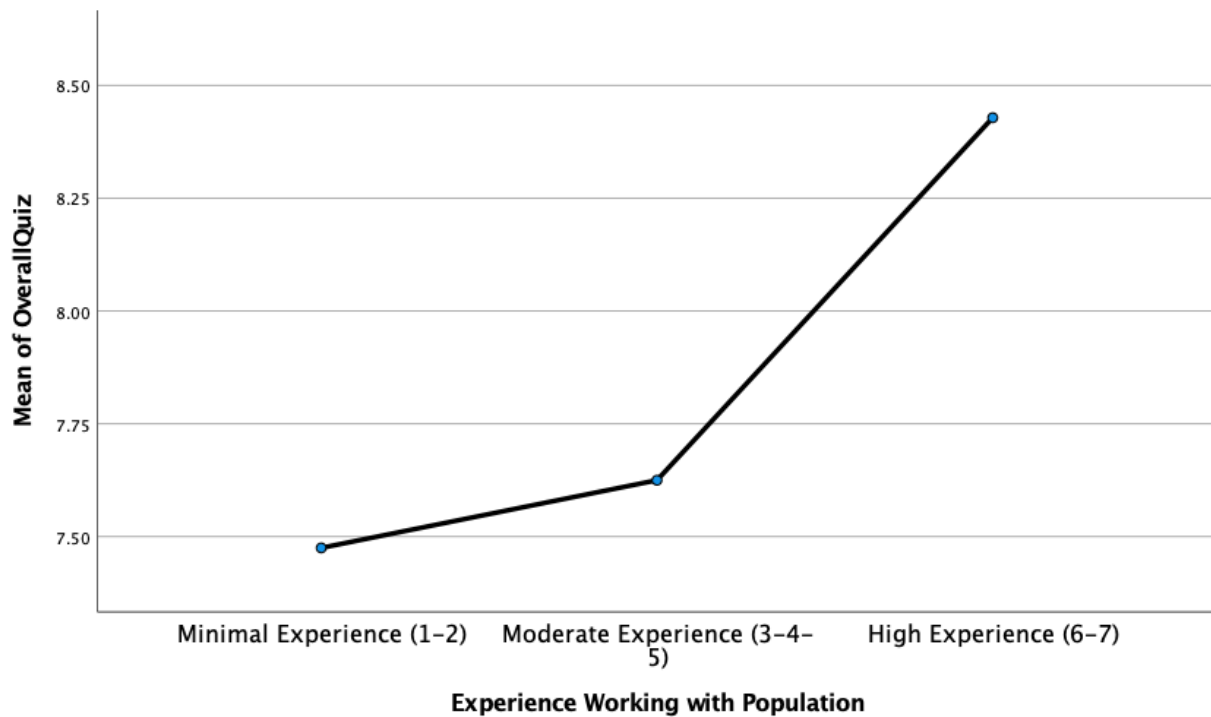
### **Experience with Population and Knowledge**

There was no relationship found between those who have had previous experience working with the population and scores on the base knowledge quiz. Nonsignificant results point in directions that are ripe for further explanation. The line graph of this data, Figure 5.1, does show a small rise in base knowledge scores as experience working with the population increases. The difference in score, however, is low and not significant.



**Figure 5.1**

*Mean base knowledge score in population experience groups*



This is not unexpected due to the lack of trainings on the topic and the overall low mean score on the base knowledge section of the survey. It is possible that although educators may have worked with a cancer survivor previously, specific information and support related to atypical learning needs of this population was not received by professional school staff. Despite low base knowledge scores, the lack of knowledge did not appear to be related to preparedness and confidence scores when meeting the needs of pediatric cancer survivors in the school setting, as the results for experience groups showed significant results in confidence and preparedness as discussed above. Perhaps this is due to the positive support already received from the special education department, specifically the psychologists' and social workers' hands on involvement in this school district.

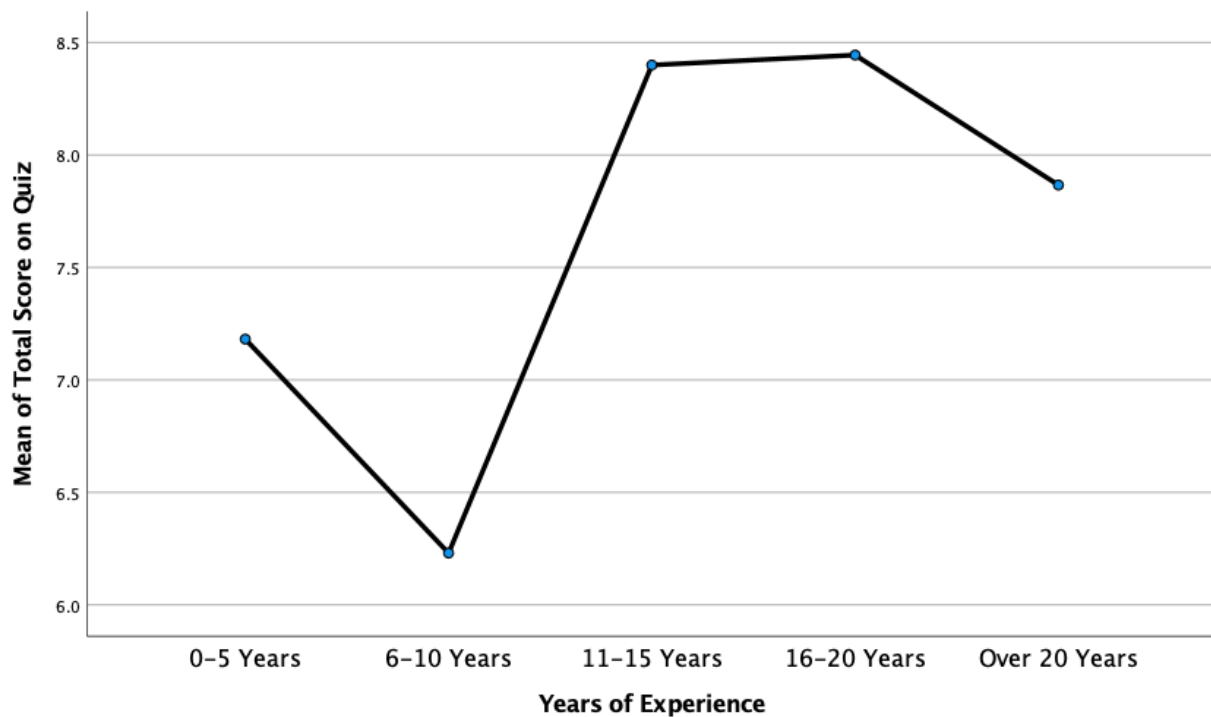
### Years of Experience and Knowledge

There was not a significant difference in scores among survey participants, depending on experience level. The line graph of this data, located in Figure 5.2 does graphically show differences in scores among experience groups, although not significant. A spike in scores is observed starting at 6-10 years of experience and begins to decline after 20 years of experience. The mean score for all groups,, however, hovered around 50%. Despite slight differences in means of the identified groups, all groups appear to have less base knowledge than desirable.

