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Family-Centered Psychosocial Care for Pediatric Oncology Patients

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FAMILY-CENTERED PSYCHOSOCIAL CARE FOR PEDIATRIC ONCOLOGY PATIENTS

By

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Abstract

Psychosocial conditions are prevalent in *pediatric oncology* patients (Kahalley et al., 2013). Family and social support are essential aspects of a patient's health care outcomes (Merck & McElfresh, 2019). *Anxiety* and *depression* are common in pediatric oncology patients due to trauma during treatment (Pao & Kazak, 2015). These patients also can have preexisting developmental or behavioral conditions before starting treatment. Treatment side effects can also cause cognitive and behavioral changes (Nixon, 2014b). Nurses should be knowledgeable and confident in their ability to care for patients' psychosocial health and *development*. The purpose of this Doctor of Nursing Practice (DNP) project is to develop, implement, and evaluate a sustainable program for pediatric oncology nursing staff to increase their knowledge and confidence of family-centered psychosocial care principles with the intent to improve patient care and reduce patient suffering. This project's intervention was to develop a sustainable program to educate pediatric oncology nurses on family-centered psychosocial care. Measurement of the outcome variables, knowledge and confidence, was done before and after the intervention. Descriptive statistics were used for demographic data, displayed as frequencies and percentages. Data from this project's knowledge and confidence assessments were analyzed using a paired *t*-test and Wilcoxon signed rank test respectively. Qualitative response questions were pooled and assessed for common themes. Statistical analysis revealed that the intervention was effective at improving nurse knowledge and confidence in psychosocial care of pediatric oncology patients. Additional resources were generated after the intervention based on needs identified in the surveys. The results of this project will be disseminated to national publishing groups in hopes of making it available to nurses across the nation.

Keywords: psychosocial, pediatric oncology, anxiety, depression, development

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Chapter I

Introduction

Pediatric oncology patients and their families face a plethora of unique stressors and psychosocial concerns during their treatment. Approximately 82% of pediatric oncology survivors have one or more psychosocial problems, but only 38% have a referral to psychological services (Kahalley et al., 2013). Studies suggest that over 28.6% of pediatric oncology patients have anxiety, 32% have depression, and 60% have full or partial Post-traumatic Stress Disorder (PTSD) (Lazor et al., 2018; Cavusoglu, 2001; Graf et al., 2012). Moreover, approximately 26% of parents of children with cancer have PTSD, 21% have anxiety, and 28% have depression (Van Warmerdam et al., 2019). These statistics suggest that not only are the children suffering from psychosocial issues, but their families are as well. Family and social support are essential aspects of patient-centered care and psychological well-being (Merck & McElfresh, 2019). Psychosocial issues can affect patient outcomes and morbidity similarly to physical disorders, and as such, should be assessed and treated with the same importance as physical conditions (Pao & Kazak, 2015).

Significance of the Problem

PTSD, anxiety, depression, cognitive decline, and behavioral disorders can negatively impact the patient's social and behavioral activity and overall well-being (Pao & Kazak, 2015). Anxiety can cause immune responses that can harm the patient's physical health by impacting pain, immunity, and potentially transplant outcomes (Papp et al., 2019). Transplant outcomes and increased risk of graft-versus-host-disease can occur with anxiety due to interleukins released in the body (Papp et al., 2019). Anxiety and trauma can hinder the development of the hippocampus and amygdala, affecting a child’s expected emotional and social development

(Shonkoff et al., 2010). Depression can cause increased morbidity in pediatric oncology patients, decreased medication adherence, and worse health outcomes (Pao & Kazak, 2015). Patients with depression prior to bone marrow transplants have worse overall survival outcomes, higher rates of graft-versus-host-disease, and shorter survival after discharge (El-Jawahri et al., 2016). Depression has a connection to increased rates of cardiovascular disease-related death, congestive heart failure, and cerebrovascular disease (Correll et al., 2017). Developmental and behavioral disorders common to the general pediatric population also occur in pediatric oncology patients and create the need for nursing staff to understand the conditions and make care plan adjustments (Bryant, 2019). Cognitive and behavioral side effects of treatment can negatively impact the patient's quality of life, social interactions and cause physical harm if not properly managed (Mickelson et al., 2015). Pediatric oncology patients' families and social support systems are an extension and essential aspect of their health (Merck & McElfresh, 2019). If the patient's parents suffer from psychological distress, it may become difficult to fully support their child during treatment (Merck & Elfresh, 2019). Social isolation during treatment can worsen psychosocial conditions such as depression or anxiety (Pao & Kazak, 2015). The sequela of psychosocial conditions is far-reaching, and nursing staff needs to understand how to care for their patients to improve health outcomes.

Pediatric oncology nurses are at the frontline of patient care and have daily interactions with their patients and families. Nurses need to know how to assess, treat, and care for patients experiencing psychosocial distress (Anderson & Herring, 2019). Education is a continuous aspect of nursing care, and nurses need to remain knowledgeable about current evidence-based practice (Anderson & Herring, 2019). Since nurses play a critical role in patient care, increasing their knowledge of psychosocial care practices and confidence in implementing these skills can directly improve patients' psychosocial health.

Purpose

The purpose of this Doctor of Nursing Practice (DNP) project is to develop, implement, and evaluate a sustainable program for pediatric oncology nursing staff to increase their knowledge and confidence of family-centered psychosocial care principles with the intent to improve patient care and reduce patient suffering.

Chapter II

Review of the Literature

To understand and treat psychosocial conditions in pediatric oncology patients, nurses must first understand the basics of trauma-informed care, family-centered treatment, assessment, pathology, diagnosis, and evidence-based treatments. Trauma-informed care is the basis for understanding and caring for patients and their families when experiencing traumatic events (Clark et al., 2014). Family and social dynamics play a vital role in child development and mental health, and these relationships have multiple layers of complexity (Merck & McElfresh, 2019). It is also possible for patients to experience periods of emotional outbursts, aggression, intellectual deficits, or delirium due to their treatment (Merck & McElfresh, 2019). All of the sequelae of treatment can become more complex when patients have underlying psychosocial and developmental conditions before diagnosis. Understanding these conditions and their impact on patient care is vital to pediatric oncology patients' effective psychosocial care. This section discusses the synthesis of a systematic review of the literature of treatments for anxiety, depression, and PTSD for pediatric oncology patients, which outlines effective means of caring for their psychosocial needs.

Trauma-informed Care. Trauma-informed care is a term to describe the integration and understanding of the effects of trauma on individuals to assess and care for them (Clark et al., 2014). Pediatric oncology patients face many traumas during their treatment, from life-changing diagnoses to numerous invasive procedures (Pao & Kazak, 2015). Parents and other family members involved in the patient's care can also undergo vicarious traumatization (Clark et al., 2014). Vicarious traumatization occurs when an individual empathizes with another person undergoing a traumatic event, and the individual also experiences the intense emotions and impact of the trauma (Clark et al., 2014). Treatment for vicarious traumatization can include self-care promotion, including relaxation and healthy habits, and therapy (Clark et al., 2014). Trauma can cause long term effects in pediatric patients, such as delayed developmental milestones or impaired social relationships (Kimberg & Wheeler, 2019). The sequelae of childhood traumas make it imperative to understand how to best help patients cope and recover from their trauma to decrease dysfunctional behavior and long term consequences (Prihoda & Rodgers, 2019).

The first step to assessing trauma is to understand that the behaviors and symptoms caused by their trauma are primarily coping strategies (Clark et al., 2014). The patient’s care should come from the desire to help the patient adapt instead of "fix" them (Cohen et al., 2012). The four C's of trauma-informed care include: "Calm" through promoting a calm environment and grounding the patient, "Contain" by validating the patient's emotions and promoting boundaries, "Care" by promoting self-care and compassion, and "Cope" by supporting patient coping strategies and social support (Kimberg & Wheeler, 2019). In the context of pediatric oncology, acknowledging that the patient's history or present traumatization can incite emotional lability and affect dysregulation (Cohen et al., 2012). Affect dysregulation can induce a hyper- or hypo-aroused state in which the patient is mentally unable to process the information being told to them (Clark et al., 2014). During this time, it is helpful to use grounding techniques to pull the patient's attention back to the present moment (e.g., sensory stimulation through holding textured items or scented oils, counting breathing, or counting five items they can see, touch, and hear in the room) (Clark et al., 2014). It can also be helpful to help the patient identify their strengths (e.g., personal characteristics and family support) and self-care promotion techniques (e.g., diaphragmatic breathing through slow deep breaths using "belly breathing") (Clark et al., 2014). It is essential to validate the patient's feelings by simply telling the patient their response is expected and understood in hopes that the patient does not feel shameful or apologetic for their reactions (Cohen et al., 2012). Careful use of words during traumatic situations or patient emotional distress is vital to reflect empathy and understanding. Asking questions like "What is wrong?" can have a negative connotation and increase patient anxiety (Clark et al., 2014). The patient may better respond to questions like "What happened?" which does not imply that the patient is at fault or have negative connotations to the words (Clark et al., 2014).

When patients undergo trauma, they frequently feel they have lost control, safety, and trust (Cohen et al., 2012). It is essential to build a relationship with the patient to help them feel safe (Anderson & Herring, 2019). Allowing patients to make age-appropriate and situation-appropriate decisions is one method to promote the patient's sense of control (Merck & McElfresh, 2019). Nurses can allow children to make decisions as simple as what kind of drink they want when taking their medications (Anderson & Herring, 2019). To develop a therapeutic relationship with the patient, nurses should ask for their perspective on the situation (Anderson & Herring, 2019). Simple actions such as decorating their rooms, which can support the patient's sense of control and comfort, should be supported if they do not interfere with patient care (Anderson & Herring, 2019). Talking with the patient and allowing them to be heard and voice their fears helps to empower them and validate their emotions (Cohen et al., 2012). To help the patient feel safe, respect their space, let them know what is happening, allow the patient to have needed time, and ask questions (Clark et al., 2014). One method to respect the patient's personal space is utilizing treatment rooms in the in-patient setting, specialized rooms for invasive procedures to avoid a connection of pain or trauma within their hospital rooms (Anderson & Herring, 2019).

Signs that a patient has an instinctual response to a perceived trauma or threat could be calling out for help, flight or fight response, freezing, or changes in vital signs (Clark et al., 2014). Nursing staff needs to recognize these signs in their patients and remain calm and empathetic when they are in distress (Anderson & Herring, 2019). In addition, a few steps can help reduce the patient's anxiety and distress when they are undergoing a stressful situation. These steps include: asking the patient to identify what is causing them distress, using grounding techniques to help them slow their mental state, and talking with them about possible ways to reduce anxiety when encountering such situations (Anderson & Herring, 2019). An example of this process would be patient distress during a central line dressing change or access.

If the patient begins to exhibit physical signs of distress, ask them what is causing them distress or what they are worried about, validate their feelings of fear as understandable, ground them to their present surroundings through talking about their sensory surroundings, and ask them what would help them feel less worried in the future during the procedure (Clark et al., 2019). If the patient cannot identify the cause of their fear or ways they could feel less anxious in the future, suggestions about methods to reduce worry or increase patient choice when appropriate can be helpful (Anderson & Herring, 2019). Another essential strategy to reduce patient distress during or after traumatic events is relational soothing through connection with family or friends (Cohen et al., 2012). It can be easy to fall into a routine during standard procedures to the point of not considering the patient or family's comfort (Anderson & Herring, 2019). It is essential to reflect on patient care and assess for areas for improvement. Respecting the patient and their family and incorporating these trauma-informed care principles are the basis of understanding and caring for patients encountering trauma (Anderson & Herring, 2019).

Parent, Sibling, and Social Involvement. Relational soothing is a trauma-informed care term to describe the calming effect of social connection with family or friends (Clark et al., 2014). Nursing staff should promote family and social interaction for all pediatric patients. This interaction can be as simple as quiet times for parents and children in their rooms without interruptions as appropriate for their care plan (Anderson & Herring, 2019). When a patient is undergoing an invasive procedure, nursing staff can support relational soothing by promoting the patient's family to come close and hold the patient's hand if possible for the situation (Clark et al., 2019). Relational soothing can also be supported by promoting group activities with peers on the hospital unit or social groups outside of the hospital as appropriate for infection prevention concerns (Clark et al., 2019). Sibling relationships and friendships can become strained through the challenges that arise from pediatric oncology treatment (Anderson & Herring, 2019).

Families undergo multiple stages and periods of distress during a child's treatment for cancer. The initial diagnosis phase is a period of intense fear and uncertainty (Mosadegh, 2014). Parents, patients, and family members may undergo stages of grief as outlined by the Extended Kubler-Ross Grief Cycle: shock, denial, anger, bargaining, depression, testing, and acceptance (Wright, 2011). David Kessler, a psychologist who helped co-author the Kubler-Ross Model, also noted that finding meaning from the situation may be necessary before acceptance (Kessler, 2019). During the initial diagnosis phase, the patient will typically undergo induction therapy, where they receive intensive chemotherapy soon after diagnosis (Mosadegh, 2014). The parents will endure a plethora of changes, including new terminology and medications (Mosadegh, 2014). Nursing staff caring for the patient's family need to show empathy and support to the family during this time. The family may show periods of emotional lability or have difficulty retaining information, so compassion is vital to understanding the family's stage of grief

(Anderson & Herring, 2019). Allow the family to grow trust with nursing staff through transparency, empathy, and support of self-care and needs (Anderson & Herring, 2019). Family members should be encouraged to voice concerns, ask questions, and advocate for their children (Anderson & Herring, 2019). Education on all aspects of care, including printed materials, should be provided to parents (Anderson & Herring, 2019). Age-appropriate education for patients about their diagnosis and care should also be provided (Anderson & Herring, 2019). There are comic books, crafts, and picture books that can help patients understand their diagnosis to simplify their care plan into terms that they can understand to reduce patient fear (Anderson & Herring, 2019).

During treatment, the family and patients may experience periods of alternating emotions (Mosadegh, 2014). There can be periods of feeling secure and coping with their situation that can quickly turn to periods of emotional turmoil (Mosadegh, 2014). While patients and their families may appear calm during periods in their treatment, nursing staff must still provide support and a safe place for them to voice concerns and fears (Anderson & Herring, 2019). When this treatment period ends and the patient is entering remission, another adjustment period begins (Mosadegh, 2014). Families and patients may feel conflicting emotions of relief and fear when entering remission (Mosadegh, 2014). It is common for them to feel sadness at the transition and parting from the hospital and outpatient nursing staff (Mosadegh, 2014).

Many families and patients experience intense fear of relapse after remission (Mosadegh, 2014). Families and patients must be given education about the importance of continuing medical care after treatment is completed (Nixon, 2014a). Compliance with regular medical screening and physician visits is necessary to screen for relapse or long term treatment complications (Nixon, 2014a). Education on chemotherapy should include long term complications and survivorship concerns, such as secondary cancers or heart disease (Nixon, 2014b).

When a patient's condition becomes terminal or unresponsive to treatment, the family needs in-depth support and education. The end-of-life (EOL) period has many intense emotions for family members. Nursing staff should provide education on palliative and hospice care as appropriate and provide education on symptoms and changes to expect during this period (Docherty et al., 2019). When the patient is actively dying, contact religious clergy if the family wishes, provide privacy and patient comfort (Docherty et al., 2019). Validate the family's emotions and stage of grief (Docherty et al., 2019).

Palliative care is for patients experiencing a life-limiting or severe disease, including those with a life expectancy of fewer than 24 months, recurrent cancer, advanced-stage cancer, or inoperable cancer (National Consensus Project for Quality Palliative Care [NCP], 2018). Patients on palliative care do not need to have Do Not Resuscitate (DNR) orders, and they can still receive chemotherapy or standard treatments if the patient and family wish (NCP, 2018). In addition, palliative care provides a deeper level of social services, case management, home health, bereavement counseling, pain management, and family support (NCP, 2018). The palliative care team should include collaborating individuals from multiple specialties focused on the patient's overall improved quality of life, including assessing psychological needs (NCP, 2018).

Hospice is a sub-category of palliative care for patients with a life expectancy of fewer than six months (NCP, 2018). Patients on hospice care do not need DNR orders (NCP, 2018). Treatment is limited by what the patient and their family want, and their wishes should be respected (NCP, 2018). The patient's caregivers should have anticipatory guidance on the stages and symptoms the patient may face at the EOL (NCP, 2018). Weeks before death, the patient may be fatigued or sleep more, have shortness of breath, increased pain, experience dysphagia, or be less willing to speak to others (Hockenberry et al., 2019). Days before death, pulmonary congestion can lead to a "death rattle" where they experience noisy breathing, abnormal Kussmaul respirations, cough, hallucinations, changes in speech, or decreased urine or stool output (Hockenberry et al., 2019). Hours before death, the patient may experience moments of increased coherency, but this is not a sign of the patient improving (Hockenberry et al., 2019). They frequently experience hallucinations, labored breathing, hypotension, and decreased responsiveness (Hockenberry et al., 2019). At the point of death, post-mortem care according to local laws and the family's preferences is vital to ensuring patient dignity (Hockenberry et al., 2019).

There are several essential considerations for caregivers and health care professionals during the EOL period. Oxygen can help reduce the oxygen hunger and shortness of breath frequently experienced by patients (Hockenberry et al., 2019). Pain medications can help reduce pain which may flare, and narcotics can also aid in the oxygen hunger they may experience due to failing lungs (Hockenberry et al., 2019). Oral care and ice chips are helpful when the child is no longer drinking to soothe dry mucous membranes (Hockenberry et al., 2019). The child may become incontinent, so it is essential to regularly check them to keep them clean (Hockenberry et al., 2019). Caregivers and health care providers should ask the family about their religious practices surrounding EOL and honor them as best as is possible (Hockenberry et al., 2019). Finally, they should respect their decisions, even if they are different from their own, to provide them with the death they envision with dignity and respect (Hockenberry et al., 2019). Anticipatory grief is emotional distress that occurs either in the patient themselves or grief that happens in their loved ones during the EOL period (NCP, 2018). Bereavement support services provide support and care for caregivers who experienced the loss of their child for 13 months, and many insurance companies cover the cost of this care (NCP, 2018).

Patients and their siblings have a varied understanding of the significance of what is occurring during the EOL period (Hockenberry et al., 2019). Until toddlerhood, the egocentric thinking of children may limit their understanding of death (Hockenberry et al., 2019). Death may seem reversible, and stress may lead to regression and mood lability (Hockenberry et al., 2019). Preschool-age children tend to have magical thinking and may believe their actions or thoughts cause them to feel they made the situation happen (Hockenberry et al., 2019). They also tend to lack an understanding of death's irreversible and universal nature (Hockenberry et al., 2019). School-age children and older may have a mature level of understanding about death by seven years old (Hockenberry et al., 2019). The best way to know the status of a child's understanding is to directly ask them what they believe is happening as a starting point (Hockenberry et al., 2019).

