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The document mentioned above has been reviewed and accepted by the student's advisor, on behalf of the advisory committee, and by the Assistant Dean for MSN and DNP Studies, on behalf of the program; we verify that this is the final, approved version of the student's DNP Project including all changes required by the advisory committee. The undersigned agree to abide by the statements above.

Alesandra S. Conley, Student

Dr. Leslie Scott, Advisor

DNP Practice Inquiry Project Report
Assessment of Nurses' Views and Current Practice of Trauma-Informed Pediatric Nursing Care:
Oncology

Alesandra S. Conley, BSN, RN

University of Kentucky
College of Nursing
Fall 2015

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Dedication

I dedicate my capstone work to my family and friends. A special feeling of gratitude to all of you, I could not have been successful without the encouraging words I received throughout this journey. Thanks to all of you for helping me attain my dreams.

I also want to personally dedicate this work to my amazing mother, the woman who has cheered on the sidelines, and put my best interests ahead of hers. Without you by my side this great achievement would not have been possible. Thank you for all of your love and support, and just being you.

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Introduction to Final Practice Inquiry Project Report

Alesandra S. Conley, BSN, RN

University of Kentucky

Pediatric Medical Traumatic Stress (PMTS) is, “a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences,” (National Child Traumatic Stress Network, 2003). All of which are often associated with a cancer diagnosis and treatment, and in some cases may even lead to posttraumatic stress disorder. PTSD occurs when symptoms triggered from life-threatening experiences, like a cancer diagnosis, persist longer than one month causing a debilitating affect on the individual (Kaminer, Seedat & Stein, 2005). Research shows that traumatic stress and repeated exposure can together be linked to poor relationship development, academic difficulties, increased risky behavior, and the increased likelihood of entering the juvenile system at a young age (Ford, Chapman Hawke, & Albert, 2007). In attempts to reduce rates of PTSD and prevent these negative outcomes, researchers have worked to develop models and tools designed to identify at risk patients and families.

One model has proven to be a grounded framework for which evidence-based tools can be developed; yet a standardized practice guideline for preventing and treating PTSD in pediatric cancer patients remains undeveloped (Kazak, Kassam-Adams, Schneider, Zelikovsky, Alderfer, & Rourke, 2006). The focus of this practice inquiry project began as an examination of depression in pediatric cancer patients. The first manuscript is a review of literature that discusses psycho-oncology and its implication in the field of pediatric oncology. During this review it was discovered that posttraumatic stress disorder is a real, life-altering outcome that occurs in 5-20% of pediatric cancer patients (Kazak et al., 2007). Given that the literature identified a gap in practice regarding this area of focus, the purpose of this project moved towards the assessment of current evidence-based practices and tools utilized in practice. The second manuscript reviews the successful model used as a framework in the development of

various tools, treatments and practice models. The findings in this framework identify a specific model of care referred to as “trauma-informed care.” Trauma-informed care is a patient care delivery method designed to recognize and prevent symptoms associated with posttraumatic stress. A tool designed from the basis of this method is described in the second manuscript and referred to as the DEF Protocol. This protocol focuses on Distress, Emotional Support and Family through actively assessing, providing information, listening carefully, asking about fears, and providing reassurance; encouraging parents, empowering parents and encouraging the children; gauging distress, identifying stressors, strengths and coping methods, and encouraging parents to use resources and support established within the family (see www.healthcaretoolbox.org, enter for Pediatric Traumatic Stress, 2009). The final purpose of this project therefore was to assess current practice trends and knowledge of the nurses providing care to pediatric oncology patients in the hematology/oncology unit of the Kentucky Children’s Hospital. The final manuscript focuses on the results of a provider survey based on the DEF protocol known as the DEF Provider Survey. It is a 38-item questionnaire designed to assess knowledge, gauge opinions and self-rated competence, and identify current practices and barriers related to implementing trauma-informed care.

Manuscript 1

Integrative Literature Review- Pediatric Psycho-Oncology: Identifying standards and current practices

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INTEGRATIVE LITERATURE REVIEW

Abstract

Objective: The aim of this literature review is to identify standards, guidelines, and current evidence-based practices associated with pediatric psycho-oncology. **Background:** The concept of psycho-oncology has been around for over 30 years, yet has failed to be well established in practice. In order to improve outcomes of childhood cancer survivors and successfully develop a working model of care, providers need an increased understanding of current trends and practices used within the discipline today and how they affect the long-term outcomes of survivors.

Design: Literature review. **Methods:** CINAHL, PubMed, Google Scholar, and MEDLINE. This also included an ancestry search of the reference lists of those articles found in the databases meeting the inclusion criteria for the review. **Results:** A total of 7 articles were selected. The studies in this literature review include other literature reviews, three quantitative studies, a reflection paper, and an implementation plan of an evidence-based model for practice. All of the articles encompassed three common themes: the need of standardized guidelines for practice in psycho-oncology, a move towards implementation of an embedded psycho-oncologist into the regular medical team and early intervention to prevent negative long-term effects in survivors such as PTSD/PTSS. **Conclusion:** Increased studies and funding will aid in future research to quantify the implications of psycho-oncology and successfully develop a national framework for practice.

Key words: *psycho-oncologists, pediatric, psychosocial, adolescents, oncology, and cancer.*

Introduction

Childhood cancer is a traumatic experience for both the child and the family. However with recent advances in treatment, the overall survival rate for pediatric cancer has reached a high of 85% (Askins & Moore, 2008). In 1960 the five-year survival rate of a child diagnosed with cancer was a slim 28% (Patenaude & Kupst, 2005). With a future now in view for these children, interventions have been explored and implemented into practice to ensure a more holistic approach of care for each child. Open communication between child and parent, and child and provider regarding the diagnosis of cancer commanded a change in the approach towards holistic modalities. It was this change that led to the introduction of psychologists into the oncology treatment community (Patenaude & Kupst, 2005). This concept in pediatric oncology evolved into a new discipline known as psycho-oncology.

The concept of “psycho-oncology” began in the 1960s, when researchers were observing the psychological response of parents to the loss of their children as they transitioned through the mourning process (Patenaude & Kupst, 2005). From there it progressed into its own specialty focusing on the psychosocial aspects of cancer treatment from diagnosis through survivorship. Psycho-oncology is a facilitating discipline that ensures the psychosocial needs of cancer patients and their families are identified, and necessary interventions are implemented alongside the medical plan of care (Kazak, Rourke, Alderfer, Pai, Reilly, & Meadows, 2007).

Psycho-oncology is a multifaceted discipline that examines various aspects of psychosocial behaviors as it pertains to the diagnosis and treatment of cancer. “Psychosocial care includes assessment and monitoring of the child’s cognitive, academic, emotional, spiritual, and practical needs and the family strengths and limitations,” (Wiener, Viola, Koretski, Perper, & Patenaude, 2014). Providers are able to assist children and families cope or prevent the short-

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and long-term outcomes associated with the care and treatment of cancer. Posttraumatic stress disorder (PTSD) and posttraumatic stress syndrome (PTSS) are two common symptoms found among adolescent and young adult childhood cancer survivors; occurring in about 5-20% (Kazak et al., 2007; Patenaude & Kupst, 2005). The primary focus of the pediatric psycho-oncology specialists is to prevent young survivors from experiencing negative outcomes following the completion of their treatment (Kazak et al., 2007; Patenaude & Kupst, 2005; Askins & Moore, 2008).

Since the development of the psycho-oncology specialty, a movement has begun transitioning the specialists from a very traditional role in the office to a more practical one at the bedside position. This transition has proven to be a challenge, but while psycho-oncologists have begun to work more closely with the medical team, additional attention has been directed to the psychosocial aspects of pediatric cancer treatment.

Purpose

The aim of this literature review is to identify standards, guidelines, and current evidence-based practices associated with pediatric psycho-oncology. Studies indicate that pediatric cancer patients and families can have long-term outcomes without early and adequate psychosocial interventions. The relationship between psycho-oncology and long-term affects on childhood cancer survivors is not clearly understood. However, current themes suggest a movement of support for standardized guidelines, which integrate psychosocial personnel into the medical team in order to prevent these potential negative effects.

Methods

A search of published studies featuring pediatric psycho-oncology or psychosocial functioning was performed using CINHALL, PubMed, Google Scholar, and MEDLINE. The

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search was limited to peer reviewed articles in English published in and after the year 1996, this allowed for enough information to identify trends in the current and past practices of pediatric psycho-oncology. Key words in the search were *psycho-oncologists, pediatric, psychosocial, adolescents, oncology, and cancer*.

Inclusion criteria for the search were used to help identify the relevant articles. Articles chosen for the review focused on the pediatric population (0-18 years) diagnosed with childhood cancer. The articles were also required to discuss the implementation of psycho-oncology into treatment and/or address guidelines, standards and current evidence-based practices of pediatric psycho-oncology. Studies that focused on the adult population or did not include psycho-oncology as part of the treatment plan were omitted.

In the final phase an ancestry search was performed using the articles found in the databases. Of the total number of articles found during both searches, seven were included for review based on the inclusion criteria. The studies in this literature review include previous literature reviews, three quantitative studies, a reflection paper, and an implementation plan of an evidence-based practice model.

Themes

The review of the literature identified three themes: 1) the need of standardized guidelines for practice in psycho-oncology, 2) a move towards inclusion of a psycho-oncologist as a member of the regular medical team, and 3) early psychological intervention to prevent negative long-term effects such as PTSD/PTSS in survivors.

Standards of Practice and Guidelines

To date, current standards of practice related to pediatric psycho-oncology are not clearly delineated. The conceptual framework by which those practicing psycho-oncology is to provide

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holistic awareness of the obstacles the patient and their family may face during the cancer treatment trajectory. Pediatric psycho-oncologists focus on behavioral changes (both natural and cancer-related), spiritual needs, continuing education, assurance that pain needs during treatment and procedures are met, as well as anxiety control. They also deliver family and re-socialization support and continue to follow up as needed after completion of treatment in cases of unexpected events (Askins & Moore, 2008; Kazak et al., 2007).

Standards of care provide the medical community with a framework for developing services and programs essential to providing adequate care. Guidelines then follow the framework exhibiting ways to provide care and create goals. The review performed by Wiener et al. explores the current pediatric psychosocial standards and guidelines through an extensive database search using MEDLINE and PubMed. The authors included a total of 27 articles for use in their review. A total of five national and international organizations have attempted to develop a set of guidelines and standards for practice. The standards developed were established by the American Society of Pediatric Hematology/Oncology, the Institutes of Medicine, Canadian Association of Psychosocial Oncology, International Society of Paediatric Oncology, and the European Society of Paediatric Oncology between 1996 and 2013. However, none were successful at developing an acceptable set of practice guidelines for pediatric psycho-oncology. Most guidelines lacked details, consistency, completeness, and specifically they did not address the requirements of the pediatric population (Wiener et al., 2014). The authors concluded that despite the efforts of the participating organizations, there remains a need to develop evidence-based standards of care and the study was inconclusive at identifying acceptable guidelines (Wiener et al., 2014). It is this absence of standardized practice that impedes the consistency of

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psychosocial services provided to pediatric cancer patients and their families, and suppresses the normalization of psychosocial care within the community.