There are several factors that may have affected the outcome among differences in group scores on the base knowledge section of the Pediatric Cancer Survivor Educator Survey. Extraneous variables can only be speculated at this time but are important considerations for

### Figure 5.2

*Mean base knowledge score in years of experience groups*



future research purposes. Some extraneous variables, including poor survival rates during the early years of teaching career, increase in promotional awareness of pediatric cancer in the central Pennsylvania area, trends in trauma education, and advancement of education in professional school staff.

### **Extraneous Variables**

#### **Help-Seeking Behavior**

An explanation for these results could be the openness to help-seeking behaviors among professional school staff. Help-seeking behaviors and interprofessional collaboration are highly encouraged during teacher education programs (Kim & Klassen, 2018). Kim and Klassen (2018) reported a high prevalence for novice teacher help seeking behaviors specifically related to logistical issues that require interprofessional collaboration. Seasoned educators were also found to display help seeking behaviors, specifically during complex or urgent situations and when the need for additional training is needed to meet the needs of students (Kim & Klassen, 2018). The value of interprofessional collaboration, specific to the inclusion of school social work services for support, collaboration, and training, is a valuable addition when dealing with complex situations, such as educating a student with pediatric cancer.

#### **Local Awareness**

The examination of the group with the lowest experience level showed no significance when compared to those with 6 or more years of experience. The involvement of local schools in the philanthropic support of pediatric cancer is a consideration when examining outcomes of the research study. Specifically, the Penn State Dance Marathon (THON), who is the sole beneficiary of the Four Diamonds Fund at Penn State Children's Hospital's Pediatric Cancer Center, is in close proximity to those participating in the research study (Four Diamonds, 2021).

Since the start of this partnership, Four Diamonds and THON have expanded their philanthropic efforts to include smaller scale fundraisers called Mini-THONs in primary and secondary schools along the east coast of the United States. Implications of this program, when considering the outcome of this study, include increased education on pediatric cancer topics, research, and advocacy. It is likely that many of the least experienced professional staff members, especially in the central Pennsylvania area, would have been familiar with this organization and may have even participated in the Mini-THON program due to the timing of mini-THON expansion. This potentially explains why the lower level experience group would have some base knowledge on the topic.

### **Trauma Informed Schools**

Additional factors that may have influenced scores include the rise in popularity of trauma informed education, as well as professional and formal education throughout professional employment. While research on education and trauma began as early as the year 2000, implementation of trauma informed practices in the educational setting began to gain popularity in the year 2012 (Thomas, et al., 2019). Thomas, et al. (2019) reported trainings on topics such as mental health, neurobiology, and brain science are often provided during post-graduate professional development programs within schools and not during undergraduate education.

The school district participating in this research study provides yearly in-service trainings on trauma informed educational practices and Positive Behavioral Interventions and Supports (PBIS), which is an integral part of the school climate. Some general trauma knowledge included in the survey could have been acquired during trainings or other educational opportunities.

Formal continuing education in the form of master's degrees, doctoral degrees, or post-graduate

certification in trauma, resilience, and restorative practices have gained popularity in the district in recent years.

### **Years in the Field**

It is postulated that the historical information on pediatric cancer survival rates, discussed in Chapter 1, could play a part in the outcomes of this study. Those with more experience likely had less opportunity to work with cancer survivors early in their career because of lower survival rates during this time period. In addition, educators with this amount of experience would likely have met the top of the pay scale and may no longer be interested in participating in formal education when pursuing mandatory continuing education. Additional research suggests that as one develops experience in the field, they become less flexible in the ability to adapt to uncommon situations (Kim & Klassen, 2018). Older workers were also found to perceive their time as more limited and had lower motivation to participate in additional learning opportunities unless mandated (Kunst, Woerkom, & Poell, 2018, p. 96). This grouping, however, likely had enough world experience to answer some general base knowledge questions correctly.

### **Summary of Findings**

The data support the overall theme of this research: supplementary education on pediatric oncology would be a valuable addition to training curriculums, especially when working with this population. In this study, knowledge was a good measure of feeling prepared and confident in meeting the needs of these students. This is consistent with theoretical perspectives identified for this study. Organizational empowerment, by use of training programs, would increase the ability of the school system to effectively educate pediatric cancer survivors. Due to the complex needs of children with a pediatric cancer diagnosis, developmentally, educationally, and

systematically, social workers, as experts in cross-system navigation, would be a logical choice to provide trainings and support to educators working with this population.

The current study highlights the lack of base knowledge by educators of the unique learning needs of pediatric cancer survivors in the school setting. Additionally, the results show that experience in the educational field, alone, is not enough to help educators feel prepared in meeting these needs. Organizational and individual empowerment are important components in feeling prepared and confident when working with this population. Experience working with cancer survivors, shows improvement in both preparedness and confidence among professional school staff. This likely indicates that some knowledge of this population is associated with preparedness and confidence scores, especially given the inconsistencies with prior research on general confidence in educators.

If educational trainings were provided on the topic it is believed that additional relationships would be identified among variables, likely as a result of professional staff and organizational empowerment. The primary conclusion of this study is that knowledge and prior experience working with the pediatric cancer population is beneficial to professional school staff when tasked with meeting the learning needs of these students. The need for school social work services, in education, training, and support of colleagues in the school setting is paramount when supporting students with a history of pediatric cancer.