Ljungman et al. (2015) conducted PTSD testing on parents of pediatric oncology patients from the time of treatment up to five years after the patient's death or end of treatment. They found that bereaved parents had significantly higher rates of PTSS (posttraumatic stress symptoms) compared to parents of children in remission (Ljungman et al., 2015). For all parents, PTSS spiked at the time of diagnosis, decreased steadily until three months into treatment, and then plateaued until the end of treatment (Ljungman et al., 2015). Even five years after treatment, bereaved parents still had a five-point higher PTSD Checklist score than non-bereaved parents (Ljungman et al., 2015). This study and others like it highlight the sustained impact of the loss of a child on parents and the distinct need for psychosocial support for bereaved parents.

There are multiple services and support groups for families of children who have passed. Nursing staff caring for pediatric oncology patients at the EOL period should know their local services so they can provide information for families (Docherty et al., 2019). For children old enough to voice their concerns and expectations, typically in the adolescent period, the Voicing My CHOICES resource can be utilized by nurses and other medical staff (Wiener et al., 2012). The Voicing My CHOICES resource is a method to talk to adolescents in the EOL or terminal illness period about what they want during their final moments (Weiner et al., 2012). It is not legally binding, but it outlines advanced directives and comfort measures (Weiner et al., 2012). It helps prepare the patient to discuss their hopes, set expectations, and guide care to their wishes (Weiner et al., 2012). Ensure that advance directives follow parent and patient wishes (Docherty et al., 2019).

Parents are a pivotal support system for children with cancer. Approximately one out of four parents of children with cancer experience depression, anxiety, or PTSD (van Warmerdam et al., 2019). These statistics show an enormous need for parents to connect to psychological services and community support. Unfortunately, parents may be unwilling to seek help due to feeling like they must focus solely on their child (Merck & McElfresh, 2019). It is essential to inform parents that self-care and psychological care will help them to better support and care for their children (Merck & McElfresh, 2019). In addition to the stress of their child undergoing cancer treatment, marital relationships can also become strained during the treatment process (Merck & McElfresh, 2019). Supporting parents' psychosocial needs through trauma-informed care approaches and information about supportive care services, such as community charities or psychological services, are indirect ways to support the child's needs (Merck & McElfresh, 2019). If necessary, connect the parents to Family Medical Leave Act (FMLA) resources.

Parents may face the fear of patients participating in social activities or school, and staff should educate and support parents about activities that the patient's physician has approved (Merck & McElfresh, 2019).

Siblings can have an array of reactions to a cancer diagnosis depending on their age and development (Madan-Swain & Hinds, 2015). Data on sibling psychosocial distress is minimal but does indicate the need for psychosocial care and support for siblings of patients diagnosed with cancer (Alderfer et al., 2010). Treatment places numerous stressors on the family structure, including financial burden, isolation and changes in housekeeping or vacations for infection prevention, alteration in focus on the sibling with cancer, or strain between family members due to increased stress and irritability (Madan-Swain & Hinds, 2015). They may feel fear from changing family dynamics, fear of the unknown, fear that they somehow caused their sibling's cancer, and complicated emotions when their parents and activities focus on their sibling who has cancer (Madan-Swain & Hinds, 2015). It is essential to incorporate siblings into education periods when appropriate for their developmental stage and parental approval (Madan-Swain & Hinds, 2015). Support the parents in providing care for the patient's siblings, and connect families to community support groups and charities. The effect of treatment upon family finances, time-allocation, and stress can cause distress in siblings and lead them to act out or avoid voicing concerns to reduce parent stress (Madan-Swain & Hinds, 2015). Ways to support sibling and patient interaction include allowing interaction without interruption as appropriate for patient care or providing group projects for the siblings to work on together, such as art projects (Madan-Swain & Hinds, 2015).

During treatment, there are times when pediatric oncology patients must be absent from school. School absence and physical side effects of treatment can cause separation from peers

(Noll & Bukowski, 2015). Psychological conditions can cause patients to become socially withdrawn and further cause separation (Noll & Bukowski, 2015). Nursing staff can educate parents on how school nursing staff can best support their child when they return to school (Noll & Bukowski, 2015). Treatment may cause side effects that can affect school performance and must be communicated to school nursing staff to help accommodate the patient's condition (Noll & Bukowski, 2015). Other children and peers may fear the patient's condition or reject them due to their differences (Noll & Bukowski, 2015). It may be helpful for parents to ask teachers to educate the class about expectations and the patient's condition before they resume school. Patients should continue social interaction and peer relationships (Noll & Bukowski, 2015). In and out of the hospital, social groups with other children diagnosed with cancer can help find understanding and community with others undergoing similar experiences. When hospitalized, group activities with other children, such as group art projects or games, can support normal social development (Noll & Bukowski, 2015).

Communication in Difficult Situations. It can be challenging to broach specific topics with children and their families. Oncologists utilize several resources with adult patients, which can also prove helpful to nurses and medical staff when communicating education to parents or defining parent desires when needed to the plan of care (Baile et al., 2000; Childers et al., 2017). Unfortunately, there are no resources solely for pediatric oncology providers in communicating difficult news. This project developed a mnemonic resource that outlines how nurses should approach communication and education with these children. Nurses should remain calm and empathetic with conversations with the family and patients (Merck & McElfresh, 2019). It is essential to use translation services as necessary and assess the family's emotional state. Highly emotional states can reduce the family's ability to process new information (Merck & McElfresh, 2019). When providing education, nurses should also consider the patient's developmental stage and family's ability to comprehend the information provided, including reading level (Merck & McElfresh, 2019). Helping to set up a team meeting involving the patient's caregivers, physicians, specialists, and nursing staff can help with significant decisions (Merck & McElfresh, 2019). Nurses should ensure no extraneous or excessive number of people in the room to reduce anxiety for patients and caregivers (Merck & McElfresh, 2019).

SPIKES is a mnemonic process that helps medical staff have difficult conversations with families (Baile et al., 2000). This mnemonic stands for Setting up, Perceptions, Invitation, Knowledge, Emotions, and Summary (Baile et al., 2000). The first step is setting up the interview by establishing privacy, sitting down during the discussion, reducing interruptions, and ensuring all significant family members are present (Baile et al., 2000). The second step is assessing the patient's perceptions through asking the family what they already know or their expectations (Baile et al., 2000). The third step is obtaining the invitation to tell them the news and how much information they want at that moment (Baile et al., 2000). The fourth step is giving knowledge and information to the patient using non-technical words, no cliché phrases, small amounts of information at a time, no bluntness, and at their comprehension level (Baile et al., 2000). The fifth step is addressing emotions and providing an empathetic response by allowing the patient to express their emotions and seeing if there is a way to help them process the information (Baile et al., 2000). Finally, the sixth step is providing a strategy and summary of the plan of care and realistic expectations and goals based on the diagnosis (Baile et al., 2000).

Nurses can also utilize the REMAP mnemonic for oncologists, allowing redirection and conversation when the patient's prognosis changes (Childers et al., 2017). This mnemonic stands for Reframing, Emotion, Mapping, Align, Proposing (Childers et al., 2017). The first step is reframing by asking the family what they know and their expectations, inform them of concerns, and talk about their situation concerning the patient's overall health (Childers et al., 2017). The second step is expecting emotion from the family and reflecting on their concerns while asking if it is okay to continue the conversation (Childers et al., 2017). The third step is mapping out their goals and expectations (Childers et al., 2017). The fourth step is to align the care plan with their goals and reflect on their goals to clarify their meaning (Childers et al., 2017). The fifth step is proposing a plan of care and a means to reach their goals (Childers et al., 2017). These steps can apply to any needed changes or expectations in the patient's care plan (Childers et al., 2017).

CARAT and PEDIATRIC Resources. Many difficult conversations arise during and after treatment for pediatric cancers. Two resources were generated in this project to help healthcare professionals navigate these difficult conversations. CARAT is a mnemonic developed to help guide healthcare professionals during difficult conversations with pediatric oncology patients. These conversations could include when a patient is diagnosed with cancer, fertility decisions, transition to palliative or hospice care, and end-of-life decisions. PEDIATRIC is a mnemonic created to guide new diagnosis education and discussions.

CARAT stands for Compassion, Age-appropriate, Relatable, Acknowledge, and Truthful. Health care professionals (HCP) must approach these difficult conversations with compassion and empathy for their patients and their families, allowing them to express their emotions, fears, and coping mechanisms without judgment. The HCP must customize the conversation with age-appropriate terminology based on the patient's developmental understanding. The information provided must be constructed with relatable, non-clinical terms so that the listener can understand the discussion. Never assume the listener understands medical terminology, regardless of the listener's career or assumed common knowledge terms. Health care providers should validate the listener's emotions, allowing them to speak their concerns and fears while letting them know they are not alone in their response. Support groups can help process their feelings. Finally, all information must be truthful and transparent so that the listener builds trust and feels as though they can reach out if they have questions.

PEDIATRIC stands for Prepare, Environment, Describe, Invite, Assess, Time, Reflect, Intervene, and Close. Health care professionals should study the patient's treatment plan and medications. Health care professionals should print available educational handouts on the diagnosis, medications, side effects, home care, common disorders and complications, and basic pathophysiology related to treatment to provide to patients and their caregivers. Information should also include when to call the HCP and resources for self-care, community support groups, and charitable organizations. Education may include interpretation of CBC results, infection prevention, bleeding prevention, neutropenia, and anemia. Medical terms the patient and family may face should be defined in simple terms. Prepare for anticipated questions the family and patient may have. Ensure education is in the patient and caregiver's preferred language.

Ensure that the education occurs in an environment with minimal interruptions. Education will ideally be in the patient's room, and all primary caregivers and the patient will be present. It is best to choose a time when the patient and their caregivers are not in emotional distress, such as immediately after diagnosis or an emergency medical situation. Describe what the education session will be like before starting the conversation. Inform the family that they will provide new diagnosis education about the diagnosis, medications, treatment, side effects, home care, and expectations. Inform them that they may not remember everything covered, but printed educational information allows them to review it at their own pace.

Invite the patient and caregivers to ask questions. Tell the family that it is okay for them to ask the same question multiple times if they need. Provide them with writing supplies that they can use to write down questions they may think of later. Assess the patient and family's understanding of the education by asking them to "teach-back" what was covered and ask questions. Before asking questions, let the caregivers and children know that this is not a "test," and there is no judgment on their answers.

Give realistic time frames based on the treatment plan. Inform the patient of how long the chemotherapy or immunotherapy run over and predicted infusion times. Let the family and patient know what days they will be receiving treatment during their admission. Allow the family and patients to express their fears, emotions, concerns, and needs. Reflect upon their feelings and concerns to clarify if the educator's interpretation is correct (e.g., "So you are concerned about infection risks at school?"). Also, let the caregivers and patient know that the diagnosis is not their fault if they voice feelings of guilt or confusion. Provide empathetic responses and validation of their emotions. Let them know their reaction is understandable.

If the caregivers or patient have any misconceptions, incorrect expectations, or misunderstandings from the education, clarify these by repeating correct information. Provide additional written information if requested. Close the discussion by reiterating that the caregivers and patients will likely not remember everything covered. Let them know to feel free to reach out with any questions. Provide them with information for support groups, and let them know that they have the support of the nursing staff.

Social Determinants of Health. Social determinants of health and socioeconomic status play a pivotal role in pediatric oncology outcomes. Erdman et al. (2019) reviewed pediatric cancer registries across numerous countries. This study showed that survival rates were significantly lower in low- to middle-income countries than high-income countries like the United States (Erdman et al., 2019). Low socioeconomic status (SES) had a significantly negative impact on survival rates even within high-income countries (Erdman et al., 2019). Pediatric oncology diagnosis can also negatively impact the SES of families and reduce the SES of patients when they reach adulthood (Erdman et al., 2019). The impact on SES is from multiple causes, including leave from work to care for the patient or psychological effects of treatment on the child. Bona et al. (2021) conducted a retrospective study on 371 high-risk neuroblastoma patients and discovered that household poverty significantly reduced patient event-free survival and overall survival. Neighborhood poverty without household poverty was not associated with reduced survival rates (Bona et al., 2021).

A retrospective study of 3,913 pediatric thyroid cancer patients showed a significant reduction in survival in males, those who did not speak English, and children in poverty (Gruszczynski et al., 2021). Johnson (2020) discussed the results of the SEER program, which showed that pediatric oncology patients of all racial and ethnic groups had lower survival rates than non-Hispanic White children. In addition, treatment abandonment, where patients do not start or complete treatment, was significantly increased among low- and middle-income countries (Friedrich et al., 2016). Low socioeconomic status, decreased parent education, and distance from treatment centers were significant factors for treatment abandonment in low-income countries (Friedrich et al., 2016). These studies suggest the need for additional research, support, and programs to care for children from low SES households and children from non-White races or ethnicities. A thorough assessment of the needs and SES of pediatric oncology patients and their families is necessary at the beginning of treatment. Social work and case managers can also aid families to be connected to support services.

Developmental Considerations. Psychosocial disorders have been documented in pediatric oncology patients from infancy through adulthood (Lazor et al., 2018; Cavusoglu, 2001; Graf et al., 2012). Cancer treatment can cause psychological and physical disorders that impact normal pediatric development (Nixon, 2014b). Nursing staff must understand their patients' developmental milestones to provide age-appropriate care that promotes development (Merck & McElfresh, 2019). Patients' emotional, social, and physical development can lead to lifelong consequences if not adequately supported (Merck & McElfresh, 2019). There are multiple developmental theories for pediatric patients, including Erikson's psychosocial theory of development, Piaget's cognitive development theory, Kohlberg's theory of moral development, and Freud's psychoanalytic theory. Erikson's theory states that infants are in the stage of trust vs. mistrust, toddlers are in autonomy vs. shame and doubt, preschool-age children are in initiative vs. guilt, school-age children are in industry vs. inferiority, and adolescents are in identity vs. role confusion (Kidd & Rodgers, 2019; Duffy, 2019; Monroe, 2019; Rodgers, 2019; Deronin, 2019). Piaget's theory outlines children's cognitive development stages from sensorimotor, preoperational, concrete operational, to formal operational cognitive ability (Kidd & Rodgers, 2019; Duffy, 2019; Monroe, 2019; Rodgers, 2019; Deronin, 2019). Kohlberg's theory outlines moral development stages for children, including pre-conventional, conventional, and post-conventional (Kidd & Rodgers, 2019; Duffy, 2019; Monroe, 2019; Rodgers, 2019; Deronin, 2019). Freud's theory outlines psychosexual development stages for children, including oral, anal, phallic, latent, and genital (Kidd & Rodgers, 2019; Duffy, 2019; Monroe, 2019; Rodgers, 2019; Deronin, 2019).

Most nurses will be familiar with the four above theorists due to their nursing courses. Newer childhood developmental theorists include female, minority, and varied socioeconomic factors. Carol Gilligan (1977) developed the Care Based Morality theory of moral development for women after studying under Kohlberg. Her theory has three main stages, pre-conventional where the female focuses on survival above the needs of others, conventional where they accept harm to themselves to help others, and post-conventional where the female seeks to prevent harm to themselves and others (Gilligan, 1977). Phinney (1989) created the Ethnic Identity development model, which outlines the stages of unexamined ethnic identity, to ethnic identity search, and finishing at achieved ethnic identity. Marcia (1966) developed the Four Ego and Identity Statuses theory, where an individual can be in identity achievement (committed and exploring meaning to their questions), identity foreclosure (committed without exploring meaning), identity moratorium (where they are uncommitted but still seeking meaning), and identity diffusion (no commitment or exploration of meaning). Cross (1971) developed a model of African-American identity development where individuals go from pre-encounter (prefer the dominant culture), encounter (reinvest in their minority group), immersion/emersion (rejects the dominant culture, immerses themselves in their group), internalization (fulfilled by joining their minority group and engaging with the dominant culture), and commitment (healthy racial identity and positive relationship with other cultures). Kim (1981) developed the theory of Asian American Identity Development, which outlines the stages of ethnic awareness, white identification, awakening to social-political consciousness, redirection, and incorporation. Ferdman and Placida (2001) developed the Latino/a Racial Identity Orientations Model, which outlines ways in which individuals identify themselves, including Latino integrated, Latino identified, subgroup identified, Latino as other, undifferentiated, and white identified.

Red flags for delayed development in children include a lack of responsiveness or verbalization in all children, regression in skills in children of any age. In a newborn, red flags include decreased muscle tone. In an infant, red flags include (a) inability to raise the head in 2-month old, (b) inability to move hands to their center in a 4-month-old, (c) inability to transfer objects to opposite hands in a 6-month-old, (d) unilateral hand preference by 6-months-old, (e) inability to roll or sit in a 9-month-old, and (f) inability to stand when supported in a 12-month-old (Kidd & Rodgers, 2019). In a toddler, red flags include a lack of pincer grasp or intentional pointing in a 15-month-old, using less than six words or inability to walk in an 18-month-old, decreased coordination while walking and lack of imitation in a 24-month-old, and falling and lack of pretend play in a 36-month-old (Duffy, 2019). In a preschool-aged child, red flags include the inability to jump or lack of use of pronouns in a 4-year-old, and inability to draw or balance with extreme emotional lability and resistance to self-care in a 5-year-old (Monroe, 2019). In a school-age child, red flags include the inability to skip, write, retell stories, or remember others' names (Rodgers, 2019).

Developmental and Behavioral Disorders. All children, including those with developmental and behavioral disorders, need to be encouraged to perform self-care and skills to their full capacity (Bryant, 2019). Children with developmental and behavioral disorders frequently require normalizing the hospital environment with routine and ritualistic behaviors to function at their baseline (Docherty et al., 2019). Parents and caregivers should have information on community support groups and services. Patients should also have appropriate therapy services, such as physical and occupational therapy, and medical equipment, such as wheelchairs (Bryant, 2019). Education and support on different communication methods allow patients to find a way to communicate their needs (Bryant, 2019). Patients should be encouraged to still have social interaction with their peers through school and group activities (Bryant, 2019). A patient's home routine should continue during their hospital stay and patient preferences respected as is possible for their treatment requirements (Bryant, 2019). Nursing staff should ask the patient's parents what the child's baseline is so that an assessment of changes and expectations can be set (Bryant, 2019).

Down syndrome or trisomy 21 occurs in children with an extra chromosome 21 (Bryant, 2019). Patients with Down syndrome are predisposed to having respiratory tract infections, cardiac abnormalities such as septal defects, thyroid disorders, hypotonicity, deficits of the immune system, and leukemia (Bryant, 2019). They have common physical characteristics such as oblique palpebral fissures, inner epicanthic folds, high arched palate, short and broad neck, learning difficulties, small ears and nose, hearing loss, and short stature (Bryant, 2019). In addition, patients are at increased risk of respiratory infections, altered feeding from a protruding tongue, hyperextensibility, obesity, and dry skin (Bryant, 2019). Nursing staff should be aware of these risks appropriate care and modifications as necessary. There is a broad spectrum of symptoms and intellectual impairment, and each patient must be cared for based on their needs (Bryant, 2019). Patients with Down syndrome may communicate in alternative methods, such as sign language, and nursing staff should ask caregivers about the patient's preferred form of communication (Bryant, 2019). Patients may need a referral to physical therapy, occupational therapy, speech therapy, and, if required, a hearing assessment or hearing aids (Bryant, 2019).