Kiernan, Meyler & Guerin, explored physicians' and nurses' perceptions of psychosocial issues in pediatric oncology (2010). Kiernan et al. identified that both nurses and physicians were aware of the psychosocial needs exhibited by the patient and their family, but needed further education to execute appropriate interventions. Implementing guidelines and utilizing care that includes formally trained, psychosocial professionals would be beneficial to both patients and families (Kiernan et al., 2010). Implementation of a national standardized model of care into the pediatric oncology discipline for psycho-oncologists would clarify the uncertainty of the "next step" once the need for psychosocial intervention have been identified. The concept of psycho-oncology has continually evolved medicine for nearly 30 years, yet it has failed to develop as intended due to poor clarification of guidelines for practice.

Along with the national organizations, there are universities and hospital enterprises that have begun to develop care models of their own. The Children's Hospital of Philadelphia presented a blended model framework as a potential evidence-based guideline tool for use in pediatric psycho-oncology practice. The model integrates the Pediatric Psychosocial Preventative Health Model (PPPHM) and the Medical Traumatic Stress Model (Kazak et al., 2007). This blended model was developed with the goal of standardizing the delivery of care regarding psychosocial needs of pediatric cancer patients and their families. The framework provided allows for both psychological and medical needs to be met without interference from one another, promoting the concept of an "embedded" psycho-oncologist within the medical team.

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Implementation of “embedded” psycho-oncologists

Research has revealed, there is a strong need for standardization of care practices within the pediatric psycho-oncology discipline. One practice implemented the transition from the typical consulting psychologist, psychiatrist, or social worker to the concept of an embedded psycho-oncologist (Kazak et al., 2007). This concept places the psychologist directly on the medical team responsible for care and treatment. Their role within the primary medical team includes rounding as well as actively participating in the plan of care for patients. Having a psycho-oncologist working along side the medical team is more conducive to the treatment and care provided to the patient and family, ultimately improving survivor outcomes (Kazak et al., 2007; Askins & Moore 2008; Patenaude and Kupst, 2005).

An evidence-based model of care was designed to implement psychological research into clinical practice, which ensures the psychosocial needs of pediatric cancer patients are being met (Kaza et al., 2007). Models in which the psychologist worked directly with the medical team were compared to those that the psychologist acted as a consulting service (Kazak et al., 2007). It was concluded that when psycho-oncologists worked directly along side the medical team and actively participated in the plan of care, they were able to facilitate interventions, education, activities, and develop programs needed to increase psychosocial functioning. Whereas those utilizing a consulting service tend to have less collaboration and limited resources (Kazak et al., 2007). Although no quantitative data were found in this literature search on the relationship between long-term effects and the use of psycho-oncology during treatment, the articles reviewed imply that after psychosocial personnel were introduced into the oncology community, around 1960, the journey became more manageable for both patients and families.

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As pediatric cancer survival rates began to improve during the 1960's and 1970's the outlook among parents and providers began to change (Patenaude & Kupst, 2005). Parents and providers reported it pertinent to explain the implications of their cancer diagnosis using open communication regarding treatment, and the possibility of death. These strategies best allowed psychological professionals to assist families with coping. This transition among the oncology community brought about further awareness of the difficult challenges both the patients and families were facing (Patenaude & Kupst, 2005).

Prevention of Negative Outcomes

The primary focus of pediatric psycho-oncology specialists is to prevent young survivors from experiencing negative outcomes following the completion of their treatment (Kazak et al., 2007; Patenaude & Kupst, 2005; Askins & Moore, 2008). The transition into survivorship should be a happy time for these children and their families, but it can become the hardest step of the journey. Childhood cancer survivors often have to relearn self-identity, as they are no longer 'just a kid with cancer'. They have to re-socialize with their peers and most are also entering adolescences, which includes dealing with the changes puberty brings. All of this can be a difficult and confusing process for children. In some cases those who survive childhood cancer are unable to successfully transition back into their reality. Some experience constant fears of relapse; worry if they are growing like their friends, and even the possibility of sterility secondary to the harshness of their treatments.

Posttraumatic Stress Disorder has been identified among the many possible negative outcomes that childhood cancer survivors often suffer from during adolescence and into young adulthood. PTSD is frequently associated with sexual abuse cases or severe traumatic events, however 5-20% of childhood cancer survivors experience PTSD due to the exhausting gamut of

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treatment they have endured (Kazak et al., 2007; Patenaude & Kupst, 2005). PTSD is not the only disorder survivors face, but it is one that has been often identified and studied among researchers driving providers to develop better programs and interventions alongside medical treatment.

A study conducted by Stuber, Christakis, Houskamp, and Kazak, *Posttrauma Symptoms in Childhood Leukemia Survivors and Their Parents (1996)*, found that 12.5% of the leukemia survivors participating in their study had a score placing them in the severe range of posttraumatic stress disorder symptoms. The authors used a twenty item self-report questionnaire known as the Child Posttraumatic Stress Disorder Reaction Index. This tool has been used in other traumatic events such as the Gulf War and Hurricane Hugo to assess the stress symptoms in children ages 9-19, “scores correlated with clinical PTSD diagnosis, indicating a strong validity,” (Stuber et al., 1996). Like previous studies, the data found in this study correlated with those children who were clinically diagnosed with PTSD (Stuber et al., 1996).

In an effort to decrease posttraumatic stress symptoms in families with childhood cancer an intervention has been studied in which group and personal therapy in a four-session, one-day program take place (Kazak, 2005). The new program is referred to as the Surviving Cancer Competently Intervention Program (SCCIP). Implementation of this program on a selected 150 families of childhood cancer survivors revealed a significant reduction in PTSS, specifically in survivors and fathers (Kazak, 2005).

Long-term effects often occur in cancer survivors that require health interventions. Psychological effects should not be considered any different. There continues to be a disconnect and inconsistency in the care provided regarding psychosocial care in pediatric cancer. With the

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growing psychological research in pediatric oncology there are several new opportunities for the future, which can lead to a more focused and consistent intervention.

Discussion

Limitations of this review include the selection of terms used to perform the database searches as well as the years selected to review. For this topic, it may have been better to extend the search beyond the year 1996. This would have allowed for further exploration of the past practices of this discipline, leading to a better comparison of transition throughout the years. Overall the literature found was inconclusive regarding quantifiable data that correlated pediatric psycho-oncology with reduced negative outcomes for pediatric cancer survivors. Nevertheless, key concepts were identified across the studies that can be used to inform clinical practice, promote the development of standards and guidelines and aid research.

Although there have been similar themes among the studies reviewed, the literature is lacking a consistency of definition and framework from which the practice of psycho-oncology is based. It appears as though a conceptual idea about what a psycho-oncologist is has evolved from basic psychology concepts and other working frameworks within the medical field, yet a functioning model of its own does not yet exist. The delay from those working within the profession of psycho-oncology to develop their own medically functioning model may be due to the limited resources and number of relevant studies that have been performed. To date, there is not much known regarding the correlation between the outcomes and implementation of psycho-oncology. However this, is not due to the lack of faith in the practice of the profession, but rather credited to the continuing spectrum of patients transitioning from cancer patient to cancer survivor. In order for outcomes to be studied, researchers ideally need to follow the subject from diagnosis through re-socialization into their everyday reality as a survivor; making it difficult to

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conclude that there is a positive correlation between psycho-oncology and decreased negative outcomes.

It is important to continue to support the attempt to develop a standardized model of practice. The act of standardization and development of guidelines would facilitate researchers to study the impact and that psycho-oncology has on children and families. It would also assist providers with implementing resources for those who have been identified with increased psychosocial risk factors as well as ensure that all children and families are receiving an appropriate level of psychosocial care throughout their journey with childhood cancer.

Conclusion

Further studies are needed to better understand psycho-oncology and its implications in childhood cancers. In order to develop useful studies and design a working model of care, providers from multiple disciplines (psychology, oncology, pediatrics, child life specialist, nurses, and researchers) need to collaborate both nationally and internationally. As advanced practice providers (APRN) nurses can use this information to educate other staff and disciplines of the role psycho-oncologists play in the medical field. APRNs also have the ability to spread awareness of psychosocial risks children with cancer are suffering from and can aid in the development of programs designed to prevent long-term negative effects that may occur once they reach survivorship.

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References

- Askins, M. A., Moore, B. D. (2008). Psychosocial support of the pediatric cancer patient: Lessons learned over the past 50 years. *Current oncology reports*, 10, 469-476.
- Kazak, A. E., (2005). Evidence-based interventions for survivors of childhood cancer and their families. *Journal of Pediatric Psychology*, 30, 29-39. doi: 10.1093/jpepsy/jsio13
- Kazak, A., Rourke, M., Alderfer, M., Pai, A., Reilly, A., & Meadows, A. T. (2007). Evidence-based assessment, intervention and psychosocial care in pediatric oncology: A blueprint for comprehensive services across treatment. *Journal of Pediatric Psychology*, 32, 1099-1110. doi: 10.1095/jpepsy/jsm031
- Kierman, G., Meyler, E., Guerin, S. (2010). Psychosocial issues and care in pediatric oncology. *Cancer Nursing*, 33, E12-E20
- Patenaude, A., Kupst, M. J., (2005). Psychosocial functioning in pediatric cancer. *Journal of Pediatric Psychology*, 30(1), 9- 27. doi: 10.1093/jpepsy/jsi012
- Stuber, M., Christakis, D., Houskamp, B., Kazak, A.E., (1996). Posttrauma symptoms in childhood leukemia survivors and their parents. *Psychosomatics*, 37, 254- 261
- Wiener, L., Viola, A., Koretski, J., Perper, E. D., Patenaude, A. F. (2014). Pediatric psycho-oncology care: standards, guidelines, and consensus reports. *Psycho-Oncology*. doi: 10.1002/pon.3589

Manuscript 2

Implementation of an Evidence-Based Screening Tool for Identification of Posttraumatic
Stress Disorder: D-E-F Protocol

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IMPLEMENTATION OF AN EVIDENCE BASED SCREENING TOOL

Background

Over the past several decades, research and medicine have made great advancements in improving the five-year survival rates for childhood cancer up to 80% (Askins & Moore, 2008; Ward et al., 2014). However with these advancements often come long-term side effects. Some side effects may be instantaneous while others occur later. We know from extensive research that posttraumatic stress symptoms (PTSS) or posttraumatic stress disorder (PTSD) related to a medical trauma like cancer is just one of the long-term effects adolescent and young adult survivors may face. According to the American Childhood Cancer Organization, “In 2014, an estimated 15,780 new cases of cancer will be diagnosed and 1960 deaths from cancer will occur among children and adolescents aged birth to 19 years,” making childhood cancer the leading causes of death by disease among children and adolescents in the United States (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014).