### **Limitations**

Challenges associated with this study include the restriction of participation to educators at the targeted institution, thereby limiting the generalizability of its findings, particularly to areas that are more urban and/or demographically diverse (Field, 2018). The voluntary nature of the study could have created a selection bias (Field, 2018). Participants in the sample could have

had a personal interest in the topic or perhaps additional time for survey completion. Self-report strategies may allow for bias, and participants in this study did rate their own knowledge and interests in this area. However, in this analysis, most participants did appear to be honest and transparent, as evidence by the consistency between base knowledge self-rating and actual base knowledge scores. The Cronbach's Alpha was also encouraging this conclusion. Specific to data analysis, the groupings used for the ANOVA were considered small and, in some cases, did not include equal numbers of subjects in the groups. This led to the utilization of non-parametric testing, which hindered the ability to draw generalizable conclusions from some of the data (Field, 2018).

While the percentage of respondents compared to the total number of professional staff members in the district was around one third, the total sample size was still considered small due to the size of the school district. In addition, the survey lacked participation from administrative level professional staff. Those who hold leadership positions often have a large amount of experience in the field when compared to other groups of professional staff and their experiences would be a valuable addition to this research.

### **Strengths**

The benefits of pursuing research on the role of school social workers related to the support of childhood cancer survivors, educational needs, and teacher confidence and preparedness includes the lack of published research in this area. This was evident during the literature review process. This research provided a clear framework and direction for future research, as guided by current results. This study successfully showed the need for additional training on the topic as well as the need for social work involvement in policy, interprofessional education, and leadership in the school setting. Participation in the research study by professional

school staff members was encouraging. Significant relationships and outcomes provided reasonable insight into the identified problem and research questions. The current study justifies the need for school social work leadership in the development of trainings and programs, as well as systems navigation, all which are vital to support educators in feeling confident when providing services to this student population. Expanded educational services for pediatric cancer survivors may increase educators' capacity to meet effectively the unique learning needs of survivors. This, subsequently, will also increase the chance for higher academic achievement among students in this population.

### **Social Work Implications and Considerations**

This research has implications for school social workers, teachers, and administrators. Research findings could contribute significantly to the field of school social work, specifically on leadership of social work staff in the school setting. Results also raises important questions about the lack of policy, procedures, and support provided to pediatric cancer survivors with learning differences. Upon further investigation and research in this area, school policies and protocols related to serving pediatric cancer survivors educationally, should be reviewed. Knowledge gathered in this study will allow school social workers to advocate effectively for students who are cancer survivors. An increased understanding of these students' needs would enable school social workers to develop trainings and programs that better prepare and empower teachers and administrators to serve this student population.

The results of this study could be used to review and shape school policies and protocols to create a more conducive learning environment for pediatric cancer survivors. Examples of beneficial changes in policy and protocols would include regularly scheduled consultations with the social worker, interdisciplinary meetings with medical team at the end of the school



trimester, educational programs and training for professional staff working with the student, and adjustments to attendance and homebound learning protocols.

Pediatric cancer survivors have complex systematic needs. Social workers can efficiently navigate complex service systems and act as liaisons across schools, medical teams, and families. The coordination of services is a task that is already completed by social workers in the school setting. The information that educators want or need from medical providers is often unclear. Professional staff may not have enough knowledge to ask important questions related to childhood cancer and implications in learning. Providing additional training in this area would not only provide empowerment in the capabilities to care for these students, but would also allow teachers and administration to provide valuable accommodations that would be included in the student's IEP. Examples of this would include automatic psychological assessments and 504 plans for cancer survivors. The social worker's role would ultimately expand educational services for pediatric cancer survivors.

Standard practices on accommodations for pediatric cancer survivors returning to school could be developed. These may include, but are not limited to, automatic school psychological assessments, addition of 504 or IEP plans to address physical, emotional, and learning needs in the classroom, the discussion of the diagnosis with classroom peers, and/or the need for additional training and emotional support for the classroom teacher. The information could also be shared via academic presentation and/or local, regional, and national conferences, which would encourage other school systems to develop similar protocols and education programs on childhood cancer and learning needs.

### **Future Research**

Study findings point to the need for additional research and illuminate important topics. The current research provided some preliminary insight into the challenges and needs of educators when working with pediatric cancer survivors in the school setting. Although exploratory, the study exposes interesting information, such as the low baseline knowledge of educators on the topic, lack of importance of years of experience in the field vs. increased confidence and preparedness as a result of experience working with this population. There would be additional benefit from the expansion of research, specifically related to the importance of school social work involvement when working with this population.

The current survey study produced a vast amount of data, with only a small percentage of data utilized for the current research project. Future research will utilize these data in several ways. For example, the researcher is interested in the relationship between different professional school staff roles and base knowledge, confidence, and preparedness. It would also be interesting to include these additional groups when examining the desire for social work involvement. Research could indicate the desire for additional training on the topic based on questions included in the educator section of the survey. Another theme that could be examined is the need for specific school policies related to addressing the learning needs of pediatric cancer survivors. This study could be replicated in additional school districts throughout the state. Including school districts outside of the initial research area would help in the effort to generalize the results by increasing diversity of the participant sample.

Future studies would include a more detailed collection of demographic information, educational status, specialties, etc., which would give more insight into which professional school staff members may require training on the topic. In addition, future research studies could

gather information from school social workers on their experiences in the educational setting, specific to pediatric cancer and professional staff support. It would also be beneficial to include additional administrative staff (such as directors of special education, superintendents, principals, etc.) to gain further understanding of their experiences with this population, policy, and special education practice and protocols.

Another opportunity for future research would include the examination of scores on the Pediatric Cancer Survivor Educator Survey both before and after an in-service training or presentation on the topic. This design would assess gains in understanding of the relationships among knowledge, preparedness, confidence, and the desire for social worker involvement as a result of the training. Qualitative data was also collected during the research study and will be used to expand on current research. Six interviews were completed and prepped for analysis.

An important inclusion for future research would also include investigating the desire for social work assistance by professional school staff members if faced with the challenge of educating a pediatric cancer survivor. The researcher could examine prior experience collaborating with social work services while accommodating medical related learning needs and the educators' opinions of social work support in their classrooms. This could also be reflective of the value of a systems theory-based practice, as social workers are experts in facilitating collaboration among various systems, while assisting in easing the transition between home, community, and school.

### **Conclusion**

Many survivors of pediatric cancer face many lifelong challenges as a result of chemotherapy and radiation treatments used in life-sustaining efforts. Childhood cancer survivors may face learning challenges when they return to the classroom setting after treatment.