Autism Spectrum Disorder (ASD) occurs in children with social difficulties and repetitive behaviors or hobbies (Bryant, 2019). As implied in the name, ASD is a spectrum of symptoms ranging from mild high functioning deficits to severe symptoms where patients may be nonverbal or unresponsive (Bryant, 2019). The exact cause of ASD is not fully understood and has multifactorial causes, such as genetics or environmental components (Bryant, 2019). As mentioned previously, decreased communication and social interaction are red flags for autism at any age (Bryant, 2019). Patients can become obsessed with specific subjects, potentially having high intelligence or academic performance (Bryant, 2019). ASD assessment at 18 and 24 months old includes assessing the child's verbalizations and social interaction (Bryant, 2019). In toddlerhood, assess children using the Modified Checklist for Autism in Toddlers (M-CHAT) and follow-up assessment (M-CHAT/F) (Bryant, 2019). Children with ASD typically favor routines and familiar objects, such as a favorite cup or toy (Bryant, 2019). They can also have the potential for emotional outbursts or discomfort if those everyday routines are broken (Bryant, 2019). Nursing staff needs to ask the parents about routines and ways to reduce patient distress. Those routines should be respected, and care should be modified as much as possible while ensuring the patient's treatment is completed (Bryant, 2019). Children with ASD may also have particular food preferences, and again if it does not interfere with treatment, their preferences should be respected (Bryant, 2019). ASD can also be associated with sensory overload and sensitivity issues, and nursing staff should respect the patient's physical boundaries and reduce unnecessary sensory stimulation (Bryant, 2019). If the patient does experience emotional outbursts or aggression, patient safety is the top priority. It is important to remove items that could cause patient harm, incorporate family who can help calm the patient, remove the noxious stimuli, and calmly attempt to understand and reduce patient distress (Bryant, 2019). It may be necessary to utilize medications such as risperidone, aripiprazole, or lorazepam during periods of acute distress (Bryant, 2019).

Cerebral Palsy (CP) is a condition in which a brain injury during gestation or up to 2 years old causes disorder in motor function and the potential for a range of disabilities in sensation, communication, intellect, or seizures (Stanton & Lavenbarg, 2019). Children with CP typically are delayed in meeting developmental milestones, have unilateral hand preference by 6-

months-old, abnormal crawl in infancy, scissoring of legs, and muscle tone changes (Stanton & Lavenbarg, 2019). Spastic CP involves the retention of primitive reflexes with hypertonicity and can affect any combination of extremities (Stanton & Lavenbarg, 2019). Dyskinetic CP can present as the athetoid subtype with chorea writhing or dystonic slow twisting movements (Stanton & Lavenbarg, 2019). It involves a lack of control of the oral cavity, pharynx, and larynx leading to drooling and alteration in verbalization (Stanton & Lavenbarg, 2019). Ataxic CP involves frequent repetition of movements and a lack of control when making deliberate movements of the arms (Stanton & Lavenbarg, 2019). Mixed CP consists of a mixture of abnormal movements from different types listed above (Stanton & Lavenbarg, 2019). Over 50% of children with CP have intellect within the average or above-average range of adults (Stanton & Lavenbarg, 2019).

Patients should be connected to appreciate therapy services such as Occupational Therapy, Speech Therapy, and Physical Therapy (Stanton & Lavenbarg, 2019). Due to motor abnormalities, children with CP can have an increased risk for respiratory infection, aspiration, dental issues, skin breakdown, issues with toileting and constipation, and visual and auditory disability (Stanton & Lavenbarg, 2019). Patients should be provided with necessary medical equipment such as wheelchairs or braces if needed, educational support, ophthalmology, dentist, a bowel plan such as the use of laxatives, and care to prevent pressure ulcers or soiled clothing (Stanton & Lavenbarg, 2019). Patients may require medication for seizures, Botox injections for spasticity, muscle relaxants, laxatives or suppositories, or aid while eating (Stanton & Lavenbarg, 2019). In addition, children with CP frequently have allergies to latex and hip dislocation (Stanton & Lavenbarg, 2019). There are several methods to aid children in communicating, and staff should utilize the patient's preferred form of communication (Stanton

& Lavenbarg, 2019). Nursing staff should communicate with the patient and their caregivers to understand their baseline, medication needs, and routine respect (Stanton & Lavenbarg, 2019). Nursing staff should not assume the patient has an intellectual disability and should provide the patient with developmentally appropriate care and respect (Stanton & Lavenbarg, 2019).

Some common behavioral disorders include oppositional defiant disorder (ODD), attention deficit hyperactivity disorder (ADHD) or attention deficit disorder (ADD), and conduct disorder (Rodgers, 2019). ODD is characterized by intentionally going against authority figures and rules, and patients can seek treatment from behavioral therapy, clear rules, and calm reaction to aggression or disobedience (Rodgers, 2019). Conduct disorder is similar to ODD but involves aggressive or disobedient behavior, possibly leading to lying and property destruction (Rodgers, 2019). Conduct disorder treatment includes behavioral therapy, clear rules, and consistent intervention during disruptive behavior (Rodgers, 2019). ADHD has either hyperactivity/impulsivity or inattention (Rodgers, 2019). ADHD diagnosis requires the patient to have at least six symptoms for at least six months (Rodgers, 2019). Symptoms of ADHD for inattention include lack of attention to detail, lack of focus, lack of listening when being spoken to, not following instructions, losing items required for tasks, being distracted frequently, and leaving required tasks undone (Rodgers, 2019). Symptoms of ADHD for hyperactivity/impulsivity include the inability to do activities silently, frequently talking and moving at inappropriate times, interruption of others, lack of patience, or not taking turns with others (Rodgers, 2019). Treatment for ADHD varies based on the child's age. Simple interventions for caregivers include reducing distractions such as TV when required to do tasks, clear rules and charts for chores and desired tasks, and educational support (Rodgers, 2019). ADHD in children 3-5 years old is treated primarily by behavioral therapy, which seeks to help the child correct maladaptive behaviors (Woo, 2020). If the patient does not improve after behavioral therapy, patients can begin taking stimulant medications (Woo, 2020). In children six years of age or older with ADHD, behavioral therapy in conjunction with stimulants is the primary treatment (Woo, 2020). If the medication is ineffective after two follow-up visits, the treatment should change to a different stimulant class (Woo, 2020). Medications for ADHD can decrease appetite and delay growth and weight gain while increasing blood pressure. Assessment of the patient's growth and vital signs is necessary (Woo, 2020). Common medications for ADHD include Methylphenidate (a.k.a. Ritalin, Concerta, or Methylin), Dexmethylphenidate (a.k.a. Focalin), Dextroamphetamine (a.k.a. Zenzedi), Amphetamine-Dextroamphetamine (a.k.a. Adderall), and Lisdexamfetamine (a.k.a. Vyvanse) (Woo, 2020). Prescription for non-stimulant medications, such as atomoxetine, guanfacine, and ER clonidine, can treat patients who still have symptoms despite initial stimulants and therapy or who have signs of medication diversion (Woo, 2020). Medications should be given in the morning without food for effectiveness throughout the day (Rodgers, 2019). When the patient is experiencing symptoms, an intervention can be as simple as refocusing them on the situation, providing scheduled medications, and connecting them to proper support and therapy (Rodgers, 2019).

Systematic Literature Review of Treatment for Anxiety, PTSD, and Depression

Searches for articles on the effectiveness of different treatments and therapies for anxiety, depression, and PTSD in pediatric oncology patients were conducted systematically on CINAHL, PubMed, Cochrane, and Ovid databases. The results were filtered to include only randomized controlled trials (RCT), non-randomized controlled trials (NRT), systematic reviews (SR), peer-reviewed journals, and meta-analysis (MA). Search terms "treatment," "therapy," "pediatric oncology," "children with cancer," "anxiety," "PTSD," and "depression" limited results from the searches further. Options included only English language and full-text available online articles. Boolean operators were used to combine the above terms in searches. Searches on the four above databases included the single terms and combination terms "treatment AND pediatric oncology AND anxiety," "treatment AND pediatric oncology AND PTSD," "treatment AND pediatric oncology AND depression," "therapy AND pediatric oncology AND anxiety," "therapy AND pediatric oncology AND PTSD," "therapy AND pediatric oncology AND depression," "treatment AND children with cancer AND anxiety," "treatment AND children with cancer AND PTSD," "treatment AND children with cancer AND depression," "therapy AND children with cancer AND anxiety," "therapy AND children with cancer AND PTSD," and "therapy AND children with cancer AND depression."

432,220 articles resulted from the individual term searches on CINAHL, and 341 articles resulted from the combined term searches (Table A1). 1,109,521 articles resulted from the individual term searches on PubMed, and 341 articles resulted from the combined term searches (Table A2). 243,566 articles resulted from the individual term searches on Ovid Medline, and 25,202 articles resulted from the combined term searches (Table A3). 1,621,388 articles resulted from the individual term searches on Cochrane, and 823 articles resulted from the combined term searches (Table A4).

27,350 articles resulted from these limitations and combined term searches. After excluding articles that did not have pediatric oncology participants and did not measure anxiety or depression, only 32 articles remained. Excluding articles that were simply feasibility commentary, qualitative studies that did not include statistical analysis, and articles with questionable data collection or participant qualifications further reduced the articles. For example, one excluded systematic review only had one article to assess CBT in pediatric oncology patients, and its main focus was the reduction of headaches, not anxiety. One study gave citalopram to pediatric oncology patients and showed improvement in depression. However, citalopram has not received Food and Drug Administration (FDA) approval for use in children and, for that reason, was excluded from this analysis (DeJong & Fombonne, 2007). It is important to note that many prescriptions for medications are for non-FDA-approved reasons, and numerous standard medications for children are without FDA approval. Another systematic review of psychosocial interventions for pediatric oncology patients included studies that did not assess the patient's anxiety, depression, or PTSD (Coughtrey et al., 2018). After this tertiary assessment, only 17 articles remained (Figure B1). The keeper articles included 13 RCTs and 4 NRTs. These studies were selected as keeper studies because they had pediatric oncology patients and measured reduction in anxiety, PTSD, and depression through their interventions.

Anxiety and PTSD. Pediatric oncology patients face anxiety through unique challenges such as altered life expectancy, separation from friends or school, alopecia, scars, extreme weight loss, frequent hospital visits, invasive procedures, side effects from treatment, alterations to family dynamics, potential infertility, and secondary cancers (Pao & Kazak, 2015). Anxiety leads to a significant increase in IL-1 and IL-6 levels in pediatric oncology patients (Papp et al., 2019). IL-6 increases B cell proliferation, inflammatory disorders and plays an important role in graft versus host disease (Papp et al., 2019). PTSD is an anxiety disorder that begins with a traumatic event and leads to intrusive thoughts about the trauma, hyperarousal, avoidance of triggers, numbness, and altered behavioral outcomes in children (Pao & Kazak, 2015). Multiple medical conditions can also cause anxiety in these patients, such as altered electrolytes, cardiovascular disease, pulmonary disease, neurological disease, or endocrine disruptions (Pao & Kazak, 2015).

Physical symptoms of anxiety can include signs of activation of the fight or flight response such as tachycardia, tachypnea, increased blood pressure, diaphoresis, dilation of pupils, restlessness, flushed or pale skin, nausea or diarrhea, sleep disturbances, or changes in eating patterns (Pao & Kazak, 2015). Symptoms of PTSD can include avoidance of triggers that remind the patient of their trauma, intrusive thoughts about the trauma, hyperarousal that causes extreme reactions, sleep disturbances, feelings of guilt or depression, changes in behavior and social interaction, and risky behaviors such as substance abuse (Pao & Kazak, 2015). Apart from traumatic procedures and the social or physical impacts of treatment, different treatment aspects can increase or cause anxiety in patients. For example, uncontrolled pain, withdrawal from narcotics, decreased oxygenation such as anemia or pulmonary embolism, electrolyte abnormalities, neurologic abnormalities such as tumors or encephalopathy, or hormonal changes can increase or cause anxiety in this patient population (Pao & Kazak, 2015). In addition, patients may exhibit signs of PTSD or anxiety with sudden changes in behavior, fearfulness of all medical staff despite not actively having a procedure done, or repetitive or phobic behaviors (Prihoda & Rodgers, 2019).

The appropriate assessment resource for anxiety in children varies based on the child's age. The Faces Anxiety Scale (FAS) uses the same principles as the Wong-Baker pain scale, which allows a child too young to read to point to an image of a face that best matches the anxiety level they are experiencing (McKinley & Madronio, 2008). The Screen for Child Anxiety Related Disorders (SCARED), General Anxiety Disorder-7 (GAD-7) screen, Hamilton Anxiety Rating Scale (HAM-A), Pediatric Anxiety Rating Scale (PARS), and Hospital Anxiety and Depression Scale-Anxiety (HADS-A) are appropriate for children at least eight years old who can read, and involves the patient filling out a self-assessment questionnaire (Pao & Kazak, 2015). The SCARED can further assess subtypes of anxiety disorders, such as social anxiety disorder or separation anxiety disorder (Pao & Kazak, 2015). The Beck Anxiety Inventory (BAI) is a self-assessment questionnaire intended for patients 17 years of age or older (Pao & Kazak, 2015). The Brief Summary Inventory (BSI) is a self-assessment resource for children old enough to read the questionnaire to assess somatization, depression, anxiety, and panic (Shoshani et al., 2016). The Child PTSD Symptom Scale (CPSS), PTSD Checklist-Civilian Version (PCL-C), the PTSD Symptom Scale-Interview (PSS-I), Clinician-Administered PTSD Scale (CAPS), and Structured Clinical Interview for DSM-IV (SCID), assess PTSD symptoms which also utilize questionnaires to evaluate the severity of symptoms (Pao & Kazak, 2015; Spoont et al., 2013).

Current practice for managing anxiety in pediatric oncology patients includes anti-anxiolytics such as benzodiazepines (Pao & Kazak, 2015). Non-pharmacological management of anxiety includes therapy, distraction, relaxation techniques, and alternative therapies, including play and art (Pao & Kazak, 2015). Research on the treatment of anxiety in pediatric oncology patients is limited. Standard family therapy effectively reduces anxiety in pediatric patients (Pao & Kazak, 2015). Play therapy involves allowing children to socially interact and express their emotions in a non-threatening environment (Pao & Kazak, 2015). Child Life Specialists are Master's degree prepared medical staff at many pediatric hospitals throughout the country trained in childhood development and stress reduction (Diener et al., 2018). Child Life Specialists can help patients get involved in crafts, play, social activities, and calming techniques (Diener et al., 2018). Nurses can also utilize Child Life Specialists to help provide distraction and grounding when the nurse is performing an invasive procedure (Diener et al., 2018).

Cognitive-behavioral therapy (CBT) involves identifying cognitive distortions and problems, learning effective approaches to situations, and reframing thinking or behaviors to improve mental health (Branch & Wilson, 2019). Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) is method of CBT which incorporates TIC principals to care for patients who have experienced traumatic events (Cohen et al., 2012). A person's life experiences and thought patterns affect the way that they interpret events which occur, and that interpretation can cause a positive or negative emotional, behavioral, or physical reaction (Sokol & Fox, 2019). Cognitive distortions are negative, false, or unrealistic thoughts (Branch & Wilson, 2019). Steps involved in most CBT take the patient through identification to modification and reflection on their cognitive distortions. Health care professionals can implement CBT techniques with their patients during or after stressful events. Other methods in CBT can include mindfulness, writing exercises, self-reflection, and grounding exercises to help focus on the present moment (Branch & Wilson, 2019).

Examples of cognitive distortions that involve exaggeration with the belief that the worst-case scenario will occur or where the situation has to be perfect, or it is worthless (Branch & Wilson, 2019). Cognitive distortions involving exaggeration can also include the belief that everything must be the exact way they wish and where one situation defines all other situations (Branch & Wilson, 2019). Patients can also have cognitive distortions where they attribute negative terms to themselves and others and where they believe if a situation is difficult, then it is impossible to complete (Branch & Wilson, 2019). Sokol & Fox (2019) named the act of attributing negative terms to oneself as a "doubt label" which can stem from childhood trauma. Examples of cognitive distortions involving avoidance or negativity are where they ignore anything that does not fit their narrative and ignoring any positives in their situation (Branch & Wilson, 2019). Finally, examples of cognitive distortions involving magical thinking are the attempt to predict the future, assuming others are thinking negative things without proof, believing their feelings are proof of negative things, and where they believe everything fits their worldview or situations revolve around them (Branch & Wilson, 2019).

Relationship, behavioral, and emotional problems can also be addressed with TF-CBT through identification and processing of maladaptive or negative environments and reactions (Cohen et al., 2012). TF-CBT varies somewhat in the steps involved with care. The steps of TF-CBT involve providing education about CBT, providing a safe environment where the patient can be at ease, allowing the patient to express their emotions, identifying coping mechanisms, discuss their trauma, and help them to find ways to react differently to events in the future (Cohen et al., 2012). The provider can guide the patient through relaxation techniques, such as visualization, in order to help the patient process their anxiety and encourage coping (Cohen et al., 2012).

Before beginning the process of CBT and identifying thought patterns, the provider needs to let the patient and their family know that their reaction to the trauma they are facing is valid and valued (Cohen et al., 2012). Typically, the first step in CBT is having the patient analyze what event or trigger occurred to cause their reaction (Sokol & Fox, 2019). The patient then identifies what caused their reaction and their beliefs, thoughts, and attitudes about the meaning of the identified cause for their response (Branch & Wilson, 2019). Next, guide the patient to identify possible cognitive distortions and alternative thinking patterns based on truth and logic (Branch & Wilson, 2019). Finally, after the following stressful situation, the patient thinks about the effect those alternative thoughts had on their feelings and reactions to the problem (Sokol & Fox, 2019).

Motivational Interviewing (MI) is one method of communicating which aims to help promote positive change in the patient (Miller & Rollnick, 2013). A roadblock patient’s face when deciding to make a change in their behavior is ambivalence. Ambivalence in the context of MI means that a patient sees the reasons for and against changing, and are stuck in a position of uncertainty towards if it would be best to change (Miller & Rollnick, 2013). In a pediatric oncology setting, this may include a patient wanting to leave their bed and get involved with other patients during a group art event. In this example, the patient may see the positive experience of painting and being around others, but also sees the potential negatives of the physical expenditure to get to the play room and emotional expenditure of being around others. In MI, the nurse would support "change talk" where the patient was thinking about leaving their bed, allow them to have autonomy in their decisions, and reflect back what they are feeling about the change (Miller & Rollnick, 2013). The patient already has the capacity to make the positive changes within themselves, and nurses are to encourage and support the patient to make the decision to change instead of forcing change upon them.