Posttraumatic stress disorder can be described as a reaction related to a traumatic event, such as the life-threatening diagnosis of cancer. Symptoms of PTSD are often persistent and include unwanted thoughts about the experience, anxiety, avoidance of certain places or people, a feeling of distance from others, and hyperarousal symptoms (Ehlers & Clark, 2000). PTSD is often coupled with an anxiety disorder, both of which can severely impair social and occupational functioning in its victims (Ehlers & Clark, 2000; Kassam-Adams et al., 2014). Research shows that traumatic stress and repeated exposure can together be linked to poor relationship development, academic difficulties, increased risky behavior, and the increased likelihood of entering the juvenile system at a young age (Ford, Chapman Hawke, & Albert, 2007).

It has been recognized that post transplant patients have a poorer adherence to

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medications and continuing treatment as a result of posttraumatic stress symptoms. Therefore it may be expected that pediatric cancer patients suffering from the same symptoms may fall into similar patterns (Mintzer et al., 2005; Shemesh et al., 2000). With proper support and resources most cases cancer patients and families are able to transition smoothly through the diagnosis and management. Still, there is a small percentage of patients (5-20%) who are at risk for the development of PTSS/PTSD during their disease process (Kazak, 2005; Kazak et al., 2007; Patenaude & Kupst, 2005).

In 2011, the Agency for Healthcare Research and Quality (AHRQ) released an article that named the top five most common childhood conditions in 2008 among children 0-17 years of age. Amongst them were acute bronchitis, asthma, otitis media, trauma-related disorders, and mental disorders (Roemer, 2011). The AHRQ reported that approximately 4.9 million children were treated for a mental health disorder making it the fifth most commonly treated condition among children and adolescents in the United States (Roemer, 2011). While mental health disorders were ranked fifth among the five most common conditions, total expenditures spent on treating children and adolescents for mental disorders were estimated at a high of 2.2 billion dollars, averaging around \$2,483 per child compared with \$226 per child for treatment of bronchitis, the number one disorder reported among children (Roemer, 2011). The majority of expenses related to treating mental disorders were paid for by Medicaid, approximately 34% of the cost went to prescription coverage (Roemer, 2011). In 2012, the AHRQ released another report stating that between 2007-2009 costs for treating mental disorders increased by 8.1 billion dollars to an estimated total of 10.3 billion dollars (Davis, 2012).

A retrospective review performed at the Children's Hospital of Philadelphia (CHOP) examined rates of posttraumatic stress symptoms exhibited by patients and their parents who had

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experienced a significant medical event between the years 1999-2009. Of the total number of participants, 24% of children who had been newly diagnosed with childhood cancer, and 35% of their parents, were found to have displayed various posttraumatic stress symptoms (2014). These findings were similar to those of children and parents who had experienced transplantation, unexpected injuries, cardiac events, or a stay in the Pediatric Intensive Care Unit (CHOP, 2014). Research has shown that the time between first two weeks to two years after diagnosis is the most critical for appropriate psychosocial interventions and the development of proper coping skills (Kazak, 2005; Kazak, Barakat, Hwang et al., 2011). The Institute of Medicine is emphasizing the importance of distress screening in this vulnerable population, referring to it as the 6th vital sign. The American Society of Clinical Oncology, the Oncology Nursing Society, and the International Psycho-Oncology Society are recommending further screening of all patients as well (Kazak, Barakat, Hwang et al., 2011).

Based on the overwhelming evidence of risks and costs associated with PTSS/PTSD, researchers and clinicians are working to develop a standard of care aimed at the prevention and early recognition of those who are most likely to develop posttraumatic side effects. With the development of evidence-based traumatic stress assessment tools, institutions have been encouraged to reevaluate their current practices of prevention and recognition of posttraumatic stress effects on patients and families, and implement up-to-date practices and available resources.

Purpose

To facilitate the implementation of a pediatric trauma-informed care program it is important to have an understanding of current literature. The purpose of this paper is to assess

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current practice trends of pediatric providers as they relate to pediatric trauma-informed care as a standard method of practice. The results of this assessment will describe the steps necessary to implement a pediatric trauma-informed care program at a university teaching facility.

Description of an Evidence-Based Pediatric Medical Traumatic Stress Management Model

Pediatric Medical Traumatic Stress (PMTS) is, “a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences” (National Child Traumatic Stress Network, 2003). Each year five in every 100 children in the United States are hospitalized for an acute or chronic illness, injury or disability. Yet hospital staff remain inadequately educated on the serious emotional and functional, long-term effects these hospitalizations have on some children and families (Stuber, Schneider, Kassam- Adams, Kazak, & Saxe, 2006). In 2006, Kazak and her team from the Children’s Hospital of Philadelphia released an article outlining a model originated from extensive research and reports designed as a pediatric trauma-informed guide for healthcare providers in pediatric settings. The model focuses on the concepts of stress related to medical events in three phases: Phase I. Peritrauma, Phase II. Early, Ongoing, and Evolving Responses, and Phase III. Longer-Term PMTS (Kazak, Kassam-Adams, Schneider, Zelikovsky, Alderfer, & Rourke, 2006). The three phases were developed on the basis of illness (diagnosis, treatment, long- term outcomes) along with a biopsychosocial design in which medical and psychosocial events occur simultaneously. The length of each phase varies depending on the course of the medical event (Kazak et al., 2006).

Phase I. Peritrauma: During and Immediately Following the Potentially Traumatic Medical Event

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In the peritrauma phase, the provider takes into consideration pre-existing factors, characteristics of the event, the potentially traumatic event (PTE) (objective), and the experience of the event (subjective). Child and parent reactions immediately following the event can be predictors of PMTS over time. The goal in this phase is to change the subjective experience of the PTE (Kazak et al., 2006).

Phase II. Early, Ongoing, and Evolving Responses

During phase II demands are being made on the child and parents regarding the medical diagnosis and treatment. The response to these demands in the acute stage can potentially affect ongoing responses as well as those later in treatment. The goal of phase II is to prevent the development of posttraumatic stress symptoms.

Phase III. Longer-Term PMTS

The focus of phase III is long-term responses of the child and parent to the diagnoses, treatment and outcomes of the medical event (6months-1year after). It is important to recognize that responses in this phase are separate from the acute response and therefore may vary in the ability to cope with the long-term outcomes of the illness. Providers must be cognizant of PTSS development in this phase and have a goal of symptom reduction (Kazak et al., 2006).

Along with the three phases of understanding the effects of a potentially traumatic medical event, Kazak et al. (2006) describe the interventions customized to each phase. The interventions were calculated based on five fundamental elements crucial to understanding a child and their family. Key elements crucial to understanding child and family- each individual experiences an event personalized to them, one that fosters a defining moment when the event

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becomes life-threatening and an acute response is summoned; an acute stress response is a normal response to a potentially traumatic event, but when the stress response fails to subside after 2-4 weeks it can become persistent and disruptive to daily living progressing into PTSD; the majority of patients and families have preexisting psychosocial risk factors; all interventions and assessments must be age and developmentally appropriate for both child and family; providers must take into consideration social relationships and resources within the community (Kazak et al., 2006).

Phase I. Trauma Informed Practice and Early Intervention

The goal of this phase is to change the subjective experience of the event. Healthcare providers are directly involved with the care of the child and family at this time and have the opportunity to reduce stress related to the incident. Ways in which providers are able to do this is through anticipatory guidance, parent involvement during treatment, and implementation of the toolkit designed by the Medical Traumatic Stress working group to support trauma-informed practices and assess for the D-E-F (distress, emotional support, and family needs) (Kazak et al., 2006).

Phase II. Assessing, Preventing, and/or Reducing PMTS

It is key during this phase that proper assessment of the family is performed. During this time providers will want an accurate understanding of the family relationships, roles, support, financial situation, beliefs, previous traumatic experiences, and their abilities to cope in times of stress. There are various screening tools appropriate for this type of assessment, but the Psychosocial Assessment Tool (PAT) was designed specifically for children and families with a new diagnosis of cancer (Kazak et al., 2006).

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After a proper screening has been performed providers can then focus on reducing or preventing the development of PTSS. Along with ensuring that the family has the proper resources in place to move forward, an intervention has been developed aimed at newly diagnosed cancer patients and families. The Surviving Cancer Competently Intervention Program- Newly Diagnosed (SCCIP-ND) is a pediatric tool based on the frameworks of cognitive- behavioral therapy and family therapy in a side-by-side role (Kazak et al., 2006).

Phase III. Reducing PMTS

During this phase, providers should be focused on PMTS symptom reduction. According to the article, the only identified intervention for reducing symptoms is Kazak's Surviving Cancer Competently Intervention Program (SCCIP). It is similar to the SCCIP-ND in that it integrates cognitive- behavioral therapy with family therapy, but is geared towards survivors of cancer instead of the newly diagnosed (Kazak et al., 2006).

By implementing comprehensive Pediatric Medical Traumatic Stress management models, institutions can provide adequate, safe, efficient healthcare that minimizes and prevents the effects of potentially traumatic events within the community and in turn reduces health care costs spent on mental health disorders.

Steps to Implement an Evidence-Based Pediatric Medical Traumatic Stress Management Program

The National Child Traumatic Stress Network (NCTSN) is a group that was established in 2001 from a series of grants initiated by the United States Congress, aimed to improve access to services for children and adolescents exposed to traumatic events. The group strives to raise

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the standard of care for delivering treatment to those exposed to a traumatic event through a conceptual framework, which encompasses the use of a medical trauma- informed care toolkit designed by clinicians and researchers working for the NCTSN (Ko et al., 2008). In the article, *Creating Trauma-Informed Systems: Child Welfare, Education, First Responders, Health Care, Juvenile Justice*, the authors describe how traumatic events impact victims and how organizations can tailor care to a more trauma centered approach, and provide recommendations on how institutions can make advancements toward providing trauma centered care (Ko et al., 2008).