Changes in brain development, damage to the brain because of cancer treatments, and trauma can increase learning disabilities, exacerbate inattention, and impact memory (Mitby, et al., 2003).

Poor educational achievement and decrease in cognitive functioning often lead to poorer educational outcomes for pediatric cancer survivors (Boman, Lindblad, & Hjern, 2010).

Despite research showing learning-related concerns, many educators and school systems may not be prepared to educate a child with a cancer history (Hay, Nabors, Sullivan, & Zygmund, 2015). There appears to be minimal training for educators on how chronic diseases, and specifically pediatric cancer, impacts learning in the school environment. Prior research found that teachers and administrators express the need for additional education, training, and support to respond to the unique learning needs of pediatric cancer survivors, which appears to be consistent with the current research study (Dubowy, et al., 2006).

School social workers advocate for the most vulnerable populations. Their advocacy and leadership skills in the school setting can be utilized to benefit students who are facing the most difficult of circumstance. School social workers provide leadership to professional school staff and are likely to collaborate with educators to reduce learning barriers. The development of needs assessments and advocacy for teacher education by school social workers will promote a successful educational experience for childhood cancer survivors. Cancer specific trainings on brain anatomy, side effects, and the utilization of special education services has previously been shown to be helpful to educators (Dubowy, et al., 2006).

Measuring and investigating the current knowledge of teaching staff, along with social work led training initiatives, have the potential to expand educational services for pediatric cancer survivors. This knowledge may also empower educators in their ability to provide

services to students, and assist them as they address students' unique learning needs throughout their educational career.

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## Appendix A

### The Pediatric Cancer Survivor Educator Survey: Educator and Base Knowledge Sections

The Google Form Version of this survey can be found at:  
<https://forms.gle/zVoZvNwe3knNuTGf7>.

#### Educating Pediatric Cancer Survivors: Educator Opinion Section

Current Teaching Assignment (grade, specialty, etc):

Number of years in education:

Primary building:

Do you hold a current certification or license in your field?

**Scenario:** A student in your classroom was diagnosed with cancer over the summer and is now returning to school full time. Please use the following 7-point Likert scale to answer the survey questions *as if you were preparing to educate this student and for when they return to the classroom setting*.

These questions are also not specific to your school district.

PLEASE ONLY SELECT 1 RESPONSE

1. I would be very comfortable educating the child with minimal additional trainings.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

2. I would feel comfortable prepping the student's classmates for their return, including fielding questions about the child's condition (with parent permission).

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

3. I have experience working with a child/children with this diagnosis in the past.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

4. I would feel comfortable knowing how to handle medical accommodations or emergencies in the classroom.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

5. I would have a difficult time with my own emotions related to the child’s health.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

6. I would be concerned for the child’s social adjustment during reintegration into the classroom.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

7. I would be able to identify if the child is having cognitive side effects from their treatment that affects learning.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

8. I would be interested in attending a brief asynchronous in-service to learn more about meeting the educational needs of this child.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

9. I would know who to call or reach out to if I needed help understanding the child’s needs in the classroom.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

10. I would be worried about having this child in my classroom.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

11. It would be helpful for the child to have an IEP or 504 plan prior to their return to school.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

12. There are policies specific to students with pediatric cancer available to help guide me through the students learning needs.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

13. I would want there to be a liaison between the school, medical providers, and parents, to help navigate meeting the child’s needs.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

14. When initially reading the above questions, I also found myself concerned about meeting the needs of any siblings of this student.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

15. I feel confident that I have some base knowledge of this topic.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree

**Neurocognitive Side Effects of Cancer Treatment: Base Knowledge Section**

**\*\*You are not expected to know the answers to these questions. Please select your best guess.\*\***

1. \_\_\_\_\_ children are diagnosed with a pediatric cancer in the United States per year.
  - a. 5,000
  - b. 15,000\*
  - c. 10,000
  - d. 2,000
  
2. The current survival rate for pediatric cancer is:
  - a. 65%
  - b. 75%
  - c. 85%\*
  - d. 95%
  
3. Approximately \_\_\_\_\_ of cancer survivors develop significant memory issues, learning disabilities, or other cognitive effects.
  - a. 25%\*
  - b. 55%
  - c. 70%
  - d. 85%

4. Which part of the brain is most involved in executive functioning?
  - a. Temporal lobes
  - b. Frontal lobes\*
  - c. Occipital lobes
  - d. Cerebellum
  
5. The likelihood of a pediatric cancer survivor developing attention deficit disorders is close to:
  - a. 25%
  - b. 55%
  - c. 70%\*
  - d. 85%
  
6. "Late effects" is a term used to describe the cognitive, physical, and socio-emotional problems that:
  - a. Can emerge years after the completion of treatment for childhood cancer \*
  - b. Are due to the effects of a late-emerging tumor
  - c. Occur early in the course of the disease but improve with treatment
  - d. Occur if treatment is not given soon after diagnosis
  
7. What percentage of children treated a pediatric cancer diagnosis would likely qualify for special education services of some kind?
  - a. Less than 10%
  - b. 20%
  - c. 40%
  - d. 50% or more\*
  
8. Neuroplasticity effects are commonly associated with:
  - a. Deficits in memory
  - b. Deficits in retention
  - c. Deficits in social skills
  - d. Both A & B\*
  - e. All of the above
  
9. With childhood cancer, the primary goal of a neuropsychological evaluation is to:
  - a. Help establish the stage of the cancer or tumor
  - b. Determine the appropriate disability classification
  - c. Make recommendations to the referring physician for medication trial
  - d. Identify cognitive and psychological strengths and weaknesses\*

10. Depending on age of onset, some patients are more vulnerable to brain injury. The age most at risk is:
- Under the age of 5\*
  - Elementary school age
  - Middle school age
  - High school age
11. Sherry was diagnosed with Rhabdomyosarcoma and underwent both surgery and radiation. There is now evidence of right visual neglect. What would be an appropriate accommodation that the teacher can implement within the classroom to better suit Sherry?
- Sherry should be given extra time to complete all assignments and exams
  - Sherry should be given fewer homework problems to complete
  - Sherry's seat should be placed in the front of the room and on the right side of the classroom\*
  - Visual information should be presented to Sherry in large print
12. Treatment for which two childhood cancers is likely to result in permanent brain injury?
- Hodgkin's disease and acute lymphoblastic leukemia (ALL)
  - Acute myelogenous leukemia (AML) and Ewing sarcoma
  - Cerebellar medulloblastoma and acute lymphoblastic leukemia (ALL)\*
  - Ewing Sarcoma and Hodgkin's disease
13. In a recent study by Park, et al. (2016) \_\_\_\_\_ of students with a pediatric cancer diagnosis reported bullying when returning to school.
- 15%
  - 30%\*
  - 60%
  - 75%
14. Almost \_\_\_\_\_ of pediatric cancer survivors will develop significant mental health diagnoses such as depression, anxiety, or posttraumatic stress disorder.
- 5%
  - 15%
  - 25%\*
  - 40%