An example of going through these steps in a pediatric oncology setting is talking through the port accessing experience. Port accessing involves the insertion of a needle into a port underneath the skin of a patient's chest. After a patient is accessed, their nurse can ask how they felt during the port access. The nurse should not demean the patient's reaction or fear, but should verbalize that they were brave during the process and having one's port accessed can be scary. The nurse can then ask the patient what caused them to feel the way they did and what made them feel that way. For example, a patient may feel anxious during port accessing after seeing the needle because they are afraid of pain or that the needle will cause them harm. The nurse should then guide the patient to identify possible cognitive distortions. In this example, the patient may fear the needle will puncture their organs or cause other damage. After identifying cognitive distortions, the nurse should guide the patient in identifying thinking patterns based on truth or logic. In this example, the nurse could discuss how the needle is too short to reach their internal organs and will go into the port, which has a metal back and walls that prevent the needle from reaching other tissues. Finally, instruct the patient to focus on these new thinking patterns when they are reaccessed in the future, and the nurse can assess how the patient felt during the next accessing to see if there was an improvement.

During an acute panic attack, the patient may feel like they cannot breathe, be terrified, sweat, have tremors, and may have difficulty describing to the caregiver why they feel anxious (Pao & Kazak, 2015). When the patient is exhibiting signs of a panic attack or similar nonspecific symptoms, it is essential to assess the patient's vital signs for hypoxia and ensure their safety by removing any environmental risks in their immediate area (Pao & Kazak, 2015). Stay with the patient and attempt to speak in a calm voice (Anderson & Herring, 2019). Help guide the patient through grounding exercises by informing them they are safe, and that staff will stay with them (Anderson & Herring, 2019). Continue to guide them in deep breathing exercises and guided meditation if they are calm enough to participate (Clark et al., 2014). Finally, help them connect back to their surroundings by guiding them to describe their blanket, providing a cool drink, and administering anti-anxiolytics (Clark et al., 2014).

Care for an acute PTSD episode is similar to care for a panic attack, but there are some vital differences. Panic attacks are also possible with PTSD, but there are times when a patient who has PTSD will dissociate from their situation mentally or have triggers by external events (Prihoda & Rodgers, 2019). During this time, patients with PTSD may feel like they are back in their traumatic situation and can experience emotional lability, dissociation, excessive fear, or aggression (Prihoda & Rodgers, 2019). Staff must ensure the patient does not harm themselves or others. Attempt to guide the patient through grounding techniques as described above, and inform the patient of their current surroundings, which are safe and do not pose a threat (Prihoda & Rodgers, 2019). Nursing staff can also guide the patient through CBT techniques to help the patient reduce their focus on past trauma and decrease hyperarousal (Prihoda & Rodgers, 2019).

As of 2021, the FDA has not approved any medications to treat standard anxiety in children (Brodrick, 2020). The FDA has approved four medications to treat OCD in children: fluoxetine for children eight years of age or older, sertraline, fluvoxamine, and clomipramine for children ten years of age and older (Brodrick, 2020). Sertraline and fluoxetine are approved to treat PTSD in adults, but studies have not adequately been completed in children to prove their efficacy (Brodrick, 2020). Buspirone, citalopram, and propranolol also treat anxiety in children, but the studies for their effectiveness are limited (Brodrick, 2020). There have only been two studies on the efficacy of these medications in pediatric oncology patients (Gothelth et al., 2005; DeJong & Fombonne, 2007).

Depression and Suicidal Ideation. Depression can result in altered life expectancy, physical appearance changes, social isolation, and loss of control (Pao & Kazak, 2015). Depression may manifest as social withdrawal, flat affect, dysphoria, anhedonia, sleep disturbances, or eating pattern changes (Pao & Kazak, 2015). Self-harm and verbalization of suicidal ideation require emergent intervention due to their life-threatening consequences (Mickelson et al., 2015). When patients start on medications for depression, there is a black box warning for increased suicidal behavior and thoughts (Pao & Kazak, 2015). Risk factors for increased risk of suicide include a history of suicidal or self-harm behavior, suicidal ideation, recent losses, feelings of hopelessness, trouble at school, and access to items that they could use to commit suicide (Mickelson et al., 2015). Treatment and physical side effects can cause or worsen depression in pediatric oncology patients (Nixon, 2014b). Other than the social and trauma-related causes of depression in this patient population, certain medications (e.g., corticosteroids, vincristine, IL-2, PEG), brain tumors or radiation, uncontrolled pain, or electrolyte or hormonal abnormalities can all put the patient at risk for depression (Pao & Kazak, 2015).

The most common assessment resource for depression in children is the Children's Depression Inventory (CDI) which requires children to read and self-assess their symptoms (Mickelson et al., 2015). In addition, the Center for Epidemiologic Studies Depression Scale for Children (CES-DC), Montgomery Asberg Depression Rating Scale-Self Assessment (MADRS-S), Hospital Anxiety and Depression Scale-Depression (HADS-D), and Children's Depression Rating Scale-Revised (CDRS-R) are also self-assessment resources for children old enough to read and answer a questionnaire about their symptoms (Pao & Kazak, 2015). Screening and assessment for suicide risk include the Ask Suicide-Screening Questions (ASQ) and Columbia Suicide Severity Rating Scale (CSSRS) (Mickelson et al., 2015). Regardless of the resource used to assess the patient, if nursing staff notes depression or suicide risk, it must be immediately addressed to assure patient safety.

Standard treatment of depression in pediatric oncology patients includes using antidepressants such as benzodiazepines, family therapy, CBT, alternative therapies, and management of underlying causes of their depression (Pao & Kazak, 2015). The FDA has approved only two SSRIs for depression in children: escitalopram for Major Depressive Disorder (MDD) in children 12 years of age or older and fluoxetine for MDD in children eight years of age or older (Brodrick, 2020). Research on antidepressant medications or interventions specifically with pediatric oncology patients is quite limited. Only one study has been completed in pediatric oncology patients to test the effectiveness of fluvoxamine to reduce depression and anxiety (Gothelf et al., 2005).

Cognitive Behavioral Therapy for Anxiety, PTSD, and Depression.

Similarities and Consistencies. Seven of the keeper articles showed a significant reduction in anxiety after a CBT intervention (See Table C1). It is important to note that many pediatric oncology patients undergo intensive induction treatment after initial diagnosis in the hospital and are subsequently followed at outpatient settings and in hospital outpatient treatment for multiple years, even after being considered in remission. Patients are seen in pediatric oncology units until 21 years of age and, in certain circumstances, beyond 21 years of age. Since many patients have appointments after their initial treatment, it would be essential to consider CBT's effects on these pediatric oncology patients after remission. Hagstrom et al. (2020) chose pediatric oncology patients in remission and measured the impact of 15 in-person CBT sessions. They reported a reduction in BAI, MADRS-Self Assessment, PTSD Checklist-Civilian Version, and Short Health Anxiety Inventory scoring (Hagstrom et al., 2020). Seitz et al. (2014) implemented an online program with 10 CBT writing modules and online 45 minute CBT psychotherapy sessions twice a week among pediatric oncology patients in remission over 15 years old. They reported a significant reduction in PTSD symptoms, HADS-A, and short-term fear of progression or relapse scoring (Seitz et al., 2014). These two studies are keeper studies due to their applicability to pediatric oncology patients and measurement of patient anxiety, depression, and PTSD. These studies showed that CBT is effective in pediatric oncology patients in remission to significantly reduce anxiety, PTSD, and depression (Hagstrom et al., 2020; Seitz et al., 2014).

Liossi and Hatira (1999) studied the effectiveness of hypnosis, used CBT as one of their control groups, even excluded the imagery technique of CBT, and still showed an anxiety reduction and reported pain after two CBT sessions five days before bone marrow aspiration in pediatric oncology patients with a mean age of eight years old. Liu et al. (2019) showed a significant reduction in anxiety after eight weeks of CBT mindfulness training in pediatric oncology patients with a mean age of 15.9 years old. Tsai et al. (2013) showed a significant reduction in anxiety, salivary cortisol levels, and heart rate after a five-day-a-week CBT and group play intervention in pediatric oncology patients with a mean age of 8.9 years old. Van Dijk-Lokkart et al. (2016) reported that two weekly 45 minute sessions of physical activity for 12 weeks and six sessions of CBT over 12 weeks reduced parent-reported patient anxiety but did not reduce patient-reported anxiety with a mean patient age of 12.6 years old. Zhang et al. (2019) reported that five weeks of CBT sessions reduced anxiety, depression, and stress among pediatric oncology patients, with an even distribution of participants from 8-12 years old and 13-18 years old. These five studies are keeper studies due to including only pediatric oncology patients, with participants from age 3 to 18, given CBT interventions and proper length for the intervention to reduce anxiety levels. CBT was shown in these studies to reduce anxiety and depression in pediatric oncology patients across the lifespan.

Dissimilarities and Inconsistencies. The studies that did not significantly reduce anxiety had limited exposures to their intervention but did have other psychosocial improvement areas (See table D1). Kazak et al. (2004) showed no significant decrease in anxiety after four CBT sessions in one day. Still, they did show a substantial reduction in hyperarousal at the three to 5-month follow-up assessment in pediatric oncology patients with a mean age of 14.32 years old (Kazak et al., 2004). Klosky et al. (2004) tested one exposure of a CBT toy before treatment and showed no significant decrease in observed behavioral distress but did show a significant reduction in HR. Rosenberg et al. (2018) tested anxiety and depression after four CBT sessions with an online platform over four weeks and showed no significant decrease in HADS-A measurement of anxiety but showed a considerable reduction in Kessler-6 global distress and improvement in resilience. Van Dijk-Lokkart et al. (2016) had two-week breaks between CBT sessions, and this break in continuity could have accounted for the patient-reported anxiety findings. Kazak et al. (2004) and Klosky et al. (2004) used only limited one-day interventions, which is likely why there were no significant findings. These studies are keeper studies due to having exclusively pediatric oncology patients given CBT interventions with a measurement of anxiety post-intervention. These studies showed the importance of CBT intervention design, specifically personal contact and frequency, in changing patient anxiety levels and outlined the specifics required for CBT to be effective (Kazak et al., 2004; Klosky et al., 2004; Rosenberg et al., 2018; Van Dijk-Lokkart et al., 2016).

Klosky et al. (2014) had the youngest participant age, with a mean age of 4.2 years old. Tsai et al. (2013) had participants as young as three years old, but they still showed a significant decrease in anxiety. Liossi and Hatira (1999) also had a younger participant group than most studies and showed a significant reduction, possibly due to their in-person intervention and frequency of CBT sessions. The remainder of the studies had participants over 12 years of age. These studies suggest that patients across various development stages can improve anxiety with a frequent CBT intervention (Liossi & Hatira, 1999; Tsai et al., 2013).

Rosenberg et al. (2018) had a limited number of sessions but is distinct from the other studies. Rosenberg et al. (2018) did not include in-person or video psychotherapy sessions but instead opted for the online PRISM training platform for CBT. Limited sessions and impersonal interaction possibly decreased the effectiveness of the interventions. Seitz et al. (2014) showed that patients could reduce anxiety with CBT administered consistently and increased frequency even with online video psychotherapy sessions (two sessions a week in this study). In addition to having personal interaction, either through video sessions or in-person interaction, the frequency of CBT sessions appears to impact patient outcomes. Liossi and Hatira (1999) showed that despite having limited sessions (two sessions over five days before BMA), there could be a significant reduction in anxiety with in-person CBT. Klosky et al. (2004), Kazak et al. (2004), and Van Dijk-Lokkart et al. (2016) had infrequent or limited sessions of CBT to one day. They showed no significant change in psychosocial distress, while Liossi and Hatira (1999) showed decreased anxiety after two sessions within five days. The keeper studies with improved patient anxiety, depression, and PTSD also had weekly CBT sessions. It could be theorized from these studies that consistency and frequent CBT sessions would be necessary to have consistent patient improvement (Kazak et al., 2004; Klosky et al., 2004; Liossi & Hatira, 1999; Rosenberg et al., 2018; Sietz et al., 2014; Van Dijk-Lokkart et al., 2016).

In these studies, CBT was effective across multiple developmental stages, from toddlerhood and beyond adolescence (Hagstrom et al., 2020; Liossi & Hatira, 1999; Seitz et al., 2014; Tsai et al., 2013). Synthesis of the keeper studies suggests that personal contact can impact anxiety, depression, and PTSD reduction when implementing CBT. Seitz et al. (2014) showed that online CBT could be helpful if it involves video CBT twice a week with a trained professional. Nursing staff working with the patients regularly interact with patients to implement these techniques without requiring additional nursing staff or in-person interactions. Synthesizing and comparing these articles would suggest that CBT effectively reduces anxiety, depression, and PTSD in pediatric oncology patients when implemented over an extended period of at least weekly sessions with in-person or video sessions with trained nursing staff.

Specific CBT techniques utilized in these studies which nursing staff can use include journaling, aiding the patient in identifying negative thinking patterns, role-playing to identify and restructure negative thinking patterns, deep breathing, relaxation exercises, positive affirmation and encouragement, writing exercises reflecting on the past and future, appointments with therapists, mindfulness, and storytelling (Zhang et al., 2019). Nurses can provide patients with journaling supplies, guide them through relaxation techniques, and talk to allow them to express their feelings. Relaxation exercises can include deep breathing, muscle relaxation to release tension, and meditation. In addition, nurses can support patients during episodes of anxiety, depression, or PTSD by talking to them about what they are thinking and re-centering them to reality by identifying cognitive distortions.

Art and Music Interventions for Anxiety and Depression.

***Similarities and Consistencies*.** Four of the keeper studies used art or music interventions to assess their effectiveness at reducing anxiety or depression in pediatric oncology patients. Altay et al. (2017) showed that five consecutive days of therapeutic writing, drawing, and mutual storytelling guided by nursing staff show a significant improvement in pediatric oncology patients' anxiety. Cheung et al. (2018) showed that 45-minute, weekly music training sessions with a music teacher showed a significant reduction of depression in pediatric oncology patients compared to the control who received 45-minute weekly sessions for 52 weeks of leisure activities. Liu et al. (2019) showed that a CBT-based mindfulness intervention with music therapy, including 30 minutes of cheerful or natural music, significantly reduced patient anxiety and improved sleep quality. Both Liu et al. (2019) and Cheung et al. (2018) included staff-guided music interventions and showed significant patient distress improvements. Abdulah and Abdulla (2018) showed that 20, two-hour, artist-guided painting and handcrafting sessions showed a significant improvement of depression in pediatric oncology patients. Tahasebi et al. (2017) showed that six weekly 25 minute sessions of watercolor painting in a group that discussed the paintings showed a significant reduction in patient depression. In addition, they showed that the patients who painted alone in their rooms as the control group also substantially decreased patient depression. Still, the experimental group significantly reduced depression rates compared to the control group. Tsai et al. (2013) also used play therapy with toys, painting, clay, and papercrafts with others as a part of their intervention, including CBT. They showed a significant decrease in FAS, heart rate variability, decreased salivary cortisol level, and decreased Beck Youth Anxiety score (Tsai et al., 2013). These studies suggest that writing, arts and crafts, and music interventions effectively reduce patient depression and anxiety.

Dissimilarities and Inconsistencies. Cheung et al. (2018) showed that leisure activities with staff did not significantly reduce depression, but music education and playing the piano with trained staff reduced anxiety. Liu et al. (2019) did not measure depression rates and used listening to music, and Cheung et al. (2018) did not measure anxiety rates and used learning to play the piano, but both studies did show a decrease in the measures they used after their music intervention. Tahasebi et al. (2017) did not have a non-intervention control group. Their study showed that art intervention could also reduce patient anxiety even if the patients were to complete the activity from their rooms, which can be helpful for patients who are unable or unwilling to leave their rooms. Altay et al. (2017) prompted participants to draw, write, tell stories, and self-reflect on their emotions and experiences to reduce anxiety using staff to help guide their activities. Abdulah and Abdulla (2018) also used interaction with staff during crafts, but they did not include a self-reflection on their projects' meaning.

Other Treatments for Anxiety and Depression.

Similarities and Consistencies. Gothelf et al. (2005) showed that fluvoxamine significantly reduced patient depression and anxiety in pediatric oncology patients. As previously stated, fluvoxamine is FDA approved for treating OCD in children, but not anxiety or depression. Gothelf et al. (2005) administered 25 mg/day raised in increments of 25 mg every 2-3 days to a fixed dose of 100 mg/day. The Gothelf et al. (2005) study suggests that fluvoxamine effectively treats patient anxiety and depression, but more research is needed. FDA approval is also an essential next step in advancing medication treatment of anxiety and depression in these patients. Shoshani et al. (2016) showed that a Make a Wish intervention leads to a significant reduction in depression and anxiety compared to children still waiting for their Make a Wish fulfillment. This study shows the importance of patient hope and fulfillment of internal dreams and participation in activities. Liossi and Hatira (1999) also found that two thirty-minute "hypnosis" sessions significantly reduced patient anxiety. Their hypnosis sessions involved mindfulness techniques like relaxation, deep breathing exercises, and guided imagery including telling the patient to imagine the part of their body that will be experiencing pain is numb (Liossi & Hatira, 1999). This study would indicate that guided imagery and relaxation techniques can significantly improve patient anxiety before invasive procedures. Tsai et al. (2013) also incorporated watching cartoons or playing video games with others as a part of their intervention, including CBT with a significant reduction in patient anxiety.

Dissimilarities and Inconsistencies. As described in the CBT subsection, van Dijk-Lokkart et al. (2015) implemented a physical activity intervention for 45 minutes, twice a week for 12 weeks, and CBT sessions for 60 minutes every two weeks for 12 weeks. This study did not show significant improvement in patient-reported distress (van-Dijk-Lokkart, 2015). This study suggests that their physical activity intervention did not reduce patient distress despite occurring twice a week for 12 weeks. Li et al. (2011) showed that 30 minutes per day of therapeutic play using a virtual reality computer game five days in one week showed a significant improvement in depression but not anxiety in pediatric oncology patients. Tsai et al. (2013) also incorporated video games in their intervention and showed a significant decrease in anxiety, but their intervention had the children play games with other children. This study would suggest that an essential difference between these two studies was the patients' interactions with others when playing games. Tsai et al. (2013) included patients from 3-12 years old, with a median age of 8.12 years old in the intervention group. Li et al. (2011) had a mean patient age of 11.6 years old in their intervention group and included children from 8-16 years old. These data show that the Tsai et al. (2013) study did use a younger patient population than the Li et al. (2011) study, but both had a mean or median age of participants in the school-age stage of development.

Systematic Literature Review of Long Term Survivorship

The ultimate goal of pediatric oncology treatment is to help the patient live more quality years of life. The advancements in pediatric oncology treatment during the 20th Century have provided a drastic increase in survival rates (Erickson & Steiner, 2001). As childhood cancer and survival rates increase, more patients survive into remission. Pediatric oncology care does not end at the point of remission but continues with the side effects of their treatment. This systematic review of the literature was completed to identify the psychosocial needs of long term childhood cancer survivors.