Pediatricians and nurses, along with other healthcare providers often have a multi-dimensional role in the implementation of trauma-informed care. They function as educators, first responders and the face of continuity while providing treatment during a traumatic event to children and their families. Research tells us that most pediatric providers naturally deliver care associated with core concepts from the pediatric stress model despite having not been formally educated (Alisic, Conroy, Magyar, Babl, and O'Donnell, 2014; Kassam-Adams et al., 2014; Ko et al., 2008). Therefore, Ko et al. (2008) suggest that educators and providers focus education on building off of the well- established skills of those in a pediatric setting to recognize and identify abuse or maltreatment. The toolkit developed by the NCTSN promotes the ease of putting these techniques into practice. A multistep process for implementation of this toolkit at a facility like the Kentucky Children's Hospital requires planning, education, and evaluation.

Therefore, to properly plan for an implementation like this a committee must first be developed. It will need to consist of all appropriate staff representation to create balance, and ease for buy-in and transitional purposes. The committee will be responsible for presenting up to date literature, providing education, developing a method for evaluation, and following through

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with implementation.

The committee should include a committee leader; this could be a staff nurse, clinical nurse specialist for the department, nurse manager, or even a member from quality and safety. The rest of the committee will include, a staff nurse representative from the unit, the clinical nurse specialist, nurse manager, a member from quality and safety, a provider representative, and a social worker. It is important that all areas involved in caring for pediatric oncology patients and families are represented within the committee. As mentioned above, it allows for ease of transition and implementation.

The D-E-F protocol is a quick screening tool that encompasses the pediatric medical traumatic stress management model to identify those at risk who may need further evaluation or resources. D-E-F stands for: Distress- actively assess, provide information, listen carefully, ask about fears, and provide reassurance; Emotional Support- encourage parents, empower parents and encourage the children; Family- gauge distress, identify stressors, strengths and coping methods, and encourage parents to use resources and support established within the family (Stuber et al., 2006). The education required to successfully launch the use of this toolkit in the hospital can be found online at www.healthcaretoolbox.org. The goal of the education is to teach nurses and providers how to use the D-E-F protocol in their practice to help reduce the number of children who may develop posttraumatic stress disorder from trauma related to a medical event. The toolkit also provides resources for providers on which tools are available and have been validated for use in cases of children and families who need more services.

In order to properly disseminate the required education the committee members will be comprehensively educated about the D-E-F protocol and its uses by the committee leader. Once

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the leader confirms that all members are appropriately educated through pre- and posttests, the members will be identified as validated super users of the D-E-F protocol. The members will then be responsible for the education of their represented staff members. Each member will conduct educational meetings within their departments using the tools and pamphlets provided by the committee leader from www.healthcaretoolbox.org. The members will hold their fellow workers accountable for the education through similar pre- and posttests. After all staff has been formally educated and validated on how to use the D-E-F protocol in practice subsequent web-based training tools will be utilized thereafter to keep all staff up to date on current literature and any practices changes.

Once the educational services have been delivered and the tool implemented into practice, committee members will need to monitor adherence rates in order to evaluate future outcomes of patients. One way for members to do this is through charting audits. An area will be added to the flow sheet, which allows nurses or providers to select whether or not they used the D-E-F protocol and if further referral was needed. This permits committee members to track how many patients the tool is being used on, and how many required further referral. Ideally within the first six months of implementation the facility would expect a 70-80% compliance rate, with a goal of a 20% increase in the following three to six months. Placing the facility around a 90-95% compliance rate with the new practice by the end of the first year. The process of implementing change is lengthy and requires consistency, but will facilitate evidence-based practice and improved patient outcomes.

Overall the goal of implementing this evidence-based practice tool is to create provider awareness of the incidence of PTSD in medically traumatized children. Researchers and providers hope that with the consistent use of this tool among large facilities like the University

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of Kentucky the rates of PTSD in this population will be significantly reduced. Although the focus of practice within this paper is with pediatric oncology patients, the D-E-F protocol can be utilized with any medically traumatizing experiences among children and families.

Review of Evidence

Current literature provides evidence that describes PTSD as a real existence in childhood cancer survivors, occurring in 5-20% of survivors (Kazak et al., 2007; Patenaude & Kupst, 2005). However, what the literature doesn't show is a formal "gold standard" of care developed by those within the disciplines of hematology/oncology or psycho-oncology. This means that tools or interventions, developed with the goal of prevention or early identification of PTSD among this population, are being applied inconsistently across the continuum.

The literature indicates the best way to reduce long-term effects of cancer treatment, specifically PTSD/PTSS, is through early identification of patients and families at risk through use of evidence-based screening tools. Dr. Anne Kazak worked with a group in the Division of Oncology at the Children's Hospital of Philadelphia (CHOP) to design an early assessment tool referred to as the PAT, Psychosocial Assessment Tool. Its focus is to identify those patients and families at risk for the development of posttraumatic stress symptoms (Kazak, Prusak, McSherry et al., 2001). Studies have shown that there is a link between the use of the tool, and the quality of psychosocial services provided to the patients and families. The tool has also been shown to provide consistency in predicting the continuity of risk level throughout the course of treatment (Alderfer, Mougianis, Barakat et al., 2009; Kazak, Barakat, Hwang et al., 2011; Kazak, Cant, Jensen et al., 2003). Another tool that has been studied in the use of screening children and families for PTSD symptoms is the STEPP, Screening Tool for Early Predictors of PTSD.

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STEPP has been implemented and studied in acute care and emergency rooms. A positive STEPP has been linked to increased levels of posttraumatic symptoms in a post survey conducted at a later time (Winston, Kassam- Adams, Garcia- Epana, Ittenbach & Cnaan, 2003).

Like the STEPP, the DEF protocol was designed as a quick and easy way to assess children and families for posttraumatic symptoms. Unlike the other tools, the DEF protocol is a model-based way to practice. There is not a set of questions or forms to complete when facilitating the DEF, but instead it is a method used to guide the type of care practiced by nurses and providers. Kassam-Adams et al. conducted a study in which nursing staff completed a survey about their knowledge, practice, and attitudes regarding pediatric trauma- informed care, the DEF protocol (2014). The survey concluded that the nursing staff felt knowledgeable, favorable about screening for psychosocial risk factors, and already practiced most of the techniques in their daily routines (Kassam- Adams et al., 2014). However, it also exhibited the need for further educational services in a more formal, uniform manner.

It is well known that long-term effects often occur in cancer survivors who require health interventions, including psychological effects. Still, there continues to be an inconsistency in the psychosocial care provided to pediatric oncology patients. With the growing psychological research in pediatric oncology there are several new opportunities for the future, like the DEF protocol. Thus it is important to continue to support the development of a standardized model of practice. The act of standardizing and developing guidelines would facilitate researchers to study the impact and outcomes that psycho-oncology has on children and families when implemented into practice. It would also assist providers in implementing resources for those who have been identified with increased psychosocial risk factors as well as ensure that all children and families

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are receiving an appropriate level of psychosocial care throughout their journey with pediatric cancer.

Conclusion

PTSD treatment is costly and rates continue to rise, the implementation of a pediatric trauma-informed care program at a large facility like the University of Kentucky has the potential to reduce the rate of posttraumatic stress in pediatric oncology patients. Despite the efforts of current literature to support the practices of PTSD prevention methods, healthcare providers are failing to be consistent. As described in this paper the application of available evidence-based practice models and the knowledge of current literature support the steps necessary to implement an evidence-based pediatric medical traumatic stress management tool.

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References

- Alderfer, M., Navsaria, N., Kazak, A. (2009). Family functioning and posttraumatic stress disorder in adolescent survivors of childhood cancer. *Journal of Family Psychology, 23*, 717-725. doi: 10.1037/a0015996
- Alisic, E., Conroy, R., Magyar, J., Babl, F.E., O'Donnell, M.L. (2014). Psychosocial care for seriously injured children and their families: A qualitative study among emergency department nurses and physicians. *Injury, 45*, 1452-1458.
- Askins, M. A., Moore, B. D. (2008). Psychosocial support of the pediatric cancer patient: Lessons learned over the past 50 years. *Current oncology reports, 10*, 469-476.
- Davis, K. (2012). Expenditures for treatment of mental health disorders among young adults, ages 18-26, 2007-2009: Estimates for the U.S. civilian noninstitutionalized population. *Agency for Healthcare Research and Quality, 358*, 1-7.
- Ehlers, A., D, Clark. (2000). A cognitive model of posttraumatic stress disorder. *Behavior Research and Therapy, 38*, 319-345.
- Ford, J., Chapman, J., Hawke, J., Albert, D. (2007). Trauma among youth in the juvenile justice system: Critical issues and new directions. *National Center for Mental Health and Juvenile Justice, 1-8*.
- Kassam-Adams, N., Rzucidlo, S., Campbell, M., Good, G., Bonifacio, E., Slouf, K., Grather, D. (2014). Nurses' views and current practice of trauma-informed pediatric nursing care. *Journal of Pediatric Nursing, 1-7*. doi: 10.1016/j.pedn.2014.11.008
- Kazak, A. (2005). Evidence-based interventions for survivors of childhood cancer and their families. *Journal of Pediatric Psychology, 30*, 29-39. doi:10.1093/jpepsy/jsi013
- Kazak, A., Barakat, L., Hwang, WT., Ditaranto, S., Biros, D., Beele, D., Reily, A. (2011). Association of psychosocial risk screening in pediatric cancer with psychosocial services

IMPLEMENTATION OF AN EVIDENCE BASED SCREENING TOOL

provided. *Psycho-Oncology*, 20, 715-723. doi: 10.1002/pon.1972

Kazak, A., Cant, M. C., Jensen, M., McSherry, M., Rourke, M., Hwang, W. T., Lange, B.

(2003). Identifying psychosocial risk indicative of subsequent resource utilization in families of newly diagnosed pediatric oncology patients. *Journal of Clinical Oncology*, 21, 3220–3225.

Kazak, A., Kassam-Adams, N., Schneider, S., Zelikovsky, N., Alderfer, M., Rourke, M. (2006).

An integrative model of pediatric medical traumatic stress. *Journal of Pediatric Psychology*, 44, 343–355.

Kazak, A., Prusak, A., McSherry, M., Simms, S., Beele, D., Rourke, M., Lange, B. (2001). The

psychosocial assessment tool (PAT): Pilot data on a brief screening instrument for identifying high risk families. *Families, Systems & Health*, 19, 303- 317.

Kazak, A., Rourke, M., Alderfer, M., Pai, A., Reilly, A., Meadows, A. T. (2007). Evidence-

based assessment, intervention and psychosocial care in pediatric oncology: A blueprint for comprehensive services across treatment. *Journal of Pediatric Psychology*, 32, 1099-1110. doi: 10.1095/jpepsy/jsm031

Ko, S., Kassam-Adams, N., Wilson, C., Ford, J., Berkowitz, S., Wong, M., Layne, C. (2008).