15. According to research, approximately \_\_\_\_ reported needing additional education on this topic in order to successfully meet the learning needs of students with a history of pediatric cancer treatment.
- a. 10%
  - b. 25%
  - c. 50%
  - d. 75%\*



## Appendix B

### Email Recruitment Letter (Draft)

Dear Colleagues,

I am currently completing my dissertation for the Doctorate of Social Work program at Millersville University. As part of my dissertation process, I am conducting a research study focused on meeting the needs of pediatric cancer survivors in the school setting. Please consider participating in my research by completing the survey at the link provided. The survey will only take about 10-15 minutes. Please complete by September 30<sup>th</sup>, 2020. After completion of the survey, several participants will be asked to participate in a brief one on one interview to discuss the topic. My goal is to have 10 teachers from each building complete the survey and then select 1-2 participants from each building for the in-person interview. Please note that participants must be a certified educator (ex. Certified teacher) or licensed staff (ex. Nursing license, school psychologist, etc.). I cannot complete my research without your assistance and sincerely thank you for your help with my project! Please contact me with any additional questions or concerns.

Thank you,

Amanda L. Musser, MSW, LCSW  
Doctoral Candidate  
Millersville University

Elementary School Social Worker

## Appendix C

### In-Person Interview Questions (for future research)

1. Have you ever had a pediatric cancer survivor in your classroom?
2. Have you had any trainings specific to this topic? Or any trainings that could be loosely applied?
3. What questions would you have when welcoming a pediatric cancer survivor back into the classroom? What information would you want/need? What worries would you have?
4. How would you manage your own emotions related to this diagnosis in a child? What about the emotional impact of the classmates?
5. Does your institution have protocols for this specific situation? 504 plans or IEP plans? How to talk to the class? How would you proceed?
6. What type of help or support would you want/need/expect from your school social worker? The medical team? Special education department? Parents? Student?
7. What was your experience as a parent and accommodations or information needed for the school staff? As a cancer survivor? As a teacher (if you have had a student in your class with this diagnosis)?
8. What are your thoughts/interest in this type of education being offered as an in-service training or at a conference?

## Appendix D

### Institutional Review Board Proposal (Draft)

#### IRB Proposal

**Principal Investigator:** Amanda Musser

**Email:** almusser@millersville.edu

**Approved by another institution:** N/A

**Co-Investigators:** Dr. Heather Girvin (Dissertation Chair), Dr. Laura Granruth (Dissertation Committee), Dr. Karen Rice (Dissertation Committee).

**Project Title:** Social Work Leadership and the Needs of Pediatric Cancer Patients in Schools: Providing Education and Support to Teachers and Administration on the Front Line

**Any outside project funding (if yes, please specify):** The Roothbert Fund Fellowship Award

#### Nature of Risk

**In your judgment, does your research involve more than minimal risk? “Minimal risk” means that the risk of harm anticipated in the proposed research is not more likely than those risks encountered in daily life, or during routine physical or psychological examinations/tests.**

No. The study is minimal risk.

#### Protected Populations and Sensitive Subjects

**Will your research have as its primary focus any protected populations or deal with illegal, potentially illegal or otherwise sensitive subjects?**

No. The study does not include any protected populations or other sensitive subjects.

#### Project Background and Purpose

##### **Background**

Children are increasingly living with and surviving cancer diagnoses due to advances in cancer care and treatment. As such, these children are likely to be enrolled in school with the same hopes and aspirations as their fellow students.

Marusak et al. (2017) reports that cognitive effects, such as attention difficulties, difficulty reintegrating in school and social settings, and decrease in academic functioning are common occurrences in the pediatric survivor population. In addition, cognitive dysfunction is as high as 67% for attention and up to 28% for deficits in executive functioning, IQ, memory, and processing speed (Marusak, et al., 2017). Despite the high incident in occurrence of neuropsychological effects, there has been limited research in this area as seen in the limited

amount of peer review articles that were identified during the research process. Marusak, et al. (2017) and Bisen-Hersch, Hine, and Walker (2013) also identify limitations in available research on this topic. In addition, Reddick, et al. (2014) discusses the lack of understanding of the mechanisms of neurotoxicity from cancer treatment in the brain.

Studies have identified that as high as 23% of pediatric cancer survivors utilize special education services in a school setting, with higher utilization among students diagnosed prior to age 6 and those who experienced treatments identified to negatively impact white matter in the brain (Mitby, et al., 2003). It was also reported that younger age at diagnosis, regardless of cancer type and treatment, was consistent with a higher, long-term need of special education services, overall (Mitby, et al., 2003). It has been recommended, by the Children's Oncology Group (n.d.) that children who have received a diagnosis of cancer be monitored and evaluated for learning disabilities, allowing for early intervention if learning problems are identified. Benefits to involving special education services, both during and after cancer treatment, include an increase in graduation rates among survivors who utilize special education services (Mitby, et al., 2003).

Unfortunately, teacher and administrator education, training, and support may not be sufficient to respond to the unique needs of pediatric cancer survivors. School social workers have an opportunity to provide a leadership role in schools by providing curriculum supports to school staff. Children who are able to succeed in their academics will be more likely to find success in adulthood (Mitby, et al., 2003). Current research indicates a need for extended neuropsychological support during the treatment process and into survivorship (Nabors, Little, Akin-Little, & Iobst, 2008). This includes support through special education services in the school setting. Providing training for educators, evaluation of learning needs, and learning interventions for students with cancer, early on in the educational process, will increase the student's chance of success throughout their lifetime. Unfortunately, many teachers report a lack of education and training to best teach children with cancer (Dubowy, et al., 2006; Hay et al., 2015).