Searches for articles on psychosocial issues in childhood cancer survivors (CCS) were conducted systematically on CINAHL, PubMed, Cochrane, and Ovid databases. The results were filtered to include peer-reviewed journals. Search terms "long term survivorship," "survivor," "pediatric oncology," "childhood cancer," "anxiety," "PTSD," and "depression" limited results from the searches further. Options included only English language and full-text available online articles. Boolean operators were used to combine the above terms in searches. Searches on the four above databases included the single terms and combination terms "long term survivorship AND pediatric oncology AND anxiety," "long term survivorship AND pediatric oncology AND PTSD," "long term survivorship AND pediatric oncology AND depression," "survivor AND pediatric oncology AND anxiety," "survivor AND pediatric oncology AND PTSD," "survivor AND pediatric oncology AND depression," "long term survivorship AND children with cancer AND anxiety," "long term survivorship AND children with cancer AND PTSD," "long term survivorship AND children with cancer AND depression," "survivor AND children with cancer AND anxiety," "survivor AND children with cancer AND PTSD," and "survivor AND children with cancer AND depression."

868,327 articles resulted from the individual term searches on CINAHL, and 454 articles resulted from the combined term searches (Table E1). 939,888 articles resulted from the individual term searches on PubMed, and 1,178 articles resulted from the combined term searches (Table E2). 35,918 articles resulted from the individual term searches on Ovid Medline, and 27,349 articles resulted from the combined term searches (Table E3). 83,392 articles resulted from the individual term searches on Cochrane, and 16 articles resulted from the combined term searches (Table E4).

28,997 articles resulted from these limitations and combined term searches. After excluding articles that did not have pediatric oncology participants and did not measure anxiety or depression, 122 articles remained. The number of articles was further reduced by excluding feasibility commentary articles and articles with questionable data collection or participant qualifications. For example, one excluded systematic review was a feasibility discussion about a tool to help with guided breathing to reduce anxiety in CCS. After this tertiary assessment, only 90 articles remained. The keeper articles included seven Systematic Reviews (SR), one Meta-Analysis (MA), one Randomized Controlled Trial (RCT), 72 Cohort Studies, one Qualitative study, and eight expert opinion articles (Figure F1). These studies were selected as keeper studies because they discussed the psychosocial concerns of CCS.

In Their Words. In qualitative studies on the CCS experience, CCS frequently reported feeling powerless due to their diagnosis (Ander et al., 2018). Feeling powerless may be an essential factor in CCS anxiety and their sometimes overwhelming sense of uncertainty (Ander et al., 2018; Carney et al., 2019). CCS discussed how their cancer was a "shadow" that lingered over their lives, marking them different than non-CCS peers (Carney et al., 2019; Ander et al., 2018). This sense of being different from others frequently made CCS report feeling lonely and like they were socially disconnected (Ander et al., 2018). It can be difficult for many CCS to find meaning in their experiences or move forward in their lives beyond an identity consumed by cancer (Ander et al., 2018; Carney et al., 2019). Another common thread discussed by CCS was the desire to avoid being reminded of their treatment because it triggered emotional distress (Ander et al., 2018). CCS require psychosocial support tailored to their unique experiences and struggles.

Anxiety, PTSD, and Depression. The literature was not conclusive if CCS have increased anxiety, depression, or PTSD compared to the general population. Four studies reported no difference in the frequency of anxiety and depression compared to non-CCS (Table G1). In comparison, 13 studies did show an increase in anxiety and depression in CCS, and one said there were lower rates of anxiety and depression in CCS (Table G1). Four studies stated no difference in the number of CCS who had PTSD compared to non-CCS, while five studies showed an increase of PTSD in CCS (Table G1). Regardless of whether these conditions are more frequent in CCS, it is still important to screen patients and treat them just as it is in the general population.

A frequent source of anxiety for CCS was fear of relapse (Simard et al., 2013). Somatic symptoms and chronic pain were the common causes of fear of relapse in CCS (Cunningham et al., 2021). CCS listed fear of relapse and the lack of education about relapse as a top unmet need and concern (Simard et al., 2013; Kelada et al., 2019). The studies estimate that 10.2-26% of CCS have chronic pain over five years after treatment (Anderson et al., 2020; Patton et al., 2021). There was an increased risk of chronic pain after treatment among CCS with osteosarcoma or sarcoma, stem cell transplant, PTSD, or being a female CCS (Anderson & Woods, 2020; Patton et al., 2021). Therefore, health care providers should address pain in CCS, and treatment may include pharmacological treatment or alternative treatments such as physical therapy (Anderson & Woods, 2020). To address the fear of relapse as a significant cause of anxiety, health care providers should provide education, anticipatory guidance, and plans for screening for relapse to address these concerns (Cupit-Link et al., 2018).

Another cause of anxiety and depression in CCS is social withdrawal (Desjardins et al., 2019). Suicide was higher among CCS who reported loneliness, depression, uncontrolled pain, CNS tumors, chronic health concerns, and sleep disruption (Ernst et al., 2020; Ernst et al., 2021; Recklitis et al., 2010). Studies also suggested that parent or caregiver anxiety and depression can increase psychosocial distress in CCS as well (Tutelman & Heathcote, 2020). Head scarring or disfigurement was a significant source of psychological distress and social anxiety in CCS (Vuotto et al., 2017; Kinahan et al., 2012). These studies would imply that an important aspect in reducing the risk of anxiety and depression in CCS would be the support of social interaction, psychological support for caregivers, and bolstering the CCS's support systems.

The uncertainty of life after childhood cancer is a primary factor that increases rates of PTSD (Lee, 2006). PTSD in CCS reduces the patient's quality of life and health-promoting behaviors, such as seeing a primary care provider (Meeske et al., 2001; Santacroce & Lee, 2006). While PTSD was not conclusively more common among CCS, several studies showed high post-traumatic stress symptoms (PTSS) or partial PTSD rates. The distinction between PTSD and partial PTSD or PTSS occurs at the point of diagnosis. Patients can experience symptoms of PTSD but be below the threshold for official diagnosis with PTSD. Examples of this may be a patient who exhibits avoidance of anything which may trigger memories of their treatment, but not clinically significant intrusive thoughts or changes in their emotional state (Klosky et al., 2014). Erickson & Steiner (2001) reported that 88% of CCS experienced at least one significant symptom of PTSD. An interesting trend in the literature review was the connection between post-traumatic growth (PTG) and PTSD. PTG is related to increased resilience, hope, or character after a traumatic event (Klosky et al., 2014). Three studies found that there was a direct correlation between rates of PTSD and PTG (Cook et al., 2020; Klosky et al., 2014; Wilson et al., 2016). Studies showed that CCS who have increased levels of hope in the potential for positive meaning and outcomes in their situations experience the most PTG (Yuen et al., 2014).

These studies suggest that there is an increased risk of PTSS in female patients, unemployed, diagnosed at an older age, lower education attainment, adolescent survivors, and those with a significant disease burden (Langeveld et al., 2004; Wilson et al., 2016; Katzman & John, 2018). Screening at follow-up appointments for PTSS could help identify distressed patients, particularly if providers focused on these high-risk subgroups of patients.

Survivorship Clinics and Transition. A critical continuation of the pediatric oncology patient's treatment is long term medical follow up. After patients finish their treatment, there is an expectation for them to follow up for surveillance and screening (Grandy et al., 2021). The frequency and type of screening vary by the patient's type of cancer but typically involves close follow up to assess for relapse in the patient's cancer. The primary cause of mortality in CCS is the relapse of their original cancer (Davies, 2007). After the patient completes the initial screening period after treatment, they frequently are transitioned to receive care from primary care providers (Ginsberg et al., 2006). While the initial screening is essential, adult CCS are at increased risk for many chronic and acute health concerns for over thirty years from diagnosis (Davies, 2007; Zhang et al., 2012). The type of complications and comorbidities a patient faces varies based on the chemotherapy or radiation therapy they receive (Lindell et al., 2015). There is a clinically significant increase in infertility, neurocognitive deficits, cardiac toxicity, reduced bone mineral density, endocrine dysfunction, psychosocial disorders, dental abnormalities, renal toxicity, ocular toxicity, and obesity in CCS (Lindell et al., 2015). Despite the increased risk for comorbidities in CCS, many adult CCS do not have a primary care provider, and only a third receive survivor care (Lee, 2006; Schwartz, 2020).

The transition into autonomy and self-efficacy in health care for CCS is an essential milestone in their psychosocial development. Unfortunately, CCS tend to have higher rates of unemployment, lower educational attainment, and delayed psychosocial development (Brinkman et al., 2018). Common reasons CCS give for not following up with a health care provider are life responsibilities, not seeing a need for follow-up, and fear of discovering a relapse (Schwartz, 2020). On the other hand, reasons for why CCS did follow up with survivorship care were provider behavior and rapport, allowing their family to be present at appointments, and the clinic environment or resources (Grandy et al., 2021).

CCS have increased mortality compared to non-CCS for up to 25 years after diagnosis and increased risk of secondary malignant neoplasm (SMN) up to 35 years after diagnosis (Davies, 2007; Zhang et al., 2012). In addition, CCS have significantly lower screening rates for cancer and health conditions in adulthood, such as mammogram rates of 12.6% compared to non-CCS mammogram rates of 57.1% (Yan et al., 2020). One suggested method to improve screening for comorbidities is survivor care plans, which inform primary care providers about the types of treatment their patients received and which screenings they require (Yan et al., 2020). Many CCS patients exhibit avoidance or wishful thinking behaviors and may fear screenings. Patients may believe that if they do not adhere to screening and discover a SMN or disease, then maybe it does not exist (McDonnell et al., 2015). Providing education about the importance of long term follow-up, long term effects of treatment, and risks during the immediate follow-up after treatment is an essential foundation for future follow-up (Cox et al., 2017).

Psychosocial Side Effects of Treatment

Nursing staff must identify any adverse effects of the patient's treatment plan to prevent harm. The patient requires the treatment to prevent disease progression, which will likely cause secondary patient discomfort but avoiding treatment to avoid side effects will undoubtedly lead to disease progression and patient harm. While side effects are accepted risks of treatment, certain side effects need to be promptly treated and are unexpected. These unexpected side effects include medication toxicity, which needs to be treated by rescue medications (Nixon, 2014a). Early detection of psychosocial side effects of treatment allows medical nursing staff to start treatment or therapies that can improve long term outcomes (Nixon, 2014a).

Corticosteroids are standard in many treatment plans for pediatric oncology patients due to their ability to increase treatment efficacy, but they carry the risk of personality changes during treatment, such as aggression or emotional lability (Nixon, 2014a). Fatigue, somnolence, encephalopathy, progressive learning disability, confusion, hallucinations, insomnia, cerebellar ataxia, cerebellar ischemia, and neurotoxicity are a few side effects caused by various standard chemotherapies (Nixon, 2014a). These side effects of treatment generally resolve after treatment but can cause lifelong neurologic or intellectual disability (Nixon, 2014a). Bone marrow transplant and hematopoietic stem cell transplant require intensive chemotherapy for myeloablation to prepare the recipient patient, and many of these chemotherapies, including thiotepa, can cause the above described side effects (Nixon, 2014a). Cytokine release syndrome (CRS) can also occur secondary to immunotherapy administration and involves a significant release of cytokines in response to treatment and can present with fatigue, anaphylactic-type reactions, confusion, hallucinations, seizures, and incoordination (Nixon, 2014b).

Cranial radiation therapy (CRT) and brain surgery can cause psychosocial side effects (Nixon, 2014b). Surgery involving the brain carries the risk of immediate neuron injury that can cause psychosocial disorder and postoperative conditions (Nixon, 2014b). Posterior Fossa Syndrome occurs after brain surgery and can include mutism, emotional or behavioral lability, intellectual and cognitive deficits, in addition to neurologic and musculoskeletal deficits (Nixon, 2014b). These symptoms typically resolve over time, but patients need to be treated by occupational therapy (OT), speech therapy (ST), physical therapy (PT), supportive services, and psychological services (Nixon, 2014b). Not only do the effects of radiation and surgery cause physical damage on their own, but they can also carry the risk of injury or alteration of endocrine glands within the brain (Nixon, 2014b). Endocrine disruption can cause alterations in hormonal function, including adrenal, thyroid, and pituitary dysfunction (Nixon, 2014b). These hormonal changes can cause electrolyte disturbances, changes in metabolism and vital signs, and emotional and behavioral changes (Nixon, 2014b).

Delirium can occur secondary to chemotherapy or other medications, conditions that cause inflammation or injury to the CNS, toxins, sleep deprivation, psychiatric emergencies, uncontrolled pain, or withdrawal (Mickelson et al., 2015). Inflammation or damage to neurons can occur with encephalopathy, meningitis, hydrocephalus, toxin exposure, or in response to medications (Nixon, 2014b). Delirium can present as alterations in consciousness, hallucinations, extreme emotional lability, sleep disturbances, restlessness, anxiety, and aggression (Nixon, 2014b). Medications or medical conditions which cause delirium have the risk of permanent cognitive changes, and the longer the symptoms persist, the worse the prognosis will usually be for the patient’s cognitive recovery (Mickelson et al., 2015). The Delirium Rating Scale (DRS) can be used to assess the level of delirium (Mickelson et al., 2015). It is essential to ensure patient safety during acute delirium by removing environmental risks, addressing the delirium's underlying cause, establishing routines while hospitalized, and maintaining a calm and consistent demeanor (Mickelson et al., 2015). After addressing the cause of delirium, treatment for acute delirium includes haloperidol, risperidone, or lorazepam (Mickelson et al., 2015). If all treatment fails and the patient is at severe risk of harm to themselves or others despite treatment and medication, it may be necessary to use restraints for short periods (Mickelson et al., 2015).

According to Centers for Medicare and Medicaid Services, physical restraint orders must be reassessed and limited to four hours in adult patients over 18 years old, two hours for patients between 9 and 17 years old, and 1 hour for patients under nine years old (Mickelson et al., 2015).

Cognitive impairment can be caused secondary to neurotoxicity from medications, secondary to neurological injury or scarring from CRT or surgery, by manifestations of emotional disorders such as anxiety or depression, or secondary to brain tumors or CNS metastasis (Daly & Brown, 2015). Cognitive disorders and long term therapy side effects are common among pediatric oncology patients (Daly & Brown, 2015). Between one to four out of five patients with acute lymphoblastic leukemia or brain tumors have residual neurocognitive dysfunction (Daly & Brown, 2015). Medical staff can assess cognitive deficits through the use of resources such as the Wechsler intelligence and memory scales, which have multiple tests for different age groups, Children's Memory Scale (CMS), Behavior Assessment System for Children (BASC-2), and the Behavior Rating Inventory of Executive Function Scales (BRIEF) (Daly & Brown, 2015). Patients should be assessed for cognitive impairment to connect them to treatment and services to reduce long term effects and low academic performance (Daly & Brown, 2015). Connection to educational services, therapy, community support groups, and cognitive remediation can help reduce the impacts of cognitive side effects on quality of life (Daly & Brown, 2015).

Chapter III

Theoretical Underpinnings

The supporting theoretical framework for this project is Johnson's Behavioral System Model for Nursing. This project's influences include classical developmental theorists, including Erickson, Piaget, and Kohlberg (Kidd & Rodgers, 2019; Duffy, 2019; Monroe, 2019; Rodgers, 2019; Deronin, 2019). Together with Johnson's Behavioral System Model, these theories will guide age-appropriate nursing care. Johnson (1980) outlined seven behavioral systems in her theory. These behavioral theories, balance of stability to instability, external regulatory forces, functional requirements, and structural factors combine to explain an individual's behavior (Johnson, 1980). The seven behavioral systems include (a) attachment/affiliative subsystem with social interaction, (b) dependency subsystem with the need for approval and need for help from others, (c) ingestive subsystem with eating and drinking, (d) eliminative subsystem with excretion, (e) sexual subsystem with sexual behavior, (f) aggressive/protective subsystem with defense, and (g) achievement subsystem with the need for control and success (Johnson, 1980). In Johnson's (1980) theory, functional requirements include protection, nurturance, and stimulation. Structural components include drive and goals, choices, actions, and behaviors (Johnson, 1980). Furthermore, external regulatory forces can effect each of these behavioral components and can create control and coping mechanisms (Johnson, 1980).

Johnson (1980) has four assumptions about each behavioral system: each system is related and structured, seeks homeostasis by changing with the environment, demonstrates significance to the patient's life, and each system reaches homeostasis from successfully evolving with the environment. A patient's family makes social influences on each behavioral system through acceptance, dependency, cultural expectations, or behaviors (Johnson, 1980). The theory outlines how the patient's environment can directly influence their behavior and potential causes of maladaptive behaviors. Understanding each subsystem's effect on the patient can help nurses individualize care plans and value social structure.

Poster and Beliz (2012) integrated Johnson's Behavioral System Model into the nursing care of 38 adolescents admitted to a neuropsychiatric hospital. The 38 adolescents were assessed over 12 months from admission and then weekly throughout hospitalization. The participants received a rating for each behavioral subsystem. The patients had a range of psychosocial disorders, including eating disorders, affective disorders, conduct disorders, schizophrenic disorders, borderline personality disorder, adjustment disorder, and organic disorders (Poster & Beliz, 2012). The mean overall scores in each behavioral subsystem showed significant improvement at discharge from the facility (Poster & Beliz, 2012). This study suggests that Johnson's Model helps identify areas that require care, and if incorporated into nursing assessment, it can improve adolescent psychosocial health outcomes.

Change Theory

Kotter and Cohen's Model of Change (2012) is a change theory that outlines eight steps in implementing change. The first step is communicating the need for change to staff to increase a sense of urgency. The second step is completing team selection by identifying staff members that will help implement change. The third step is discovering the correct strategy and vision. The fourth step is communicating with staff for buy-in by helping others see the need for change. The fifth step is empowering others so that change can occur freely. The sixth step is short-term successes to motivate staff to continue the changes. The seventh step is persistence until the change sticks by continuing the new behavior (Melnyk & Fineout-Overholt, 2019). Finally, the eighth step is to maintain sustained change and implement the changes through encouragement, recognition of improvement, and barrier management.

The implementation plan strategy follows the eight steps in the work of Kotter and Cohen (2012). The first step will be communicating to management and staff that there is a need for additional intervention to reduce psychosocial distress in pediatric oncology settings. When approaching management, presenting background data on the prevalence of psychosocial conditions in this patient population and feasibility will be important. Second, it will be necessary to identify staff members who support psychosocial care in pediatric oncology patients and influence the unit. These members will support the implementation plan and help in future steps. Third, communicate the change vision to consistently implement family-centered psychosocial care to reduce patient distress. Fourth, to generate staff, oncologists, and management buy-in, the data from the above keeper studies will be presented to illustrate the effectiveness of psychosocial care interventions on reducing patient distress. During this time of establishing buy-in, realistic techniques that staff can apply during standard patient care will provide the training they need to feel comfortable using psychosocial care techniques.