Creating trauma-informed systems: Child welfare, education, first responders, health care, juvenile justice. *Professional Psychology: Research and Practice*, 39(4), 396-404. doi: 10.1037/0735-7028.39.4.396

Mintzer, L., Stuber, M., Seacord, D., Castaneda, M., Mesrkhani, V., Glover, D. (2005).

Traumatic stress symptoms in adolescent organ transplant recipients. *Pediatrics*, 115(6), 1640-1644.

National Child Traumatic Stress Network. (2003) Definition of medical traumatic stress.

Retrieved from, <http://www.NCTSNet.org>

IMPLEMENTATION OF AN EVIDENCE BASED SCREENING TOOL

Patenaude, A., Kupst, M. J., (2005). Psychosocial functioning in pediatric cancer. *Journal of Pediatric Psychology*, 30(1), 9- 27. doi: 10.1093/jpepsy/jsi012

Roemer, M. (2011). Health care expenditures for the five most common children's conditions, 2008: Estimates for U.S. civilian noninstitutionalized children, ages 0-17. *Agency for Healthcare Research and Quality*, 349, 1-6.

Shemesh, E., Lurie, S., Stuber, M., Emre, S., Patel, Y., Vohra, P., Shneider, B. (2000). A pilot study of posttraumatic stress and nonadherence in pediatric liver transplant recipients. *Pediatrics*, 105(2), 1-7.

Stuber, M., Schneider, S., Kassam-Adams, N., Kazak, A., Saxe, G. (2006). The medical traumatic stress toolkit. *CNS Spectr*, 11(2), 1-6.

Ward, E., C, DeSantis., A, Robbins., B, Kohler., A, Jemal. (2014). Childhood and adolescent cancer statistics, 2014. *CA: A Cancer Journal for Clinicians*, 1-21.
doi:10.3322/caac.21219

Winston, F., Kassam-Adams, N., Garcia-Epana, F., Ittenbach, R., Cnaan, A. (2003). Screening for risk of persistent posttraumatic stress in injured children and their parents, *JAMA*, 260(5), 643-649.

Manuscript 3

An Assessment of Nurses' Views and Current Practice of Trauma-Informed Pediatric Nursing

Care: Oncology

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Abstract

Purpose: The purpose of this project is to: (i) assess and evaluate the awareness, knowledge and current practice trends of pediatric oncology nurses as they relate to pediatric trauma-informed care.

Methods: A prospective, cross-sectional sample of convenience was used to assess pediatric nursing staff at the Kentucky Children's Hospital. The survey used in this study was replicated from a previous study, "Nurses' Views and Current Practice of Trauma-Informed Pediatric Nursing Care," authored by Kassam-Adams et al., nurses and doctors affiliated with Children's Hospital of Philadelphia, University of Pennsylvania, Penn State Hershey Children's Hospital, Nemours Child Health System, Children's Hospital of Pittsburgh, Geisinger Health System, and Lehigh Valley Health Network (2014).

Results: Participants in this study demonstrated that they have an overall understanding of traumatic stress, and most actually utilize trauma-informed practices in their everyday routine. The nurses working in the oncology unit had favorable opinions about trauma-informed practices, and felt competent about the specific aspects assessed by the survey.

Conclusion: Though Oncology was the focus for this study, all medical crises like illnesses/injuries can be the cause of a traumatic stress response. Therefore it is important as a provider to aim to reduce the severity of trauma related to all illnesses/injuries in all aspects of pediatric care. The next step would be to begin performing another brief study involving an educational intervention, and develop a committee to move forward with formal educational training, and the development and implementation of the DEF Protocol within the Kentucky Children's Hospital.

Introduction

Most pediatric cancer survivors transition back into their pre-cancer lifestyles after treatment without difficulty, but for 5-20% of them this transition is complicated by a mental illness known as posttraumatic stress disorder (PTSD). In 1980, PTSD entered the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) describing it as a result of a traumatic life-threatening event (Donnelly and Amaya-Jackson, 2002; Ehlers & Clark, 2000; & Kaminer, Seedat & Stein, 2005). The most recently published manual, the DSM-IV, (as cited in Donnelly & Amaya-Jackson, 2002) lists three clusters of symptoms a person must experience for more than one month in order to be formally diagnosed. These include: re-experiencing of the trauma, avoidance behavior and hyperarousal symptoms. Symptoms similar to these lasting less than one-month, but still cause developmental and debilitating affects are categorized as an acute stress disorder or ASD (Kaminer, Seedat & Stein, 2005). Symptoms associated with posttraumatic stress have been linked to, lower educational levels, higher unemployment rates, and individuals who are less likely to marry, more likely to have health problems, complex psychological issues, and finally a reported overall poorer quality of life (Stuber et al., 2010). The overwhelming evidence associated with poorer outcomes and quality of life for pediatric cancer survivors warrants the development of a standard practice of care to reduce and prevent the affects of PTSD.

Researchers have worked to develop models and tools designed to identify at risk patients and families. One model that has proven successful in more than just pediatric care is “trauma-informed care.” Trauma-informed care is a patient care delivery method designed to recognize and prevent symptoms associated with posttraumatic stress. A team of experts developed a pediatric trauma-informed care model as a guide for all pediatric providers based on three phases

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of contact with the patient after a traumatic event. Each phase revolves around fundamental elements of a patient and family- each individual experiences an event personalized to them, one that fosters a defining moment when the event becomes life-threatening and an acute response is summoned; an acute stress response is a normal response to a potentially traumatic event, but when the stress response fails to subside after 2-4 weeks it can become persistent and disruptive to daily living progressing into PTSD; the majority of patients and families have preexisting psychosocial risk factors; all interventions and assessments must be age and developmentally appropriate for both child and family; providers must take into consideration social relationships and resources within the community (Kazak, Kassam-Adams, Schneider, Zelikovsky, Alderfer, & Rourke, 2006). Research tells us that most pediatric providers naturally provide care based on these elements despite having no formal training (Alisic, Conroy, Magyar, Babl, and O'Donnell, 2014; Kassam-Adams et al., 2014; Ko et al., 2008). Therefore, a group known as the National Child Traumatic Stress Network (NCTSN) designed a toolkit on the basis of putting these techniques into practice.

This design resulted in the DEF protocol, a condensed screening tool or method of care delivery that embodies the major goals of the pediatric trauma-informed care model. The overall goal of the protocol is to prevent the development of PTSD and identify those most at risk for developing symptoms. D-E-F stands for: Distress- actively assess, provide information, listen carefully, ask about fears, and provide reassurance; Emotional Support- encourage parents, empower parents and encourage the children; Family- gauge distress, identify stressors, strengths and coping methods, and encourage parents to use resources and support established within the family (see www.healthcaretoolbox.org, Center for Pediatric Traumatic Stress, 2009). Although studies show that this method of practice is being used, in most cases nurses are not receiving

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formal training (Kassam-Adams et al., 2014; Ward-Begnoche, 2006). This study speaks to the gaps in literature by surveying five categories regarding the practice of trauma-informed care delivered by nurses to pediatric oncology patients.

Description of the Practice Inquiry Project

This capstone project involved the dissemination and evaluation of a provider survey on the knowledge, opinions, self-rated competence, current practice, and perceived implementation barriers related to pediatric trauma-informed care, for hematology/oncology nurses at a university children's hospital located in central Kentucky. The project took place in the hospital's Hematology/Oncology Unit. A one-time survey was used to assess the current strengths and barriers to providing trauma-informed nursing care to pediatric oncology patients to determine the need for future practice changes and improved consistency in care.

Purpose/Objectives

In order to facilitate the implementation of a pediatric trauma-informed care program it is essential to first have an understanding of current nursing knowledge, awareness, practices, and beliefs related to pediatric trauma-informed care. Identifying strengths and barriers to delivering trauma-informed care provides necessary evidence for practice change and improved consistency in care. The purpose of this project is to: (i) assess and evaluate the awareness, knowledge and current practice trends of pediatric oncology nurses as they relate to pediatric trauma-informed care. Specific aim: to focus on identifying the knowledge and barriers surrounding the delivery of trauma-informed care.

Methods

Following the endorsement for use of the survey and the development of a project proposal, approval was obtained from the project committee to seek necessary authorization of

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the University of Kentucky's Institutional Review Board (IRB) to perform this study. No direct interaction by the primary investigator with participants was involved during this study.

Participants received a formal letter of invitation describing the details of the study via email that was sent by an employee of the Kentucky Children's Hospital. The letter explained that the study was completely voluntary and would involve the completion of a survey that required an estimated thirty minutes of their time. Their completion of the survey constituted as consent for study participation. It was made clear to participants that there were no personal benefits associated with participating, and the risks identified were minimal and consisted of the potential loss of confidentiality and psychological distress as they reflected on their experiences.

Educational resources were included for these purposes. Participants were notified that study material could only be accessed using the primary investigators password protected account and would be stored securely in a locked office in the University of Kentucky College of Nursing for the required time by the IRB at which point the data will be destroyed per instruction of university policy NISTSP800-88 REVISION 1.

Study Design and Sample Selection

A prospective, cross-sectional sample of convenience was used to assess pediatric nursing staff at the university's children's hospital. The sample included those nurses caring for pediatric oncology patients on the Hematology/Oncology Unit.

All nursing staff employed full-time or part-time on the Hematology/Oncology Unit of the children's hospital who worked at least one shift per month were eligible to participate in the study. Nursing staff working full or part-time in other units of the children's hospital was excluded from the study along with the nursing managers, clinical nurse specialists, nurse educators, and nursing care technicians.

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Measures

The survey used in this study was replicated from a previous study, “Nurses’ Views and Current Practice of Trauma-Informed Pediatric Nursing Care,” authored by Kassam-Adams et al., nurses and doctors affiliated with Children's Hospital of Philadelphia, University of Pennsylvania, Penn State Hershey Children's Hospital, Nemours Child Health System, Children's Hospital of Pittsburgh, Geisinger Health System, and Lehigh Valley Health Network (2014).

The survey was designed to encompass research findings and practices regarding the development of posttraumatic stress disorder in children after the experience of a traumatic medical crisis (Kassam- Adams et al., 2014).). “The survey includes 38-items in five categories, assessing: 1) knowledge about trauma-informed pediatric care (11 items); 2) opinions about trauma-informed pediatric care (6 items); 3) self-rated competence (10 items); 4) recent practice (7 items); 5) perceived barriers to implementation of trauma-informed (4 items),” (Kassam- Adams et al., 2014). The survey items within the five different categories listed above are rated on a 3-4 point Likert-scale. Cronbach’s alpha was used in the previous study to assess internal consistency, which ranged from excellent to fair (.60- .90) (Kassam-Adams et al., 2014).