The increase in survival of pediatric cancer patients has led to an additional need for research in regards to how best support survivors during the educational career. To gain a better understanding of the supports provided in the schools for these students, it is important to first understand the education and support offered to teaching staff and administration on this topic. Hay et al. (2015) reported a lack of training in teachers to meet the unique needs of pediatric cancer survivors, also noting the emotional impact on the teacher, and the lack of school policies to address the needs of pediatric cancer survivors. Teachers may often need additional support to provide the appropriate accommodations to these students. Research has shown that, often, educators do not feel equipped to provide the appropriate support to students with significant health issues, and often feel a need for guidance from medical professionals and concluding that survivors would do best with the support of a multidisciplinary team in the school setting (Hay, Nabors, Sullivan, & Zygmund, 2015). Teacher training on this topic has been identified as a positive way to increase confidence in teachers and empower them to address the challenges and unique needs of students with a cancer history (Dubowy, et al., 2006).

Dubowy, et al. (2006) found that providing training modules, for teachers, on brain anatomy, late effects and psychosocial aspects of cancer treatment, and how to incorporate special education to

accommodate the needs of cancer survivors increased preparedness and confidence of teachers, especially those working with a child undergoing cancer treatment. Both Losinski, and Ennis (2018) and Spinelli (2004) identified numerous topics for teachers to be aware of in a classroom setting, such as emotional and physical ramifications of cancer treatment, learning and attention issues, memory and retention, and social implications. It is also important to consider the emotional effects of the cancer diagnosis on the classroom and specifically peers. Teachers should also be aware of preparing other students for the child's return to the classroom and become familiar enough with the diagnosis to answer age appropriate questions, and address peer anxieties associated with a pediatric cancer diagnosis (Losinski, & Ennis, 2018; Spinelli, 2004).

Children's Oncology Group (n.d.) also addressed the needs for teachers to understand learning problems after cancer treatment, needs for psychological testing to identify and address learning needs, and accommodations that may be beneficial for pediatric cancer survivors. Teachers can become familiar with simple techniques to address learning differences, such as seating placement in the classroom, use of audio books, modifications to testing arrangements, or use of a calculator for math problems (Children's Oncology Group, n.d.). Children's Oncology Group (n.d.) also identified the importance of teachers becoming familiar with recognizing simple medical issues that may occur in the classroom, such as fevers, increased bleeding risk, and exposure to viral illnesses.

### **Purpose of the Study**

The purpose of this study is to explore perceptions of teacher preparedness from educators' and administrators' point of view (not students), when educating a child who has survived cancer. When an educator has a student in their classroom with a significant medical need, education on the diagnosis and treatment of the student is typically limited (Dubowy, et al., 2006; Hay et al.). Exploring the current knowledge and confidence levels of teachers who may encounter a student in their classroom with a pediatric cancer diagnosis will enable school social workers to develop trainings, procedures, and policy in the school setting for students with a pediatric cancer diagnosis.

### Characteristics of the Study Population

#### **What is the estimated no. of participants?**

Projected number of participants will be approximately 60 persons for the online quantitative survey and 12 persons for random qualitative in-depth interview.

#### **List participant inclusion criteria:**

Participants must hold a valid teaching certificate for the state of Pennsylvania, be employed by the selected school district.

#### **List any participant exclusion criteria:**

Employees who do not hold a valid teaching certificate (for example instructional aids or other support staff), and those who are not employed by the selected school district.

#### **Will sex or gender be used as an exclusion criterion?**

Please remember sex usually refers to the biological aspects of maleness or femaleness, whereas gender implies the psychological, behavioral, social, and cultural aspects of being male or female

No, neither sex nor gender will be used as an exclusion criterion

Yes, subject's sex is an exclusion

Yes, subject's gender is an exclusion

Yes, both sex and gender are exclusions

*Please justify exclusions based on sex and/or gender\**

### **What is the subject's age range and why was it chosen?**

From: Age 18 to unlimited.

**Please justify age range:** Participants will be adult college graduates who are currently employed by the selected school district.

### Risk and Consent

#### **Please list any potential risks. Specify types and levels of risk.**

This research does not involve risk greater than risks encountered in daily live or during routine physical/psychological exams or tests. In addition, if a participant has any personal experience with cancer they may be sensitive to questions asked in this survey. Some participants may be hesitant to criticize their employer so we have created a standard for anonymity (see below). These risks are likely low and would be addressed by the researcher in a debriefing (see below).

#### **Protection Against Risks:**

As noted above, this survey has minimal risks. The researchers contact information will be provided should respondents want to "debrief" following the survey. In the unlikelyhood that additional support is needed, the researcher has contact information for community mental health agencies.

#### **Potential Benefits**

Knowledge gathered may allow school social workers to advocate more effectively for students who are cancer survivors. An increased understanding of these students' needs would enable school social workers to develop trainings and programs that better prepare teachers and administrators to serve this student population. Additionally, with an increased understanding of the complex needs of pediatric cancer survivors, social workers can more efficiently navigate complex service systems and act as a liaison across school, medical teams, and families. Finally, at a more macro level, data from this survey could be used to review critically and (eventually) shape school policies and protocols that frame the learning environment for pediatric cancer survivors.

#### **Dissemination of your Findings:**

Upon further investigation and research in this area, school policies and protocols related to serving pediatric cancer survivors educationally, could be reviewed. Standard practices on how to accommodate pediatric cancer survivors returning to school could be developed. This may

include, but not limited to, automatic school psychological assessments, addition of 504 or IEP plans to address physical, emotional, and learning needs in the classroom, the discussion of the diagnosis with classroom peers, and/or the need for additional training and emotional support for the classroom teacher. The information could also be shared at local, regional, and national conferences, which would encourage other school systems to develop similar protocols and education programs on childhood cancer and learning needs.

### Methods and Procedures

#### **Describe the method(s) for identifying and recruiting prospective subjects.**

An email letter will be sent to all teachers in the selected school district welcoming participation in the survey. The survey will include questions to ensure that participants are meeting the requirements for the study (i.e. Do you have a current teaching certification for the state of Pennsylvania).

**Will you publicly advertise to recruit participants?** No

**State the location(s) where the study will be conducted:** Pennsylvania

**Will your research take place outside of Millersville?** Yes. Selected school district. Please see attached letter of support from superintendent.