Next, the implementation plan will focus on the staff and management applying the program techniques during patient care. The fifth step will be empowering staff to implement these techniques during patient care and reducing barriers to those implementing the program techniques. Potential barriers to staff could be lack of "buy-in" by oncologists or management, staff feeling like they do not have the time to implement program techniques, patient and family not wanting to be a part of psychosocial care and poor communication. There must be clear communication between all team members and staff, reporting successes, clear expectations, and support to overcome project barriers. Presentation of the data from the keeper studies will be shown to management and oncologists to ensure "buy-in" with an opportunity for them to voice any concerns. Families and patients require information on family-centered psychosocial care and the above research to make informed decisions to incorporate program techniques into their care. Sixth, short-term successes will be established by setting short-term goals and encouraging staff to participate. Short-term goals will include progressive increases in staff implementation of the program techniques, eventually including all willing participants. With each successive decrease in patient anxiety or increase in staff implementation of the program techniques, the staff will receive verbal praise, support, and a visible report of successes (i.e., statistics on poster board where staff can see). Seventh, continued persistence by encouraging staff to implement psychosocial care techniques with all patients and recognize and manage any new implementation barriers. Eighth, sustain change and implementation of the program by recognizing staff successes and reducing barriers to change.

Chapter IV

This DNP project was intended to produce education and resources for pediatric oncology nurses to improve their knowledge and confidence in family-centered psychosocial care for pediatric oncology patients. This chapter describes the specifics of the project plan and needs assessment.

Project Plan

Population and Sample

The population of focus for this project is nurses caring for pediatric oncology patients. The sample from this population included nurses in the inpatient setting. Twenty-eight nurses participated.

Setting

The setting is a children's pediatric oncology inpatient unit located in the southwestern United States. The DNP student has approval and access to the pediatric oncology nursing staff at this location.

Measures, Instruments, and Activities

There was an initial baseline assessment of the pediatric oncology nurses' knowledge and confidence of psychosocial care, a presentation and provision of education and resources, and a post-intervention assessment of the nurses' knowledge and confidence. For this project, the assessments were completed pre-and post- the intervention (See Table H1). The researcher created the survey questions, and a content expert assessed surveys for content validity, trustworthiness, and credibility. Questions were evaluated for quality by Dr. Alan Ikeda, the medical director and primary Pediatric Hematologist/Oncologist at the study site, and Dr. Danielle Bello, licensed clinical psychologist and neurophysiologist for survivors of pediatric oncology treatment. These experts suggested minor verbiage changes for the surveys, and modifications were made.

The initial intervention utilized all data via the pencil-and-paper method. The assessments included Likert-type rating questions related to confidence (questions 1 through 4), allowing the participants to rate their confidence on a scale of 1 to 5 wherein 1 equals ‘strongly disagree’, 2 equals ‘disagree’, 3 equals ‘neutral’, 4 equals ‘agree’, and 5 equals ‘strongly agree’ (See Table H1). Data will remain in ordinal rank form for analysis. The knowledge assessment questions each had four possible response options (e.g., A, B, C, D; Questions 5 through 9) to test the subjects' content knowledge (See Table H1). Question responses will be summed to make up the knowledge assessment score with possible scores ranging from 0-4 with one point assigned for each correct item. In addition, two open-ended qualitative questions (numbers 10 and 11) allowed participants to write what they felt would help them or hinder them in utilizing psychosocial care practices (See Table H1). Ordinal data were converted to interval data to calculate scores for all instruments and facilitate parametric statistical analysis.

Five-point Likert Scale questions have been tested extensively and proven reliable and consistent with self-confidence ratings for nurses (Mazzo et al., 2015). Multiple-choice questions have been tested extensively and proven reliable and consistent with testing knowledge. This survey's questions followed accepted guidelines for forming multiple-choice questions (Brame, 2013). Likewise, the free-response questions were worded based on accepted guidelines for formulating a question (Brame, 2013). w

Timeline

The Institutional Review Board approval for the project was completed by the end of June 2021, followed by the development of the educational program and resources (See

Appendix I). Implementation of the program and resources were available to the nursing staff in July 2021. Data were collected, and statistical analysis was completed by December 2021. The analyses and final report for this project were completed in February 2022.

Project Tasks

Project tasks include the development of an educational presentation, including information from the literature review. The initial educational intervention for the inpatient nurses at the hospital included a PowerPoint presentation and physical resources for them to reference. The topics covered in this PowerPoint focused on anxiety/PTSD, depression/SI, EOL, and psychosocial side effects of treatment due to the limited number of educational seminars for the staff to provide the education. The complete program was created after assessing the survey and intervention to provide additional information to areas of need identified in the surveys. The complete program is comprehensive on all aspects of the literature review, including developmental and behavioral disorders. There are nine guides for assessing and treating patients with psychosocial conditions, including anxiety and PTSD, depression and SI, developmental and behavioral disorders, new diagnosis care, end of life care, cognitive behavioral therapy, trauma-informed care and family involvement, long term survivorship, and psychosocial side effects of treatment (Appendix K). Two additional mnemonic guides aid in psychosocial nursing care (Appendix K). These guides include education for the family and patient and information for the nursing staff to navigate difficult conversations with pediatric oncology patients.

Risks and Threats

Constraints or issues that may have negatively impacted the project's outcome would have been initial limitations on the intervention group size due to limited in-person contact from COVID-19 precautions. However, implementing the project presentation at the education seminar for all pediatric oncology staff members mitigated this risk. In addition, the author works at the hospital's pediatric oncology unit and has access to the unit and staff, which helped facilitate follow-up with staff members. Additional risks to the project are finding a platform for the online program to reach pediatric oncology nurses nationwide after completing this project for publishing. Collaboration with the Oncology Nursing Society (ONS) and Association for Pediatric Hematology/Oncology Nurses (APHON), which have online continuing education courses for pediatric oncology nurses, will reduce this risk.

Another limitation to the study would be that there is only one male nurse at the study site, which may not accurately reflect the proportion of male nurses within the field as a whole. The U.S. Bureau of Labor Statistics (BLS) reports 13.3% of registered nurses in the United States are male as of 2021 (U.S. Bureau of Labor Statistics [BLS], 2021). BLS reports that registered nurses in the United States are 74.9% Caucasian, 13.3% African American, 8.6% Asian American, and 8.8% Hispanic or Latinx (BLS, 2021). The study demographic statistics showed more Asian (25%) and Hispanic (10.7%) participants, and fewer Caucasian (60.7%) and no African American nurses who work at the study site. These demographic differences from the country average demographics for nurses are unavoidable for the study site, since this is the demographic background of all nurses at the site. Disseminating the implementation and presentation to nurses throughout the country could help to provide the study to a demographic which more closely reflected the average demographics in the United States.

Data Analysis

Descriptive statistics were used for demographic data, and the project evaluation data was displayed as frequencies and percentages. Parametric and non-parametric tests were used for knowledge and confidence assessments. While no inference or generalizability of these data is possible or intended, statistical analyses were conducted to mathematically demonstrate differences in the pre- and post-intervention of this project. This project's knowledge assessments (interval data) were analyzed using the paired t-test, and the confidence assessments (ordinal data) were analyzed using the Wilcoxon signed rank test. Qualitative responses were pooled, and responses were reported highlighting common themes.

Evaluation Plan

The program's evaluation was done with a paper-and-pencil survey consistent with the awarding of a continuing nursing education certificate from the Nevada Nurses Association. The project was monitored through assessment surveys (See Appendix H). Before the project presentation, the objectives and basis of the project were presented to the participants. Consent forms and a survey was given to each participant. After the presentation was complete, the same questions from the first survey were provided to the participants to assess for change. Consent forms, pre-and post-surveys were collected and stored for data analysis. Demographic data on the number of years of pediatric oncology nursing experience was collected through a question with ranges of years of experience at the top of the survey. Additional demographic data on race/ethnicity, sex, and highest-level of nursing degree earned was collected from data received from study site managers.

Paper surveys were collected pre-and post- the intervention presentation. These surveys were labeled with ID numbers one to 28, which allowed association of the pre-and post-survey from each participant to be connected for data analysis purposes. Data were input into Excel and SPSS 28 software directly from the paper surveys. Multiple choice question answers were coded as one for correct and zero for incorrect answers. For each survey, multiple-choice question answers were totaled for a total possible score of five for the five multiple-choice questions.

Likert scale questions were converted from ordinal five-point scale data into interval data by associating the response with numbers one to five based on the scaled answers. Likert scale question responses were totaled for each survey, for a total possible score of 20 for the four Likert questions. Paired t-testing was conducted on the multiple-choice questions from the pre- and post-test total scores. Cronbach alpha score analysis was run on the Likert scale questions pre-and post-test total scores. The Wilcoxon signed rank test was run on the Likert scale questions from the pre-and post-test total scores. Demographic data were analyzed using descriptive statistics by the percentage of total participants. Data analysis was verified through independent analysis of the raw data by a committee member. Her results are consistent with those presented.

Needs Assessment and Description of Problem

Key Stakeholders

Stakeholders include the nurses, Child Life specialists, oncologists, charge nurses, medical staff outside of the previously listed categories, the corporate office of the hospital, and the chief nursing officer. Stakeholders also included patients and their families, DNP committee members, and the University of Nevada Las Vegas (UNLV) School of Nursing (SON).

Assessment of Available Resources

Available resources for the project include committee member expertise, including Dr. Jennifer Pfannes, an expert in pediatric nursing, and Dr. Mary Bondmass's experience with continuing education accreditation, the project sponsor's connection to the pediatric oncology unit at the hospital, and project sponsor’s ONS and APHON membership. Resources available also include the UNLV Library and health science librarians.

Team Selection and Formation

This DNP project's committee team includes the project mentor and chair, Dr. Jennifer Pfannes, who has experience in pediatrics. Dr. Mary Bondmass has extensive experience in statistical analysis, nursing education, and nursing care. Dr. Carlton Craig is a licensed clinical social worker (LCSW) specializing in trauma-focused CBT for children and adolescents. Dr. Andrew Reyes is a UNLV SON faculty and an expert in psychiatric care and trauma-informed care.

Cost-Benefit Analysis

This project's only immediate financial costs are printing costs for participants' booklets of program information. Paper, ink, and folders were purchased for approximately $200 so that resources could be printed for the participants on the DNP student’s printer. There is also a $35 copyright fee for the project in Spring 2022. The project's potential benefits include improved nurse knowledge and practice confidence to improve patient outcomes.

Chapter V

Pediatric oncology patients and their families face severe stressors during and after treatment, but training and implementation of family-centered psychosocial care principles are lacking for many health care professionals. This DNP project was intended to develop education and provide resources for pediatric oncology nurses to improve their knowledge and confidence in family-centered psychosocial care of pediatric oncology patients. The results of this project's purpose are presented below in this chapter.

Results

Sample

Participants were predominantly female, non-Hispanic White, and had Bachelor's degrees in nursing. There was a bell curve type distribution to the number of years of experience as a nurse in pediatric oncology among the participants (Table 1).

Table 1

Demographic Data on Participants

	Total (*N=28*)	Percentage
Race/ethnicity		
Asian	7	25%
Hispanic	3	10.7%
Indian	1	3.6%
Non-Hispanic White	17	60.7%
Nursing Degree Attained		
Bachelors	25	89.3%
Associates	3	10.7%
Sex		
Female	27	96.4%
Male	1	3.6%
Years of Pediatric Oncology Experience		
0-11 months	3	10.7%
1-4 years	9	32.1%
5-9 years	9	32.1%
10+ years	3	10.7%
No Answer	4	14.3%

Cronbach alpha analysis of the Likert scale questions resulted in a score of 0.905, showing high internal consistency. There was a significant improvement in both knowledge (*$p<0.001$*) and confidence (*$p<0.001$*) from the pre- to post- scores of the participants. The Likert Scale questions showed a significant increase in nurse confidence to care for anxiety, depression, suicide, psychosocial side effects of treatment, and end-of-life care (Table 2). In addition, the knowledge questions showed a significant improvement in knowledge of psychosocial side effects of treatment (*$p<0.001$*) (Table 2).

Table 2

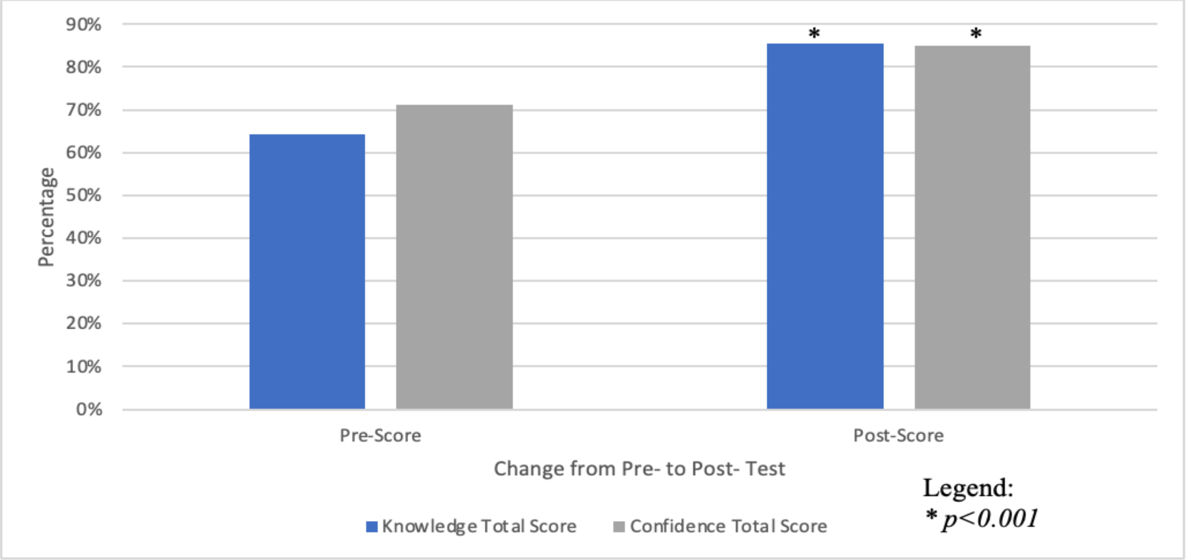
Knowledge and Confidence Assessment Scores

	Mean Pre-Total Score	Percentage	Mean Post-Total Score	Percentage	Significance	Cronbach Alpha
Knowledge	3.21	71.05%	4.82	85.05%	$p<0.001$	
Confidence	14.21	64.02%	17.07	85.60%	$p<0.001$	0.905

Note. Analyzed using SPSS 28. Wilcoxon signed rank test was used to analyze Confidence questions. Paired t-test uses to analyze Knowledge questions.

Figure 1

Comparison of Pre and Post Test Scores



Note. Scores were summed into total scores and converted into a percentage out of the possible highest total score.

Analysis of Item Responses

The primary response from participants in the pre-surveys that they felt would help them provide improved psychosocial care was increased staff education, second increased resources, and third more time with patients or improved nurse-to-patient ratios (Table 3). In the post-test, these answers varied slightly with increased availability of resources as the top response, second education, and third increased time with patients (Table 3). The primary response from participants in the pre-survey, which they felt prevented them from providing psychosocial care, was lack of education and lack of time with patients or poor nurse to patient ratios (Table 3). In the post-survey, the top barrier identified was lack of family support for the interventions and then lack of time with patients or poor nurse to patient ratios (Table 3)

Table 3

Helping to Improve Psychosocial Patient Care

	Pre-Test	Post-Test
Aids to Improve Care		
Education	13 (46%)	7 (25%)
Resources	6 (21%)	10 (36%)
Experience	3 (11%)	1 (4%)
Time with Patients/Ratios	4 (14%)	5 (18%)
Awareness	1 (4%)	-
Support/Collaboration	2 (7%)	3 (11%)
Child Life	1 (4%)	-
Protocols	1 (4%)	-
Barriers to Improve Care		
Lack of Education	8 (29%)	3 (11%)
Lack of Experience	4 (14%)	3 (11%)
Lack of Time/Ratios	7 (25%)	5 (18%)
Lack of Resources	4 (14%)	4 (14%)
Lack of Family Support	5 (18%)	7 (25%)
Personal Issues	-	1 (4%)

Note. Based on participants' free responses on surveys. Some participants wrote down multiple answers or concerns in their free-response questions.

Formal Evaluation by Participants for Continuing Education

Participants filled out standardized Continuing Education Unit (CEU) evaluation paper-and-pencil forms for this project after completion of the knowledge and confidence surveys in order to obtain CEU credit for the presentation. These CEU evaluation forms were provided by the Nevada State Board of Nursing who accredited the presentation. The first four questions were scaled rating of the quality of the presentation, rated as either excellent, good, fair, or poor in the quality. The four questions assessed the participants ratings of the presentation meeting course objectives (Question 1), the instructor's knowledge (Question 2), the instructor's presentation (Question 3), and the usefulness of the presentation to their current job (Question 4). There were two free response questions for listing two new concepts the participants learned from the job. Only 24 of the 28 participants filled out the CEU evaluation forms.

Survey results were recorded in an Excel from the paper evaluation forms and then analyzed using descriptive statistics for percentages out of the total number of participants. For the first four questions, only one participant rated “good” for the extent to which the course objectives were met, and all other participants rated excellent for all of the first four rating questions (Table 4).

Table 4

CEU Evaluation Quality Results

Question (*N=24*)	Excellent	Good	Fair	Poor
1	95.8%	4.2%	-	-
2	100%	-	-	-
3	100%	-	-	-
4	100%	-	-	-

In the free response question about the two new concepts learned, one participant did not answer these questions and three only listed one concept which was learned for a total of 43 responses from the 24 participants. The primary response that participants listed were side effects of treatment which they had not previously known (Table 5). The second most common response was about the resources provided, and third most common were the rescue treatments for neurotoxicity (Table 5). These results further underline the gained knowledge of psychosocial side effects of treatment and the value placed on the resources by the participants.

Table 5

CEU Evaluation Concepts Learned

State 2 New Concepts you Learned *(N=43)*	Frequency	Percentage
Side Effects of Treatment	18	41.8%
Resources	7	16.3%
Toxicity Rescue Medications	6	14%
End of Life Care	5	11.6%
CBT and Techniques	3	7%
Depression Can Be a Side Effect of Treatment	3	7%
National Anxiety and Depression Diagnostic Tools	1	2.3%

Chapter VI

Discussion

This chapter presents a discussion of the results of this project which was intended to increase knowledge and confidence. The purpose of this Doctor of Nursing Practice (DNP) project was to develop, implement, and evaluate a sustainable program for pediatric oncology nursing staff to increase their knowledge and confidence of family-centered psychosocial care principles with the intent to improve patient care and reduce patient suffering. Giving meaning to the project, implications for nursing practice, sustainability, and dissemination of results are presented herein.

Giving Meaning to the Project

Results of the Project and Relationship to Evidence in Theory Underlying the Project

The data analysis showed that this DNP project's resources, presentation, and implementation significantly improved nurse confidence in their ability to provide psychosocial care and their knowledge of psychosocial side effects of treatment. In addition, the systematic review of the literature provided evidence that the psychosocial care principles presented during implementation significantly improved patient psychosocial conditions and outcomes.