Data Analysis

Demographic variables and survey items with descriptive analyses were examined using SPSS statistical software (SPSS Inc., Chicago, IL). In order to properly assess the data collected, frequency variables were ran using the SPSS software.

Results

The nurses working in the hematology/oncology unit were eligible for participation in the survey if they worked full/part-time and at least one shift per month. The 39 eligible nurses received an invitation via email to participate in the study; 6 nurses completed the survey (about

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15%). One of the surveys was excluded from the data analysis due to the lack of completed items. Participants ages varied ranging from 20-50 years old, 50% were over the age of 30. The majority of those who completed the survey have been pediatric oncology nurses for less than 5 years, which was similar to the overall years spent nursing (see Table 1). Demographic details for those nurses who did not participate in the study are unknown.

Knowledge of Medical-Related Posttraumatic Stress

The assessment of knowledge items are broken down into three categories involving, prevalence, risk factors, and course; signs and symptoms; effectiveness of screening and intervention. For the items in each of these areas the majority of the nurses answered correctly (Table 2). The area of concern identified is the ability of the nurse to recognize signs and symptoms related to distress. Only half of participants responded that they knew the common signs and symptoms of traumatic stress in children and families, and that obvious symptoms are not always present. 83% of participants responded that they agreed children with a more severe injury/illness have more serious stress reactions than those with less severe injuries/illnesses. These two areas are concerning for the lack of education and relationship between signs and symptoms, and object measures.

Opinions About Trauma-Informed Care

The data collected regarding the nurses' opinions surrounding trauma-informed care concluded that well over half of participants exhibited positive attitudes (Table 3).

Self-Rated Competence in Providing Trauma-Informed Care

Overall participants felt competent, most reporting that they felt 'somewhat competent' for each item. 100% felt 'somewhat competent' in their abilities to elicit details without re-traumatizing the child or family, half did not feel competent with the empirical or scientific

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understanding behind trauma-informed care (Table 4). Others did not feel competent about educating the children or families, or responding to questions about death.

Which Trauma-Informed Practices are Nurses Already Implementing?

Participants were asked questions concerning their own practices with patients in the past six months, 50% reported having performed items 1-6 in Table 5. Less than half encouraged parents to make use of their own social support system (family, friends, church, etc.), or provided information to parents about emotional or behavioral reactions that indicate that the child may need help. Though the nurses previously responded 'not competent' in areas of teaching/educating, when identifying current practices performed in the past 6 months, over half of them reported teaching or educating parents and children ways to manage pain and anxiety during procedures.

Potential Barriers to Implementing Trauma-Informed Care

The last section of this survey assesses potential barriers to the implementation of trauma-informed care. A total of four items were assessed including: time constraints, lack of education/training, confusing information related to trauma-informed care practices, and worry about further traumatizing/re-traumatizing the child or parent. For each of the four items more than 80% of the nurses identified these elements as potential barriers for implementation.

Discussion

The participants in this study demonstrated that they have an overall understanding of traumatic stress, and most actually utilize trauma-informed practices in their everyday routine. The nurses working in the oncology unit had favorable opinions about trauma-informed practices, and felt competent about the specific aspects assessed by the survey. The results

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indicate that participants would benefit and engage in a formal educational training session regarding trauma-informed care to maximize the skills exhibited in the survey.

This study lengthens a prior study, which examined nurses' views and practices among acute care pediatric trauma nurses in various Philadelphia Children's Hospitals. Though the results from this study are not statistically significant due to low sample and response rates, results are similar to those of the trauma nurse studies. Like in this study, trauma nurses felt competent about trauma-informed skills, had a reasonable understanding of traumatic stress, and included most of the skills in their every day practice. However, it was the areas of competence and current practices that differed between the two studies. The trauma nurses' greater area of competence was in regards to responding calmly and without judgment to a child or family's emotional distress, and engaging with families, making them feel comfortable (Kassam-Adams et al., 2014). While the oncology nurses reported feeling 'somewhat competent' in their abilities to elicit details without re-traumatizing the child or family (100%). Likewise the most commonly selected practices were related to teaching or educating parents and children ways to manage pain and anxiety during procedures, as did the trauma nurses. In the study performed by Kassam-Adams et al. (2014), trauma nurses most commonly reported encouraging parents to seek out self-support, less than half of the oncology nurses selected this as a practice performed within the past six months. These similarities and differences found between the two separate specialties are intriguing, and can most likely be attributed to the vast differences in injury and illness.

Currently the Kentucky Children's Hospital does not have a protocol or delivery of care method in place to reduce stress and prevent the development of PTSD/ASD in patients or families. Though Oncology was the focus for this study, all medical crises like illnesses/injuries can be the cause of a traumatic stress response. Therefore it is important as a provider to aim to

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reduce the severity of trauma related to all illnesses/injuries in all aspects of pediatric care.

Implications for practice implied by this study are further research studies to assess nursing knowledge and awareness of trauma-informed care and its relationship to the stress response, resulting in a movement towards the development and implementation of a trauma-informed delivery of care method like the DEF protocol within the Children's Hospital. Trauma-Informed Care "incorporates an awareness of the impact of traumatic stress on ill or injured children and families as a part of treating the medical aspects of the trauma." (healthcaretoolbox.org, 2013)

The DEF Protocol is a direct result of Phase 1 of the Pediatric Medical Traumatic Stress model that focuses on changing the subjective experience of the patient and family (Kazak et al., 2006).

The protocol focuses on actively assessing, reducing stress, empowering the patients and families, and identifying strengths and weakness in order reduce the severity of the traumatic stress response felt by patients and families (Stuber et al., 2006).

The limitations of this study revolve around the small sample size and response rate. Due to this, findings were not statistically significant and therefore summary scores and demographic correlations were unable to be performed. The low response rate may have been related to the relocation of the unit for construction purposes during the time of the survey. This may have been a hectic time for the nurses, and staffing patterns may have been lower than normal due to a decrease in workspace. As a result of this, nurses may not have been checking their work emails as regularly as usual. Another consideration of why the response rate was lower than expected, is cold and flu season. Nurses may have been busier than if the survey was opened before cold and flu season began since this population is at greater risk for illness. A large contributing factor to the lack of responses was most likely due to the fact that there was a gap in my time spent in the unit with the staff during clinical, and the distribution of the survey. The six-month lag could

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have possibly resulted in lower rapport with the nursing staff, making the nurses less motivated to complete the survey. I have also taken into consideration that the nurses may have been hesitant to respond to the survey due to lack of knowledge regarding the survey name/topic, but since I do not have a pre and post test comparison I cannot be sure. Though the results from this study are not statistically significant due to low sample and response rates we are headed in the right direction by spreading awareness and expanding skills in trauma-informed nursing care.

The next step would be to begin performing another brief study involving an educational intervention, assessed with pre- and post-test questionnaires and the development of a committee to move forward with formal educational training, and the development and implementation of the DEF Protocol within the Kentucky Children's Hospital. The studies reviewed, as well as those to come can only enhance our knowledge of traumatic stress and PTSD for families and loved ones of pediatric patients whom we serve. It is our responsibility to provide this type of comprehensive care with evidence-based practices to ensure a complete patient-centered care approach in order to address both medical and psychological effects of chronic or terminal illnesses like pediatric cancer.

References

- Alisic, E., Conroy, R., Magyar, J., Babl, F.E., O'Donnell, M.L. (2014). Psychosocial care for seriously injured children and their families: A qualitative study among emergency department nurses and physicians. *Injury*, 45, 1452-1458.
- Center for Pediatric Traumatic Stress (2009). www.HealthCareToolbox.org (Website, Accessed October 14, 2014).
- Donnelly, C., Amaya-Jackson, L. (2002). Post-traumatic stress disorder in children and adolescents: Epidemiology, diagnosis and treatment. *Pediatr Drugs*, 4. 3. 159-170.
- Ehlers, A., D, Clark. (2000). A cognitive model of posttraumatic stress disorder. *Behavior Research and Therap.* 38, 319-345.
- Ford, J., Chapman, J., Hawke, J., Albert, D. (2007). Trauma among youth in the juvenile justice system: Critical issues and new directions. *National Center for Mental Health and Juvenile Justice*, 1-8.
- Kaminer, D., Seedat, S., Stein, D. (2005). Post-traumatic stress disorder in children. *World Psychiatry*, 4(2), 121-125.
- Kassam-Adams, N., Rzucidlo, S., Campbell, M., Good, G., Bonifacio, E., Slouf, K., Grather, D. (2014). Nurses' views and current practice of trauma-informed pediatric nursing care. *Journal of Pediatric Nursing*. 1-7. doi: 10.1016/j.pedn.2014.11.008
- Kazak, A., Kassam-Adams, N., Schneider, S., Zelikovsky, N., Alderfer, M., Rourke, M. (2006). An integrative model of pediatric medical traumatic stress. *Journal of Pediatric Psychology*, 44, 343-355.
- Ko, S., Kassam-Adams, N., Wilson, C., Ford, J., Berkowitz, S., Wong, M., Layne, C. (2008). Creating trauma-informed systems: Child welfare, education, first responders, health care, juvenile justice. *Professional Psychology: Research and Practice*, 39(4), 396-404.

AN ASSESSMENT OF NURSES' VIEWS

doi: 10.1037/0735-7028.39.4.396

Stuber, M., Meeske, K., Krull, K., Leisenring, W., Stratton, K., Kazak, A., Zeltzer, L. (2010).

Prevalence and predictors of posttraumatic stress disorder in adult survivors of childhood cancer. *Pediatrics*, *125*, 1124-1134.

Ward-Begnoche, W. L., Aitken, M. E., Liggin, R., Mullins, S. H., Kassam-Adams, N., Marks,

A., Winston, F.K. (2006). Emergency department screening for risk for post-traumatic stress disorder among injured children. *Injury Prevention*, *12*, 323–326,

<http://dx.doi.org/10.1136/ip.2006.011965>.

Table 1. Participant Demographics

Characteristics	N (%)
Age	
20-25	2 (33.3%)
26-30	1 (16.7%)
31-35	2 (33.3%)
41-50	1 (16.7%)
Years Experience as a Registered Nurse	
≤5 years	4 (66.7%)
+5 years	2 (33.3%)
Years Experience as a Pediatric Oncology Nurse	
1-5 years	
+5 years	4 (66.7%)
	2 (33.3%)

Table 2. Nurses' knowledge regarding injury-related posttraumatic stress and trauma-informed care (N=6).