#### **Describe *in detail* the study design and all procedures (sequentially) to be applied to subjects.**

To explore the research questions previously reviewed, a survey has been created with the intent of gathering additional information from educators related to working with a student whose history is significant for a pediatric cancer diagnosis. An email letter will be sent to all teachers in the selected school district welcoming participation in the survey. The survey will include questions to ensure that participants are meeting the requirements for the study (i.e. Do you have a current teaching certification for the state of Pennsylvania).

The survey will include questions designed to collect information from teachers and administration on the neuropsychological side effects of cancer treatment on children. This would allow the researcher to understand the base knowledge of both teachers and administrators currently employed by the school. Questions would also include demographics, such as the teacher and administrator's experience level, and if they have had the experience of working with a cancer survivor.

It would also be important to understand what trainings were offered that may be relevant to educating a pediatric cancer survivor and/or if they are aware of any trainings that they may not have attended on the topic. In an effort to understand the social worker's role, from the perspective of the educators, it would be interesting to investigate what assistance would be wanted or needed from the social worker in this situation. For potential future research opportunities, open-ended questions related to concerns, worries, and the anticipated emotional impact of educating a student with a cancer history would be included for future use of

qualitative data as a next step for research. The survey would also include asking for ideas in how to assist in increasing confidence levels of the teachers and administrators, when tasked with providing education and addressing the needs of pediatric cancer survivors. The current study will be a quantitative study. Inclusion of qualitative data may lead to a future qualitative extension of this study.

The survey will be sent out via professional emails to professional staff at all six schools in the selected school district. Those who are interested in participating will be invited to click the link to the survey, which will be available in the district's secure teacher google account via a google form. The participants will be provided with the informed consent and asked to verify that they have read the consent, agree or disagree to participation, and then asked to electronically sign the consent form. Participants who agree to participate will be asked to complete the survey within one week from the time it is sent. For the qualitative data, the researcher will utilize stratified sampling to select 10 surveys, at each building in the district, to invite for the qualitative portion of the study. There will be a total of 60 participants. The qualitative portion of the research will utilize random sampling to invite two participants from each school for an open-ended question interview/discussion of the topic via in person or zoom.

Collection of data is expected to be completed by the end of October. Data were then be analyzed, utilizing SPSS for descriptive statistics, correlations, and any other appropriate quantitative analysis as advised by the dissertation committee. Qualitative analysis will then be evaluated using NVivo for coding themes from the in-person. Data/Results will be shared with all participants (if interested) via presentation either in person or on zoom, with time for participant feedback. Please see additional details on dissemination above.

**Will you use any instruments such as surveys, rating scales, or questionnaires?** Yes. Please see attached.

**Demographics and Personal History Variables:**

**Describe any alternatives to participation in the study which might be advantageous to the subject. If the subjects are to receive academic credit for research participation, describe the alternatives available to earn equivalent academic credit.**

N/A- Findings will be available to all teachers and administrators in the selected school district.

**Will the participants receive monetary or other forms of compensation for their participation?** No

**Will any information be withheld from the participants?** No

**Describe the procedure for post-study debriefing of subjects:**

As noted above, this survey has minimal risks. The researchers contact information will be provided should respondents want to "debrief" following the survey. In the unlikelyhood that additional support is needed, the researcher has contact information for community mental health agencies.

**Describe in detail how confidentiality and privacy will be maintained:**



Though other software is available, our school district's primary data management system for file sharing is the teacher google account, which also includes various confidential school documents. Every participant will be assigned an identified number and all data will be password protected and kept on a computer that only this researcher will have access to and confidentiality will be maintained. As noted above, the intention of this research is to share information, however

Respondents names and email addresses will be removed from data and all respondents will be assigned a number to maintain confidentiality. The key to that will be kept on the researcher's computer and be password protected.

Data gathered/collected will be kept for three years after study completion. Data files will continued to be stored securely and password protected.

## IRB Approval

### Social Work Leadership and the Needs of Pediatric Cancer Patients in Schools: Providing Education and Support to School Employees on the Front Line



Rene Munoz  
To You

Oct 7

...

Amanda,

Your IRB Protocol no. [659976017](#), "Social Work Leadership and the Needs of Pediatric Cancer Patients in Schools: Providing Education and Support to School Employees on the Front Line" has been approved. Your protocol received expedited review and was found to be minimal risk. Your approval extends for 1 year from the date of this email. If you need additional time, please inform the MU IRB at least 4 weeks before expiration. If you have any questions, please feel free to contact me.

Thank you,

Rene Munoz

## Appendix E

### Informed Consent (Draft)

The Google Form Version of the consent can be found at:

<https://forms.gle/zVoZvNwe3knNuTGf7>.

### Consent to be Part of a Research Study

**Title of the Project:** Social Work Leadership and the Needs of Pediatric Cancer Patients in Schools: Providing Education and Support to Teachers and Administration on the Front Line

**Principal Investigator:** Amanda Musser, MSW, LCSW, Doctoral Candidate, Millersville University

**Co-investigator:** Dr. Heather Girvin, Dissertation Chair, Millersville University; Dr. Laura Granruth, Dissertation Committee, Millersville University; Dr. Karen Rice, Dissertation Committee, Millersville University

**Faculty Advisor:** Dr. Heather Girvin (Dissertation Chair), Millersville University

**Study Sponsor:** The Roothbert Fund Fellowship Award

### Invitation to be a Part of a Research Study

Dear Educator,

You are invited to participate in a research study that will examine educating children who have a history of cancer in the school setting. In order to participate, you must be licensed or certified by the Pennsylvania Department of Education, currently employed by the selected school district over the age of 18, and have a minimum of a completed bachelor's degree. Taking part in this research project is voluntary.

### What is the study about and why are we doing it?

The purpose of this study is to explore perceptions of teacher preparedness from educators' and administrators' point of view (not students), when educating a child who has survived cancer. When an educator has a student in their classroom with a significant medical need, such as cancer, education, for school staff, on the diagnosis and treatment of the student is typically limited. Exploring the current knowledge and confidence levels of teachers who may encounter a student in their classroom with a pediatric cancer diagnosis will enable school social workers to develop trainings, procedures, and policy in the school setting for students with a pediatric cancer diagnosis.