Johnson’s behavioral model provided a foundational understanding of the many needs patients for the formation of the presentation. Understanding of these behavioral systems allows nurses to identify and care for all aspects of their patients in order to help patients focus on healing and homeostasis with their environment. Kotter and Cohen’s model of change informed the implementation of the project. The change steps allowed successful implementation, staff buy in, and unit wide changes as a result of the project’s implementation.

The Degree to Which the Project Addressed the Problem Identified

The problem identified was a lack of family-centered psychosocial care resources, education, and implementation within nursing care for pediatric oncology patients and their families. The project addressed this problem by generating and providing 11 resources, including two mnemonic resources to help guide conversations and education, in addition to a comprehensive systematic review of family-centered psychosocial care principles for pediatric oncology nurses. In addition, education was provided to the pediatric oncology nurse participants on psychosocial care principles. Data analysis showed a significant improvement in nursing confidence to implement knowledge of psychosocial care principles.

Implications for Nursing Practice

How the Project Advanced or Improved Nursing Practice or Patient Outcomes

By improving nursing knowledge in psychosocial side effects of medications and the treatments for adverse reactions, nurses can be better prepared to identify, notify, and care for patients to prevent adverse outcomes. By improving nursing confidence in providing psychosocial care to their patients and their families, nurses can be empowered and feel better prepared to provide EBP care interventions that improve patient outcomes. The resources and literature review are sustainable and tangible ways for nurses to refresh and review to improve their practice. This project helped to improve the quality of the care provided by pediatric oncology nurses who participated by increasing their confidence in applying psychosocial care principles, the knowledge of assessment, identification, risks, side effects, management, and treatment of psychosocial care.

Potential for Sustainability

Utilization and Dissemination of the Results

Nursing staff who participated in this project utilize the resources and education in their practice. Numerous nurses have voiced their appreciation of the education in subsequent weeks. Multiple staff members were excited to identify side effects of treatment, which they had not realized were potentially caused by the patient's treatment prior to the intervention. They used that knowledge to reach out to the physician for intervention orders. They also felt more confident in their assessment for psychosocial conditions, such as depression and anxiety, and felt better empowered to voice their assessment to the physicians. Before implementation of the project, there were no therapy services or psychiatry providers at the study site. Since implementation, a pediatric psychiatrist has been hired at the study site and is beginning to see patients. The physicians at the project site have also noted plans to hire therapists and psychiatrists to come and visit the patients at the study site.

Survey results were provided to the nurse in charge of the pediatric oncology program at the study site. The participant reported barriers and aids to improving psychosocial care were discussed. Management plans to help provide more education, resources, and alleviate other concerns identified in the study results. Study results will also help improve and add to future projects, such as methods to help reduce family resistance to the identified interventions. After the implementation, five additional resources were generated to provide further education and address the identified barriers to providing psychosocial care (Appendix K).

Plan for Dissemination of Results and Future Scholarly Activity Resulting from this Project

Additional literature reviews or resource generation are possible to add to this project as new research is published. The comprehensive program can provide the education, resources, and improvements in this project to pediatric oncology nurses throughout the country. Plans can include making the program available to numerous nurses across the country through online platforms such as the APHON or ONS CEU websites. In addition, the results of this project will be disseminated to national publishing groups to obtain publication of the study so that this information can be provided to pediatric oncology nurses across the nation.

Appendix A: Search Tables for Treatment

Table A1

CINAHL Search

Search Term	Treatment	Therapy	Pediatric oncology	Children with cancer	Anxiety	PTSD	Depression
	176,284	188,688	719	1245	23460	6,158	35,666

Combination of Terms	1 AND 3 AND 5	1 AND 3 AND 7	1 AND 3 AND 8	2 AND 3 AND 5	2 AND 3 AND 7	2 AND 3 AND 8	1 AND 4 AND 5	1 AND 4 AND 7	1 AND 4 AND 8	2 AND 4 AND 5	2 AND 4 AND 7	2 AND 4 AND 8
Results	42	12	25	26	3	17	70	21	42	45	9	29

Table A2

Pubmed Search

Search Term	Treatment	Therapy	Pediatric oncology	Children with cancer	Anxiety	PTSD	Depression
	529,672	496,057	6587	12795	25720	3,093	35,597

Combination of Terms	1 AND 3 AND 5	1 AND 3 AND 7	1 AND 3 AND 8	2 AND 3 AND 5	2 AND 3 AND 7	2 AND 3 AND 8	1 AND 4 AND 5	1 AND 4 AND 7	1 AND 4 AND 8	2 AND 4 AND 5	2 AND 4 AND 7	2 AND 4 AND 8
Results	88	8	58	80	6	52	174	15	146	152	11	130

Table A3

Ovid Medline Search

Search Term	Treatment	Therapy	Pediatric oncology	Children with cancer	Anxiety	PTSD	Depression
	110538	110477	1609	1400	5335	2864	11343

Combination of Terms	1 AND 3 AND 5	1 AND 3 AND 7	1 AND 3 AND 8	2 AND 3 AND 5	2 AND 3 AND 7	2 AND 3 AND 8	1 AND 4 AND 5	1 AND 4 AND 7	1 AND 4 AND 8	2 AND 4 AND 5	2 AND 4 AND 7	2 AND 4 AND 8
Results	2355	1325	2435	2325	1283	2470	2411	2806	2541	2417	2766	2503

Table A4

Cochrane Reviews and Trials Search

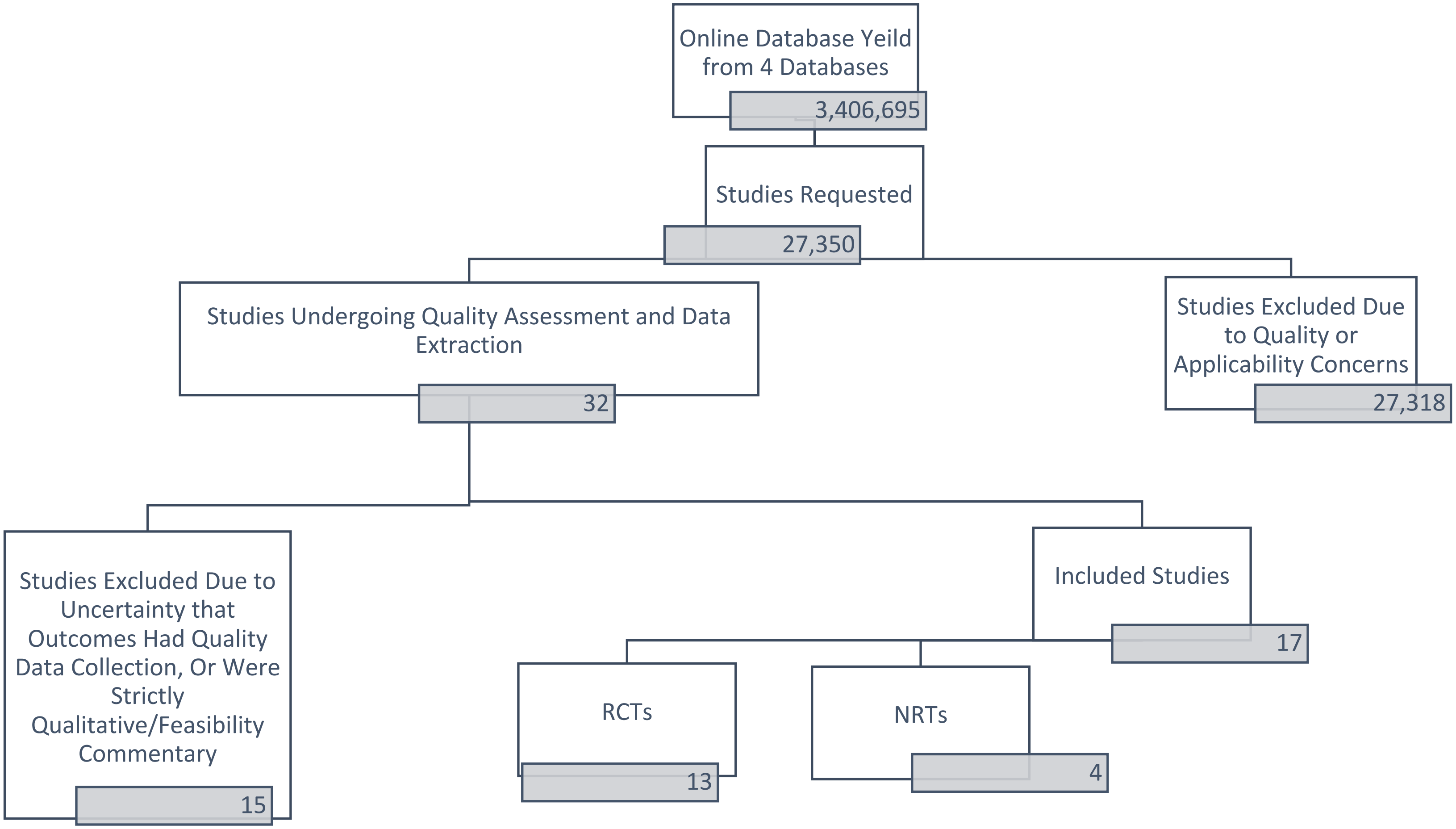
Search Term	Treatment	Therapy	Pediatric oncology	Children with cancer	Anxiety	PTSD	Depression
	778,357	695,188	1062	4663	50661	4400	87057

Combination of Terms	1 AND 3 AND 5	1 AND 3 AND 7	1 AND 3 AND 8	2 AND 3 AND 5	2 AND 3 AND 7	2 AND 3 AND 8	1 AND 4 AND 5	1 AND 4 AND 7	1 AND 4 AND 8	2 AND 4 AND 5	2 AND 4 AND 7	2 AND 4 AND 8
Results	49	2	29	42	2	21	186	13	167	11	154	147

Appendix B: Search Process for Treatment

Figure B1

Search Process



Note. (Thompson et al., 2007)

Appendix C: Evidence Table for Treatment

Table C1

Evidence Table

Treatment of Anxiety, PTSD, and Depression in Pediatric Oncology Patients

Citation	Sampling/Setting	Research Design	Data Analysis	Study Findings	Comments
Abdulah & Adbulla, 2018	Heevi Paediatric Hospital in Duhock/61 participants from the Duhok General Directorate of Health	RCT	HRQoL, Independent t-test using SPSS version 24.0.0, G*Power 3.1.9 statistical software, descriptive statistics	Depressive mood: Study (Mean SD 4.60), Control (Mean SD 6.27), *p=0.003,* Cohen's d=0.80	One patient in the experimental group passed away before completing the study.
Altay et al., 2017	Gazi University Health Sciences Hospital/30 participants	NRT	Descriptive statistics, SPSS 17, Kolmogorov-Smirnov test, Wilcoxon test	Anxiety: Pre intervention (Mean SD 42.63±4.64), Post intervention (Mean SD 38.63±4.38), *p=0.001*	The program occurred over 5 days. There was no control group.
Cheung et al., 2018	Children's home/ 60 participants	RCT	SPSS version 23.0, descriptive statistics, independent t-	Depressive Symptoms: Study (Mean SD at T1=20.60, Mean	The control/placebo group had weekly 45-minute home visits where they participated in

			test, chi-squared tests, ANOVA, Tukey test	SD T2=16.27, Mean SD at T3=15.03), Control (Mean SD T1=20.43, Mean SD T2=21.10, Mean SD T3=21.47), p value (T1=0.930, *T2=0.009, T3=0.000)*	leisure activities instead of the musical training. Both groups were given a pamphlet about mental health at the beginning.
Gothelf et al., 2005	Pediatric Hematology-Oncology Center of Schneider Children’s Medical Center of Israel/15 participants	NRT	ANOVA, Tukey test	*Adjusted CDRS-R scores: Baseline (Mean SD 41.71±9.51), 8 weeks (Mean SD 17.21±13.84), p value <0.001* *PARS: Baseline (Mean SD 13.0±4.30), 8 weeks (Mean SD 5.80±3.49), p value<0.05*	Two patients had been receiving clonazepam for insomnia before starting the study and both showed improvement. One patient stopped the study after 3 days due to poor compliance with taking the fluvoxamine.
Hagstrom et al., 2020	Children's University Hospital in Uppsala and a Stockholm psychology practice/10 participants	NRT	CONSORT, descriptive statistics, qualitative analysis	CBT reduces anxiety and PTSD symptoms in pediatric oncology survivors. *MADRS-S: baseline (mean*	Researchers noted difficulty in recruiting patients. No control group. Patients were compared to their baseline assessments.

				17, SD 6.2), post (Mean 10.9, SD 7.6), follow up (mean 9.8, SD 9.8) *Beck Anxiety Inventory: baseline (mean 14.6, SD 16.5), Post (Mean 7.9, SD 6.5), Follow up (Mean 6.1, SD 8.0)* *PTSD Checklist-Civilian Version: baseline (mean 37.0, SD 14.2), post (Mean 27.1, SD 8.1), follow up (mean 27.4, SD 11.7)* *Short Health Anxiety Inventory: baseline (mean 14.8, SD 4.6), post (Mean 11.7, SD 4.6), follow up (mean 8.0, SD 3.2)*	
Kazak et al., 2004	Children's Hospital of Philadelphia/	RCT	Independent t test, chi square, MANOVA,	SCCIP initially showed no significant	Only four sessions on one day for patients.

	150 participants		SPSS, StatXact, SOLAS	reduction in anxiety or PTSD symptoms, but did significantly reduced hyperarousal on 3-5 month measurement in pediatric oncology survivors. At T1, there was no significant reduction in anxiety (p=0.14). No significant reduction in intrusion, avoidance, or PTSD-RI total score *From T1-T2: patient hyperarousal levels vs control (M=2.72 vs M=1.14, p<0.01)*	
Klosky et al., 2004	St. Jude Children's Research Hospital/79 participants	RCT	Fisher's exact tests, RM-ANOVA	STARBRIGHT significantly reduced HR, but did not reduce observed	Only a single exposure to CBT Barney toy

				behavioral distress, for pediatric oncology patients receiving radiation therapy. *Total treatment HR decreased study vs control ($p<0.05$)* No significant reduction in observed behavioral distress	
Li et al., 2011	Hong Kong paediatric oncology unit/122 participants	RCT	SPSS 16.5, independent t-test, chi-squared test, ANOVA	State Anxiety scores: main effect for intervention p value=0.07 *State Depressive symptoms score: main effect for intervention p value=0.02*	Some participants refused to participate in play intervention after receiving chemotherapy.
Liossi & Hatira, 1999	30 participants	RCT	Wilcoxon matched-pairs signed-ranks test	Cognitive-behavioral therapy and hypnosis reduced self-reported anxiety and self-	They did not use imagery in the CBT group to prevent overlap with the hypnosis group.

				reported pain in pediatric oncology patients undergoing bone marrow aspiration. CBT: *Self-reported anxiety* $z=-2.03, p=0.04$. *self-reported pain* $z=-2.665, p=0.008$. *observed distress* $z=-2.52, p=0.012$ *Hypnosis: Self reported anxiety* $z= -2.803, p=.005$ *Observed distress* $z= -2.803, p=.005$	
Liu et al., 2019	Liaocheng People's Hospital/101 participants	RCT	SPSS, Student's t-test, chi-square test	Mindfulness stress reduction therapy and music therapy significantly reduced anxiety in pediatric oncology patients. *HAM-A: study (before* 21.4 ± 1.4*, post* 17.2 ± 1.6*,* $p=0.000$*), control (before* 21.2 ± 1.5*,*	The researchers noted that they would want additional studies with multiple control groups to isolate which aspects of their interventions were most effective.

				post 20.6±2.3, p=0.144)	
Rosenberg et al., 2018	Seattle Children's Hospital/92 participants	RCT	Unadjusted linear regression model, Cohen's d, Stata 14	PRISM CBT significantly reduced Kessler-6 global distress and anxiety and improved resilience. There was no significant improvement of HADS-A measure of anxiety. At 6 months, post-intervention: Anxiety HADS-A (β0.36, p=0.24) *Global Psychological distress Kessler-6 (β-2.1, p=0.03)* *Cancer-specific quality of life (β9.6, p=0.01)* *Resilience (β3.0, p=0.02)*	PRISM is an English only program, and its effectiveness for non-English speaking patients was not tested. Only four sessions.
Seitz et al., 2014	Multiple locations/28 participants	NRT	Student's t-test, Bonferroni-corrected alpha-	Onco-STEP with 10 CBT writing sessions, 2	No control group. Eight participants did not complete the

			level of 0.025. RM-ANOVA, Cohen's d, and reliable change indices	modules, and internet-based psychologists who conducted two 45 minute sessions each week. *Post-traumatic stress symptoms pre-treatment M15.30, post treatment M 10.10, $p<0.001$. HADS-A anxiety pretreatment M 10.10, post-treatment 6.95, $p=0.003$ Short form fear of progression/relapse pretreatment 35.60, posttreatment 31.40, $p=0.046$*	intervention, and six did not participate in the 3 month follow up.
Shoshani et al., 2016	Make a Wish Israel/66 participants	RCT	RM-ANOVA, Bonferroni correction, Cohen’s D, SPSS Missing Value Analysis, MCAR test	*Depression: Study (Mean SD T1 1.03, Mean SD T2 0.68, $p<0.001$),* Control (Mean SD T1 0.97, Mean SD T2 1.12, $p=3.04$)	The control group were children waiting for their Make a Wish to be fulfilled.

				Anxiety: Study (Mean SD T1 1.01, Mean SD T2 0.79, p<0.001), Control (Mean SD T1=0.98, Mean SD T2=1.15, p=0.114)	
Tahmasebi et al., 2017	Seyed-al-Shohada Hospital in Isfahan, Iran/65 participants	RCT	Independent t-test, paired t-test, Chi-squared test, Mann-Whitney test	This study showed a reduction in depression in both the control and study groups. The intervention group also showed significantly lower depression compared to the control group. Mean score of depression: Before intervention- study(Mean 20.3), control (mean 20.2), p=0.91	The control group still participated in painting, but not in the group setting.

				after intervention- Study (Mean 25.7), Control (Mean 9.9), $p<0.001$ *P value of* <0.001 *for both the control and intervention groups*	
Tsai et al., 2013	Medical center in Taiwan/19 participants	RCT	Independent t test, dependent t test, ANOVA	Therapeutic play, implementing CBT techniques, significantly reduces anxiety and stress in pediatric oncology patients receiving radiation therapy. *Faces anxiety scale (*$p=0.05$*): study (before 2.44±1.59, post 1.89±0.93),* control (before 2.60±1.07, post 3.00±1.33) *Beck Youth Anxiety*	The study did include children as young as 3 years old. They also included peer interaction.