Knowledge Items	Correct Responses (N, %)
Prevalence, risk factors, and course	
1. Almost everyone who is seriously injured or ill has at least one traumatic stress reaction in the immediate aftermath of the event.	6 (100%)
2. It is inevitable that most children and families who experience a life-threatening illness or injury will go on to develop significant posttraumatic stress or PTSD. (Disagree)	3 (50%)
3. Children who are more severely injured or ill generally have more serious traumatic stress reactions than those who are less severely injured or ill. (Disagree)	1 (16.7%) 6 (100%)
4. Children who, at some point during the traumatic event, believe that they might die are at greater risk for posttraumatic stress reactions.	6 (100%)
5. Many children and families cope well on their own after experiencing serious illness or injury.	6 (100%)
6. The psychological effects of an injury or illness often last longer than the physical symptoms.	
Signs and Symptoms	
7. Children and families with significant posttraumatic stress reaction usually show obvious signs of distress. (Disagree)	3 (50%) 3 (50%)
8. I know the common signs and symptoms of traumatic stress in children and families.	5 (83.3%)
9. Some early traumatic stress reactions in children and families can be part of a healthy emotional recovery process.	
Effectiveness of screening and intervention	
10. There are things that providers can do to help prevent longer-term posttraumatic stress in ill and injured children and families.	6 (100%) 6 (100%)
11. There are effective screening measures for assessing traumatic stress that providers can use in practice	

Note. For items 2, 3, and 7, “disagree/strongly disagree” represents a correct response.

Table 3. Nurses' opinions regarding trauma-informed care (N= 6).

Statements about trauma-informed care	Nurse ratings (N, %)			
	Strongly agree	Agree	Disagree	Strongly disagree
1. Providers should focus on medical care for hospitalized children as opposed to children's mental health.*	0	0	4(66.7%)	2(33.3%)
2. The way that medical care is provided can be changed to make it less stressful for children and families.	3(50%)	3 (50%)	0	0
3. Providers can teach families how to cope with trauma.	3(50%)	2(33.3%)	1(16.7%)	0
4. Health care professionals should regularly assess for symptoms of traumatic stress.	2(33.3%)	4(66.7%)	0	0
5. It is necessary for providers to have mental health information about their pediatric patients in order to provide appropriate medical care.	4(66.7%)	1(16.7%)	1(16.7%)	0
6. I have colleagues I can turn to for help with a child or family experiencing significant traumatic stress.	1(16.7%)	4(66.7%)	1(16.7%)	0

Note. For item 1, "disagree/strongly disagree" represents an opinion favorable to trauma-informed care.

Table 4. Nurses' self-rated competence in specific aspects of trauma-informed care (N= 6).

Specific aspects of trauma-informed care	Nurse ratings (N, %)		
	Very competent	Somewhat competent	Not competent
1. Engaging with traumatized children/families so that they feel comfortable talking to you/comforted by you	3 (50%)	3 (50%)	0
2. Responding calmly and without judgment to child's or family's strong emotional distress	4 (66.7%)	2 (33.3%)	0
3. Eliciting details of a traumatic event from a child or family without re-traumatizing them	0	6 (100%)	0
4. Educating children and families about common traumatic stress reactions and symptoms	1 (16.7%)	3 (50%)	2 (33.3%)
5. Avoiding or altering situations within the hospital that a child or family might experience as traumatic	1 (16.7%)	5 (88.3%)	0
6. Responding to a child's (or parent's) question about whether the child will die	0	4 (66.7%)	2 (33.3%)
7. Assessing a child's or family's distress, emotional needs, and support systems soon after a traumatic event	1 (16.7%)	5 (88.3%)	0
8. Providing basic trauma-focused interventions (assessing symptoms, normalizing, providing anticipatory guidance, coping assistance)	1 (16.7%)	4 (66.7%)	1 (16.7%)
9. Understanding how traumatic stress may present itself differently in younger children, older children, and teens	1 (16.7%)	4 (66.7%)	1 (16.7%)
10. Understanding the scientific or empirical basis behind assessment and intervention for traumatic stress	1 (16.7%)	2 (33.3%)	3 (50%)

Table 5 Nurses' report of specific trauma-informed practices performed in the past 6 months (N= 6).

Specific trauma-informed practice	Have done this in past 6 months (N, %)
1. Ask the child questions to assess his/her symptoms of distress	3 (50%)
2. Ask parents questions to assess their symptoms of distress	3 (50%)
3. Teach parents what to say to their child after a difficult/painful/scary experience	5 (83.3%)
4. Provide information to parents about emotional or behavioral reactions that indicate that the child may need help	4 (66.7%)
5. Teach parent or child specific ways to cope with upsetting experiences	5 (83.3%)
6. Teach parent or child ways to manage pain and anxiety during procedures	3 (50%)
7. Encourage parents to make use of their own social support system (family, friends, church, etc.)	2 (33.3%)

Practice Inquiry Project Conclusion

Alesandra S. Conley, BSN, RN

University of Kentucky

College of Nursing

Psycho-oncology is a facilitating discipline that ensures the psychosocial needs of cancer patients and their families are identified, and necessary interventions are implemented alongside the medical plan of care (Kazak, Rourke, Alderfer, Pai, Reilly, & Meadows, 2007). The first manuscript was a literature review that discussed psycho-oncology and its relevance to pediatric cancer treatment. The review revealed the need for increased studies and funding to aid in future research to quantify the implications of psycho-oncology in order to successfully develop a national framework for practice and support of psycho-oncologists within the regular medical team. Though the review focused primarily on psycho-oncology, it led to further research on the topic of frameworks, guidelines and tools that are in use in pediatrics for identification and prevention of PTSD, which resulted in the next manuscript about the DEF protocol. The purpose of the paper was to assess current practice trends of pediatric providers as they relate to pediatric trauma-informed care as a standard method of practice. The research revealed an integrative model of care that discusses in detail what Pediatric Medical Traumatic Stress is and how to deliver care in a way that minimizes the stress response during a traumatic injury or illness. Finally, manuscript three is a descriptive study that was mirrored after a previously performed study that examined what pediatric trauma nurses knew about trauma-informed care, and their current practices. The study in this paper examined current practices and knowledge of pediatric oncology nurses in order to assess current methods used at the Kentucky Children's Hospital with hopes of continuing forward with the implementation of a care model like the DEF protocol. The results showed that those who participated have an overall understanding of traumatic stress, and that most actually utilize trauma-informed practices in their everyday routine, but what they could benefit from is a formal delivery of care process, one like the DEF protocol. Therefore this warrants the development of a future study in which an educational

intervention is applied and assessed using a pre- and post-test questionnaire in order to move forward with the implementation of the DEF protocol hospital wide within the children's hospital.

Appendix A

Letter of Approval from the Nurse Manager of the Hematology/ Oncology Unit

October 19, 2015

To Whom It May Concern;

I am the patient care manger in Kentucky Children's Hospital; I have agreed to allow Alesandra Conley to complete a survey with staff concerning pediatric trauma-informed care in an oncology setting.

A handwritten signature in cursive script, appearing to read "Lisa L. Butcher RN".

Lisa L. Butcher RN, BSN, CNML

Acute Care Patient Care Manager

Kentucky Children's Hospital

Appendix B

Letter of Approval from the Institutional Review Board



Office of Research Integrity
IRB, IACUC, RDRC
315 Kinkead Hall
Lexington, KY 40506-0057
859 257-9428
fax 859 257-8995
www.research.uky.edu/ori/

Expedited Initial Review

Approval Ends
October 17, 2016

IRB Number
15-0789-PIH

TO: Alesandra Conley, RN
College of Nursing
3170 Mapleleaf Dr. Apt. 508
Lexington, Kentucky 40509
PI phone #: (740)357-1019

FROM: Chairperson/Vice Chairperson
Medical Institutional Review Board (IRB)

SUBJECT: Approval of Protocol Number 15-0789-PIH

DATE: October 20, 2015

On October 19, 2015, the Medical Institutional Review Board approved your protocol entitled:

Nurses' Views and Current Practice of Trauma-Informed Pediatric Nursing Care: Oncology

Approval is effective from October 19, 2015 until October 17, 2016 and extends to any consent/assent form, cover letter, and/or phone script. If applicable, attached is the IRB approved consent/assent document(s) to be used when enrolling subjects. [Note, subjects can only be enrolled using consent/assent forms which have a valid "IRB Approval" stamp unless special waiver has been obtained from the IRB.] Prior to the end of this period, you will be sent a Continuation Review Report Form which must be completed and returned to the Office of Research Integrity so that the protocol can be reviewed and approved for the next period.

In implementing the research activities, you are responsible for complying with IRB decisions, conditions and requirements. The research procedures should be implemented as approved in the IRB protocol. It is the principal investigators responsibility to ensure any changes planned for the research are submitted for review and approval by the IRB prior to implementation. Protocol changes made without prior IRB approval to eliminate apparent hazards to the subject(s) should be reported in writing immediately to the IRB. Furthermore, discontinuing a study or completion of a study is considered a change in the protocol's status and therefore the IRB should be promptly notified in writing.

For information describing investigator responsibilities after obtaining IRB approval, download and read the document "PI Guidance to Responsibilities, Qualifications, Records and Documentation of Human Subjects Research" from the Office of Research Integrity's IRB Survival Handbook web page [<http://www.research.uky.edu/ori/IRB-Survival-Handbook.html#PIresponsibilities>]. Additional information regarding IRB review, federal regulations, and institutional policies may be found through ORI's web site [<http://www.research.uky.edu/ori/>]. If you have questions, need additional information, or would like a paper copy of the above mentioned document, contact the Office of Research Integrity at (859) 257-9428.


Chairperson/Vice Chairperson

Appendix C

DEF Provider Survey Tool

DEF Provider Survey

Based on your understanding and experience, indicate whether you more strongly agree or disagree with the following:	Strongly Disagree	Disagree	Agree	Strongly Agree
1. Almost everyone who is seriously injured or ill has at least one traumatic stress reaction in the immediate aftermath of the event.				
2. It is inevitable that most children and families who experience a life-threatening illness or injury will go on to develop significant posttraumatic stress or PTSD.				
3. Children who are more severely injured or ill generally have more serious traumatic stress reactions than those who are less severely injured or ill.				
4. Children who, at some point during the traumatic event, believe that they might die are at greater risk for posttraumatic stress reactions.				
5. Many children and families cope well on their own after experiencing serious illness or injury.				
6. The psychological effects of an injury or illness often last longer than the physical symptoms.				
7. Children and families with significant posttraumatic stress reactions usually show obvious signs of distress.				
8. I know the common signs and symptoms of traumatic stress in children and families.				
9. Some early traumatic stress reactions in children and families can be part of a healthy emotional recovery process.				
10. There are things that providers can do to help prevent longer-term posttraumatic stress in ill and injured children and families.				
11. There are effective screening measures for assessing traumatic stress that providers can use in practice.				