The increase in survival of pediatric cancer patients has led to an additional need for research in regards to how best support survivors during the educational career. To gain a better understanding of the supports provided in the schools for these students, it is important to first understand the education and support offered to teaching staff and administration on this topic. Hay et al. (2015) reported a lack of training in teachers to meet the unique needs of pediatric cancer survivors, also noting the emotional impact on the teacher, and the lack of school policies

to address the needs of pediatric cancer survivors. Teachers may often need additional support to provide the appropriate accommodations to these students. Research has shown that, often, educators do not feel equip to provide the appropriate support to students with significant health issues, and often feel a need for guidance from medical professionals and concluding that survivors would do best with the support of a multidisciplinary team in the school setting (Hay, Nabors, Sullivan, & Zygmund, 2015). Teacher training on this topic has been identified as a positive way to increase confidence in teachers and empower them to address the challenges and unique needs of students with a cancer history (Dubowy, et al., 2006).

### **What will happen if you take part in this study?**

If you choose to participate, you will be asked to complete a short survey related to educating a child with a pediatric cancer history. The initial survey will be completed via secure google form utilizing your district email account. This is a secure platform.

Some participants will be randomly selected to complete brief, in person interviews (or via zoom if needed due to COVID) during the month of October. An email will be sent to you to schedule, if you are selected. These interviews will be audio/video recorded.

Data/Results will be shared with all participants (if interested) via presentation either in person or on zoom, with time for participant feedback. In addition, information learned in this study could also be shared at local, regional, and national conferences, which would encourage other school systems to develop similar protocols and education programs on childhood cancer and learning needs.

### **How will your information be protected?**

I will protect the confidentiality of your research records by utilizing our school district's primary data management system for file sharing via the teacher google account, which also includes various confidential school documents and is a secure environment. Every participant will be assigned an identified number and all data will be password protected and kept on a computer that only this researcher will have access to. Respondents names and email addresses will be removed from data and all respondents will be assigned a number. The key to that will be kept on the researcher's computer and be password protected. Data gathered/collected will be kept for three years after study completion. Data files will be continued to be stored securely and password protected. In the event that the research is presented in a professional manner, confidentiality of subjects will be maintained. It is possible that other people may need to see the information we collect about you. These people work for the Millersville University and government offices that are responsible for making sure the research is done safely and properly.

### **How could you benefit from this study?**

Participants may gain additional knowledge on the research topic, that would allow them to better prepare for meeting the educational needs of a pediatric cancer survivor in the classroom. In addition, knowledge gathered may allow school social workers to advocate more effectively for students who are cancer survivors. An increased understanding of these students' needs would enable school social workers to develop trainings and programs that better prepare

teachers and administrators to serve this student population. Additionally, with an increased understanding of the complex needs of pediatric cancer survivors, social workers can more efficiently navigate complex service systems and act as a liaison across school, medical teams, and families. Finally, at a more macro level, data from this survey could be used to review critically and (eventually) shape school policies and protocols that frame the learning environment for pediatric cancer survivors.

### **What risks might result from being in this study?**

This research does not involve risk greater than risks encountered in daily life or during routine physical/psychological exams or tests. In addition, if a participant has any personal experience with cancer they may be sensitive to questions asked in this survey. These risks are likely low and would be addressed by the researcher in a debriefing, if desired.

*Should participants want to “debrief” following the survey, please contact the principle investigator Amanda Musser at 717-202-9484 or [amanda\\_musser@pasd.us](mailto:amanda_musser@pasd.us). In the unlikelyhood that additional support is needed, the researcher has contact information for community mental health agencies.*

### **Your Participation in this Study is Voluntary**

It is completely up to you to decide to be in this research study. Participating in this study is voluntary. There is no compensation provided to you to participate in this study. There are also no costs for participation. Even if you decide to be part of the study now, you may change your mind and stop at any time. You do not have to answer any questions you do not want to answer. If you decide to withdraw before this study is completed, any data collected will be destroyed. *Please take time to read this entire form and ask questions before deciding whether to take part in this research project.*

### **Contact Information for the Study Team and Questions about the Research**

If you have questions about this research, you may contact Amanda Musser, Principle Investigator, at 717-202-9484 or [amanda\\_musser@pasd.us](mailto:amanda_musser@pasd.us) or Dr. Heather Girvin, Dissertation Chair; Millersville University, at [heather.girvin@millersville.edu](mailto:heather.girvin@millersville.edu)

### **Contact Information for Questions about Your Rights as a Research Participant**

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the following:

Dr. Rene Munoz  
c/o Millersville University  
The Office of Sponsored Programs & Research Administration  
PO Box 1002  
Millersville, PA 17551  
Phone: 717-871-4457  
Email: [rene.munoz@millersville.edu](mailto:rene.munoz@millersville.edu)

### **Your Consent**

By electronically signing this document, you are agreeing to be in this study. Make sure you understand what the study is about before you sign. You will be provided a copy of this document for your records via email. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

*I understand what the study is about and my questions so far have been answered. I agree to take part in this study.*

\_\_\_\_\_ Printed Subject Name  
 \_\_\_\_\_ Signature & Date

### **Consent to be Audio/Video Recorded**

*I Agree to be audio/video recorded if selected for the interview portion of the study.*

YES \_\_\_\_\_ NO \_\_\_\_\_

\_\_\_\_\_ Signature & Date

### **Consent to Use Data for Future Research**

*I agree that my information may be shared with other researchers for future research studies that may be similar to this study or may be completely different. The information shared with other researchers will not include any information that can directly identify me. Researchers will not contact me for additional permission to use this information.*

YES \_\_\_\_\_ NO \_\_\_\_\_

\_\_\_\_\_ Signature & Date

Appendix F

Permission to Conduct Research at [REDACTED]



May 31, 2020

To Whom It May Concern:

Supporting educators, or in this case, a school social worker, in efforts related to pursuit of a doctoral degree is something we are pleased to assist with at any time. The [REDACTED] School District is supportive of Amanda Musser's desire to conduct her study within our school district. We authorize Amanda Musser to conduct an anonymous survey to teaching staff with the understanding that her study relates to the education of children who are experiencing a history of cancer. It is our understanding that the published dissertation will maintain anonymity of school personnel and school district.

If there are any questions, please do not hesitate to contact me at [REDACTED]

Sincerely,

A large black rectangular redaction covering the signature of the Superintendent.

Superintendent

\*Identifying information has been blacked out to maintain confidentiality.