Please indicate whether you more strongly agree or disagree with the following statements:	Strongly Disagree	Disagree	Agree	Strongly Agree
12. Providers should focus on medical care for hospitalized children as opposed to children's mental health				
13. The way that medical care is provided can be changed to make it less stressful for children and families.				
14. Providers can teach families how to cope with trauma.				

15. Health care professionals should regularly assess for symptoms of traumatic stress.				
16. It is necessary for providers to have mental health information about their pediatric patients in order to provide appropriate medical care.				
17. I have colleagues I can turn to for help with a child or family experiencing significant traumatic stress.				

How would you rate your competence and comfort in...	Not Competent	Somewhat Competent	Very Competent
18. Engaging with traumatized children/families so that they feel comfortable talking to you/ comforted by you.			
19. Responding calmly and without judgment to a child's or family's strong emotional distress.			
20. Eliciting details of a traumatic event from a child or family without re-traumatizing them.			
21. Educating children and families about common traumatic stress reactions and symptoms.			
22. Avoiding or altering situations within the hospital that a child or family might experience as traumatic.			
23. Responding to a child's (or parent's) question about whether the child will die.			
24. Assessing a child's or family's distress, emotional needs, and support systems soon after a traumatic event.			
25. Providing basic trauma-focused interventions (assessing symptoms, normalizing, providing anticipatory guidance, coping assistance).			
26. Understanding how traumatic stress may present itself differently in younger children, older children, and teens.			
27. Understanding the scientific or empirical basis behind assessment and intervention for traumatic stress.			

Please indicate whether any of the following is a barrier for you in providing basic trauma-informed assessment / intervention:	Not a barrier	Somewhat of a barrier	Significant barrier
28. Time constraints or scope of practice constraints			
29. Getting training in providing trauma-informed assessments and interventions			
30. Information / evidence on trauma-informed assessment and intervention seems confusing			
31. Worry about further upsetting or traumatizing children and families			

In the past SIX (6) months, have you done the following basic trauma-informed	No	Yes
--	-----------	------------

interventions?		
32. Ask a child questions to assess his/her symptoms of distress		
33. Ask parents questions to assess their symptoms of distress		
34. Teach child or parent specific ways to manage pain and anxiety during a procedure		
35. Teach child or parent specific ways to cope with upsetting experiences		
36. Encourage parents to make use of their own social support system (family, friends, etc.)		
37. Teach parents what to say to their child after a difficult/painful/scary experience		
38. Provide information to parents about emotional or behavioral reactions that indicate their child may need help		

Kassam-Adams, Nancy et al. (2014), Nurses' Views and Current Practice of Trauma-Informed Pediatric Nursing Care. *Journal of Pediatric Nursing: Nursing Care of Children and Families*, <http://dx.doi.org/10.1016/j.pedn.2014.11.008>

The following questions are related to unit demographics. Please answer the questions as they best describe you. *Note:* all responses are confidential and by answering them you will not be putting yourself at risk for being identified.

Please select the age group that best describes you.

- 20-25 years of age
- 26-30 years of age
- 31-35 years of age
- 36-40 years of age
- 41-50 years of age
- 50+ years of age

I have been a nurse for...

- Less than 1 year
- 1-5 years
- 5-10 years
- 10 years or more

Please select the best answer to describe your number of years as a Pediatric Oncology nurse

- Less than 1 year
- 1- 5 years
- 5 years or more

References

- Alderfer, M., Navsaria, N., Kazak, A. (2009). Family functioning and posttraumatic stress disorder in adolescent survivors of childhood cancer. *Journal of Family Psychology, 23*, 717-725. doi: 10.1037/a0015996
- Alisic, E., Conroy, R., Magyar, J., Babl, F.E., O'Donnell, M.L. (2014). Psychosocial care for seriously injured children and their families: A qualitative study among emergency department nurses and physicians. *Injury, 45*, 1452-1458.
- Askins, M. A., Moore, B. D. (2008). Psychosocial support of the pediatric cancer patient: Lessons learned over the past 50 years. *Current oncology reports, 10*, 469-476.
- Center for Pediatric Traumatic Stress (2009). www.HealthCareToolbox.org (Website, Accessed October 14, 2014).
- Davis, K. (2012). Expenditures for treatment of mental health disorders among young adults, ages 18-26, 2007-2009: Estimates for the U.S. civilian noninstitutionalized population. *Agency for Healthcare Research and Quality, 358*, 1-7.
- Donnelly, C., Amaya-Jackson, L. (2002). Post-traumatic stress disorder in children and adolescents: Epidemiology, diagnosis and treatment. *Pediatr Drugs, 4*. 3. 159-170.
- Ehlers, A., D, Clark. (2000). A cognitive model of posttraumatic stress disorder. *Behavior Research and Therapy, 38*, 319-345.
- Ford, J., Chapman, J., Hawke, J., Albert, D. (2007). Trauma among youth in the juvenile justice system: Critical issues and new directions. *National Center for Mental Health and Juvenile Justice, 1-8*.
- Kaminer, D., Seedat, S., Stein, D. (2005). Post-traumatic stress disorder in children. *World Psychiatry, 4*(2), 121-125.
- Kassam-Adams, N., Rzucidlo, S., Campbell, M., Good, G., Bonifacio, E., Slouf, K., Grather,

- D. (2014). Nurses' views and current practice of trauma-informed pediatric nursing care. *Journal of Pediatric Nursing*, 1-7. doi: 10.1016/j.pedn.2014.11.008
- Kazak, A. (2005). Evidence-based interventions for survivors of childhood cancer and their families. *Journal of Pediatric Psychology*, 30, 29-39. doi:10.1093/jpepsy/jsi013
- Kazak, A., Barakat, L., Hwang, WT., Ditaranto, S., Biros, D., Beele, D., Reily, A. (2011). Association of psychosocial risk screening in pediatric cancer with psychosocial services provided. *Psycho-Oncology*, 20, 715-723. doi: 10.1002/pon.1972
- Kazak, A., Cant, M. C., Jensen, M., McSherry, M., Rourke, M., Hwang, W. T., Lange, B. (2003). Identifying psychosocial risk indicative of subsequent resource utilization in families of newly diagnosed pediatric oncology patients. *Journal of Clinical Oncology*, 21, 3220–3225.
- Kazak, A., Kassam-Adams, N., Schneider, S., Zelikovsky, N., Alderfer, M., Rourke, M. (2006). An integrative model of pediatric medical traumatic stress. *Journal of Pediatric Psychology*, 44, 343–355.
- Kazak, A., Prusak, A., McSherry, M., Simms, S., Beele, D., Rourke, M., Lange, B. (2001). The psychosocial assessment tool (PAT): Pilot data on a brief screening instrument for identifying high risk families. *Families, Systems & Health*, 19, 303- 317.
- Kazak, A., Rourke, M., Alderfer, M., Pai, A., Reilly, A., Meadows, A. T. (2007). Evidence-based assessment, intervention and psychosocial care in pediatric oncology: A blueprint for comprehensive services across treatment. *Journal of Pediatric Psychology*, 32, 1099-1110. doi: 10.1095/jpepsy/jsm031
- Kierman, G., Meyler, E., Guerin, S. (2010). Psychosocial issues and care in pediatric oncology. *Cancer Nursing*, 33, E12-E20
- Ko, S., Kassam-Adams, N., Wilson, C., Ford, J., Berkowitz, S., Wong, M., Layne, C. (2008).

- Creating trauma-informed systems: Child welfare, education, first responders, health care, juvenile justice. *Professional Psychology: Research and Practice*, 39(4), 396-404.
doi: 10.1037/0735-7028.39.4.396
- Mintzer, L., Stuber, M., Seacord, D., Castaneda, M., Mesrkhani, V., Glover, D. (2005).
Traumatic stress symptoms in adolescent organ transplant recipients. *Pediatrics*, 115(6),
1640-1644.
- National Child Traumatic Stress Network. (2003) Definition of medical traumatic stress.
Retrieved from, <http://www.NCTSNet.org>
- Patenaude, A., Kupst, M. J., (2005). Psychosocial functioning in pediatric cancer. *Journal of
Pediatric Psychology*, 30(1), 9- 27. doi: 10.1093/jpepsy/jsi012
- Roemer, M. (2011). Health care expenditures for the five most common children's conditions,
2008: Estimates for U.S. civilian noninstitutionalized children, ages 0-17. *Agency for
Healthcare Research and Quality*, 349, 1-6.
- Shemesh, E., Lurie, S., Stuber, M., Emre, S., Patel, Y., Vohra, P., Shneider, B. (2000). A pilot
study of posttraumatic stress and nonadherence in pediatric liver transplant recipients.
Pediatrics, 105(2), 1-7.
- Stuber, M., Christakis, D., Houskamp, B., Kazak, A.E., (1996). Posttrauma symptoms in
childhood leukemia survivors and their parents. *Psychosomatics*, 37, 254- 261
- Stuber, M., Meeske, K., Krull, K., Leisenring, W., Stratton, K., Kazak, A., Zeltzer, L. (2010).
Prevalence and predictors of posttraumatic stress disorder in adult survivors of childhood
cancer. *Pediatrics*, 125, 1124-1134.
- Stuber, M., Schneider, S., Kassam-Adams, N., Kazak, A., Saxe, G. (2006). The medical
traumatic stress toolkit. *CNS Spectr*, 11(2), 1-6.

Ward, E., C, DeSantis., A, Robbins., B, Kohler., A, Jemal. (2014). Childhood and adolescent cancer statistics, 2014. *CA: A Cancer Journal for Clinicians*, 1-21.

doi:10.3322/caac.21219

Ward-Begnoche, W. L., Aitken, M. E., Liggin, R., Mullins, S. H., Kassam-Adams, N., Marks, A., Winston, F.K. (2006). Emergency department screening for risk for post-traumatic Stress disorder among injured children. *Injury Prevention*, 12, 323–326,

<http://dx.doi.org/10.1136/ip.2006.011965>.

Wiener, L., Viola, A., Koretski, J., Perper, E. D. and Patenaude, A. F. (2014), Pediatric psycho-oncology care: standards, guidelines, and consensus reports. *Psycho-Oncology*.

doi: 10.1002/pon.3589

Winston, F., Kassam-Adams, N., Garcia-Epana, F., Ittenbach, R., Cnaan, A. (2003). Screening for risk of persistent posttraumatic stress in injured children and their parents, *JAMA*, 260(5), 643-649.