				Inventory: study vs control (p=0.01) *Salivary cortisol concentration (p=0.02): study (before 6.68±5.40, post 2.75±2.18),* control (before 4.88±4.90, post 2.53±0.85) *Heart Rate variability: study versus control (p=0.05)*	
Van Dijk-Lokkart et al., 2013	Various hospitals throughout the Netherlands/ 68 participants	RCT	Independent t-test, Mann-Whitney, chi-square, multivariate regression analysis	CBT with physical exercise significantly reduced parent-reported procedural anxiety for pediatric oncology patients. Patient self-report showed no significant change in procedural anxiety. *Parent-reported*	Only six sessions, one every two weeks. Two sessions for parents of participants.

				procedural anxiety at short term follow up ($p<0.025$, β12.6, [1.9;23.3], CI 95%). Patient self-report procedural anxiety no change at short term follow up (β-0.5)	
Zhang et al., 2019	Children's Hospital of Chongqing Medical University/106 participants	RCT	EpiData 3.0, SPSS, repeated t-test, chi-square, Mann-Whitney	CBT and training significantly reduced anxiety and stress for pediatric oncology patients. Anxiety: *Study (5.83±3.07),* control (8.66±4.92) Stress: *Study(7.51±4.33)*, control (11.17±4.25) *$p<0.05$ for all criteria*	The intervention was tested at only one hospital with patients over 8 years of age

Note. RCT, randomized controlled trial; NRT, non-randomized trial. PARS, pediatric anxiety rating scale; CDRS-R, children's depression rating scale-revised, MADR-S, Montgomery Asberg Depression Rating Scale-Self Assessment; HADS-A, Hospital Anxiety and Depression Scale-Anxiety; HAM-A, Hamilton Anxiety Rating Scale. (Melnyk & Fineout-Overholt, 2019)

Appendix D: Synthesis Table for Treatment

Table D1

Synthesis Table

Treatment of Anxiety, PTSD, and Depression in Pediatric Oncology Patients

Study Author	Year	Number of Participants	Mean age (or other sample characteristic)	Study Design	Intervention	Major Findings and Direction of Outcome
Abdulah & Abdulla	2018	60	Mean age: experimental (9.75yo), Control (9.47yo) Sex: experimental (36.7% male), control (46.7% male)	RCT	Artist guided 20 two-hour painting and handcrafting sessions (5 days a week for 4 weeks).	↓D
Altay et al.	2017	30	Mean Age: 12.56yo Sex: Female 76.7%, Male 23.3%	NRT	5 days of therapeutic writing with the patient, their parents, and researcher in the patient's room where the patient drew, wrote, and participated in mutual storytelling.	↓A
Cheung et al.	2018	60	Mean age: study (13.97yo), control (12.53yo) Sex: Study (60% male, 40% female), control (56.7%	RCT	Study received 45-minute musical training for 52 weeks. The control received 45-minute leisure activities for 52 weeks.	↓D

			male, 43.3% female)			
Gothelf et al.	2005	15	Mean age: 14.8yo Sex: Female 53.33%, Male 46.67%	NRT	Fluvoxamine 25 mg/day raised in increments of 25 mg every 2-3 days to a fixed dose of 100 mg/day	↓D ↓A
Hagstrom et al.	2020	10	Mean age at cancer dx: 15.9yo Sex: 40% female, 60% male	NRT	Max of 15 CBT sessions for pediatric cancer survivors from 17-25yo. Pre, post-, and 3 month follow up questionnaires.	↓A ↓D ↓PTSD
Kazak et al.	2004	150	Mean age: 14.32yo Sex: 51% female, 49% male	RCT	SCCIP (CBT and family therapy) over four sessions on a single day. Follow up at post-intervention (T1) and 3-5 months post-intervention (T2)	—A ↓ Hyperarousal
Klosky et al.	2004	79	Mean age: 4.2yo	RCT	STARBRIGHT CBT intervention with single exposure (Barney character, education, and auditory distraction)	—A ↓HR
Li et al.	2011	122	Mean age: study (11.6yo), control (12.1yo) Sex: study (53.85% male, 46.15% female), control	RCT	30 minute therapeutic play intervention using a virtual reality computer 5 days during one week	↓D —A

			(52.86% male, 47.14% female)			
Liossi & Hatira	1999	30	Mean age: 8yo	RCT	Two 30 minute sessions of CBT with relaxation training, breathing exercises, and cognitive restructuring, 5 days before bone marrow aspiration. Separate group had two 30 minute sessions of “hypnosis’ which included relaxation techniques and guided imagery 5 days before bone marrow aspiration.	↓A
Liu et al.	2019	101	Mean age: Study (15.9 yo) Control (16.2 yo) Sex: Study (female 37.7%, male 62.3%) Control (female 39.1%, male 60.9%)	RCT	Mindfulness-based stress reduction and music therapy every week for eight weeks. MBSR included education on mindfulness of emotions, thoughts, breathing, and how to face and process negative emotions	↓A
Rosenberg et al.	2018	92	Age: Study and control (12-17yo 73%, 18-25yo 27%)	RCT	PRISM (4 sessions 30-50 minutes long every other week. CBT techniques. Optional 5th session with loved ones.	—A by HADS-A ↓A by Kessler-6 —D

			Sex: Study (55% female, 45% male) Control (33% female, 67% male)		training delivered by non-clinical nursing staff with bachelor's degrees)	
Seitz et al.	2014	28	Long term pediatric cancer survivors: Mean age: 27.25±4.83yo 70% female	NRT	Onco-STEP program online with 10 writing sessions in two modules, and 45 minute online psychotherapy sessions twice a week	↓A ↓D ↓PTSD
Shoshani et al.	2016	66	Mean age: study (10.13yo), control (10.67yo) Sex: study (62.9% male), control (55.9% male)	RCT	The study group received their Make a Wish intervention. The control group were waiting for their Make a Wish to be completed.	↓D ↓A
Tahasebi et al.	2017	65	Ages: 7-12 years old No descriptive data provided. P values were not significant for age, gender, cancer type, education, or living conditions for the control and intervention groups.	RCT	Six group sessions of water color painting for 25 minutes, and then the patient's explained their paintings to the group. The control group also had painting supplies but were given supplies to paint in their rooms.	↓D
Tsai et al.	2013	19	Mean age: Study (8-12yo) Control (8-9yo) Sex: 100% male (control group),	RCT	Therapeutic play with CBT training (cognition change and desensitization) every day 5 days a week,	↓A, salivary cortisol, HR

			44.44% male and 55.56% female (study group)		token strategy (reward stickers), and recreational strategies (play distraction)	
Van Dijk-Lokkart et al.	2016	68	Mean age: Control (12.6yo), Study (13.0yo) Sex: 53% male (control and study), 47% female (control and study)	RCT	CBT (child sessions of 60 minutes once every 2 weeks for 12 weeks, and two-parent sessions at the start and end) combined with physical training (45 minutes each twice a week) for 12 weeks	↓A
Zhang et al.	2019	104	Age: Control (8-12yo 54.72%, 13-18yo 45.28%) Study (8-12yo 58.49%, 13-18yo 41.51%) Sex: Control (47.17% male, 52.83% female) Study (50.94% male, 49.06% female)	RCT	CBT over five weeks, Wechat platform to talk to other parents, psychotherapy, journaling, relaxation techniques	↓A ↓D

Note. A, Anxiety; D, Depression; PTSD, post-traumatic stress disorder; CBT, Cognitive behavioral therapy; RCT, Randomized Controlled Trial; NRT, non-randomized trial; ↓, decreased; ↑, increased; —, no effect. (Melnyk & Fineout-Overholt, 2019)

Appendix E: Search Tables for Long Term Survivorship

Table E1

CINAHL Search

Search Term	Long term survivorship	Survivor	Pediatric oncology	Childhood cancer	Anxiety	PTSD	Depression
	345	110,587	20,427	9,815	286,407	60,610	380,136

Combination of Terms	1 AND 3 AND 5	1 AND 3 AND 6	1 AND 3 AND 7	2 AND 3 AND 5	2 AND 3 AND 6	2 AND 3 AND 7	1 AND 4 AND 5	1 AND 4 AND 6	1 AND 4 AND 7	2 AND 4 AND 5	2 AND 4 AND 6	2 AND 4 AND 7
Results	0	0	0	50	28	92	0	0	0	76	48	158

Table E2

Pubmed Search

Search Term	Long term survivorship	Survivor	Pediatric oncology	Childhood cancer	Anxiety	PTSD	Depression
	3,562	99,457	119,345	38,578	228,147	41,989	447,388

Combination of Terms	1 AND 3 AND 5	1 AND 3 AND 6	1 AND 3 AND 7	2 AND 3 AND 5	2 AND 3 AND 6	2 AND 3 AND 7	1 AND 4 AND 5	1 AND 4 AND 6	1 AND 4 AND 7	2 AND 4 AND 5	2 AND 4 AND 6	2 AND 4 AND 7
Results	16	1	15	189	61	228	20	4	20	237	102	285

Table E3

Ovid Medline Search

Search Term	Long term survivorship	Survivor	Pediatric oncology	Childhood cancer	Anxiety	PTSD	Depression
	460	6,254	3,799	3,095	7,569	2,903	11,837

Combination of Terms	1 AND 3 AND 5	1 AND 3 AND 6	1 AND 3 AND 7	2 AND 3 AND 5	2 AND 3 AND 6	2 AND 3 AND 7	1 AND 4 AND 5	1 AND 4 AND 6	1 AND 4 AND 7	2 AND 4 AND 5	2 AND 4 AND 6	2 AND 4 AND 7
Results	3,158	967	3,895	1,943	1,452	2,773	2,921	1,038	2,599	2,182	1,386	3,035

Table E4

Cochrane Reviews and Trials Search

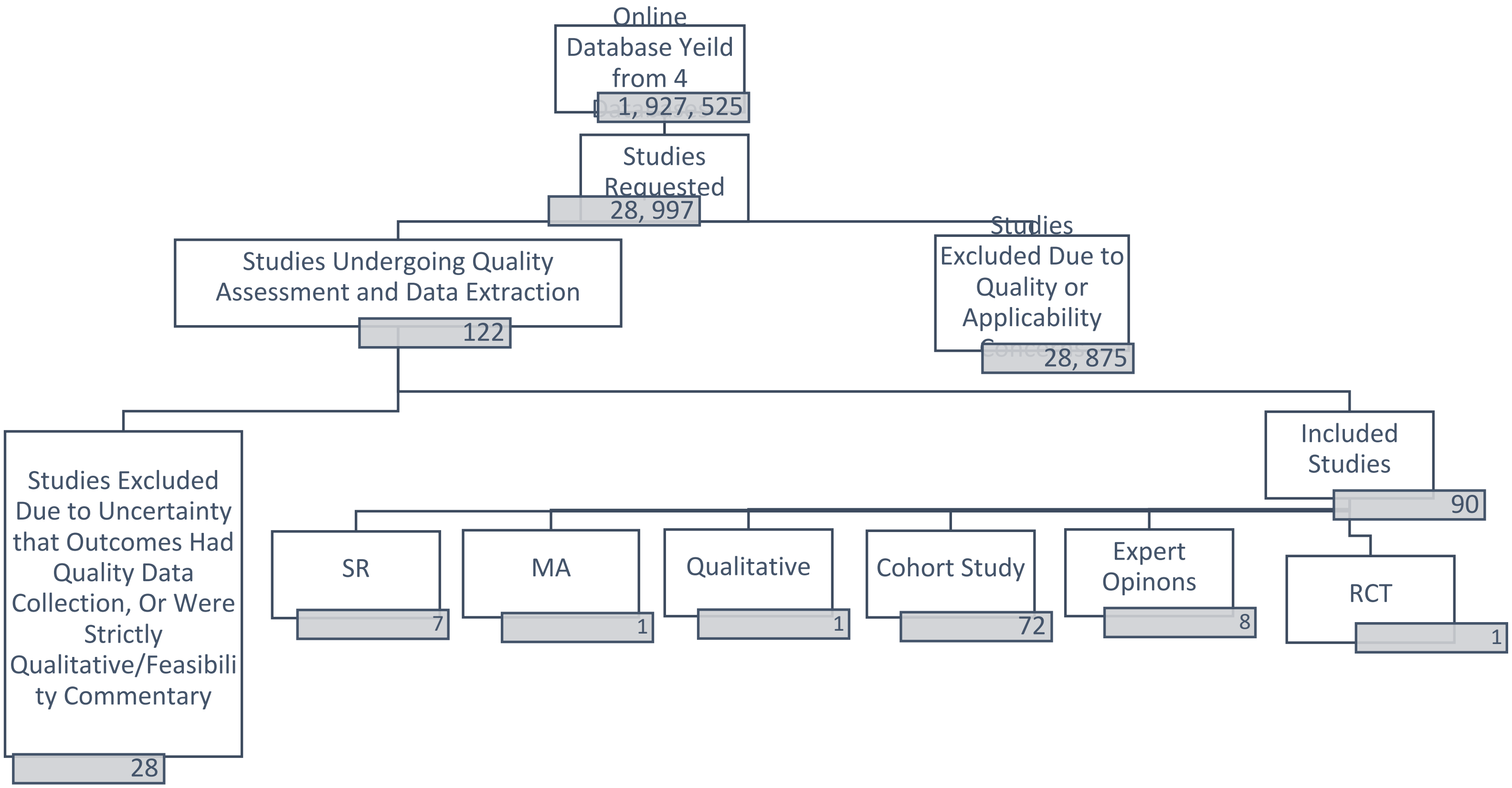
Search Term	Long term survivorship	Survivor	Pediatric oncology	Childhood cancer	Anxiety	PTSD	Depression
	4	5,220	45	660	30,822	40	46,601

Combination of Terms	1 AND 3 AND 5	1 AND 3 AND 6	1 AND 3 AND 7	2 AND 3 AND 5	2 AND 3 AND 6	2 AND 3 AND 7	1 AND 4 AND 5	1 AND 4 AND 6	1 AND 4 AND 7	2 AND 4 AND 5	2 AND 4 AND 6	2 AND 4 AND 7
Results	0	0	0	8	0	0	0	0	0	0	0	8

Appendix F: Search Process for Long Term Survivorship

Figure F1

Search Process



Note. (Thompson et al., 2007)

Appendix G: Evidence Table for Long Term Survivorship

Table G1

Evidence and Synthesis Table

Long Term Survivorship in Pediatric Oncology Patients

Study Author	Sampling/Setting	Research Design	Assessment Tools	Study Findings	Comments
Allen et al., 2017	St. Jude Lifetime Cohort- n=3090	Cohort	PTSD Checklist	Mean score of 27.7 on PTSD checklist- close to the rest of US population. 1/8 CCS have PTSS. Higher PTSS in females and those with lower education	Conducted only from St. Jude Children's Hospital patients
Ander et al., 2018	Uppsala and Stockholm, Sweden. Swedish Childhood Cancer Registry, n=10	Qual	Interviews	Difficult treatment, loss of control, marked and "otherized", low self-esteem, emotional difficulties, making meaning	Only 10 participants, location of interview may have affected results
Anderson & Woods, 2020	NA	Expert Opinion	NA	Early screening and pain management should be implemented for survivors of pediatric cancers	Expert opinion and not clinical research
Arpawong et al., 2013	Children's Hospital of Los Angeles, Miller Children's Hospital, C.S. Mott Children's Hospital.	Cohort	PedQL, Life Orientation Test-Revised, Center for Epidemiological Studies Depression Scale, Intensity of Treatment	PTG correlation to psychological functioning and PTSS, negative correlation to depression and PA	Only English-speaking children were chosen

	Phone or in-person interviews. n=94		Rating Scale, PTSD Reaction Index, PTG inventory		
Barakat et al., 2000	Mailed surveys to families on tumor registries on the east and west coasts in USA, N=56 CCS, n=65 mothers of CCS	Cohort	PTSD Reaction Index, Impact Events Scale, Assessment of Life Threat and Treatment Intensity Questionnaire, Life Events Scale, Life Experiences Survey, Child Behavior Checklist, Brief Symptom Inventory,	Early PTSS correlated to issues in long term adjustment	No overall PTSD Reaction index score, paid their participants
Barlow et al., 2020	Childhood Cancer Survivor Study, N=12,123 CCS, 720 siblings	Cohort	Behavioral Risk Factor Surveillance Survey, CCSS-Neurocognitive Questionnaire, Common Terminology criteria	CCS less PA, decreased self report of Task Efficiency, Emotional Regulation, Memory. Consistent PA associated with less neurocognitive problems.	Potential for neurocognitive problems leading to decreased PA and not the other way around
Barrera & Atenafu, 2008	N=46 HSCT survivors and 33 siblings	Cohort	Wechsler Intelligence Scale for Children Third	Survivors had significantly higher perceptual organization, internalizing problems, lower QOL, lower spelling scores, higher arithmetic and reading.	Small group of participants at only 2 years post HSCT

			Edition, Child Health Questionnaire, Child Behavior Checklist, Developmental Test of Visual Motor Integration, Wide Range Achievement Test, Family Adaptability and Cohesion Evaluation Scale	Family cohesion related to cognitive and educational differences. HL, neuroblastoma, and CRT lead to higher internalizing scores.	
Beyea et al., 2020	N=11842 survivors and 59210 controls, Ontario, Canada	Cohort	Assistive Devices Program (ADP) participants	Highest rates of hearing loss in neuroblastoma and hepatoblastoma, > 32 Gy CRT, >200mg/m2 of cisplatin	Only includes those who used the ADP in Ontario, Canada
Bhatia et al., 2015	Childhood Cancer Survivor Study	MA	Common terminology criteria	Increased rates of SMN, late mortality, endocrine disease, neuromuscular disorders, CVD, and chronic disease burden	Rates of chronic conditions, need further discussion about prevention, screening, and care to decrease disease burden
Bowers et al., 2013	Medline and Embase	SR	Rates of subsequent neoplasms	SMN in CNS nearly all had CRT, higher incidence of SMN in CNS survivors compared to non-CNS survivors	There is lack of literature for screening protocols for CNS SMN
Brackett et al., 2012	N=109 medulloblastoma survivors	Cohort	CCSS Neurocognitive Questionnaire	“GSTM1 gene deletion associated with greater distress”	Needed examination of antioxidant pathways

	and 143 siblings from Childhood Cancer Survivor Study		and Brief Symptom Inventory-18, buccal DNA samples		
Brinkman et al., 2018	NA	Expert Opinion	NA	Increased risk of delayed psychosocial development, socioeconomic attainment, worse physical functioning	Expert opinion and not clinical research
Brinkman et al., 2013	N=4569 survivors from Childhood Cancer Survivor Study	Cohort	Brief symptom inventory- 18	Increased distress particularly if worse perception of physical health, Distress led to worsening pain	Psychological distress may emerge decades after treatment
Brinkman et al., 2016	N=3893 survivors from Childhood Cancer Survivor Study	Cohort	Behavior Problems Index	≥30 Gy CRT higher internalizing, corticosteroids with externalizing, and methotrexate with global symptoms	CNS directed treatment, obesity, chronic pain, and sensory impairments were associated with worse psychosocial outcomes
Brown et al., 2003	N= 52 adolescent cancer survivors and their mothers, and 42 healthy adolescents and their mothers, university associated medical center	Cohort	Disease severity index, Marlowe-Crowne social desirability scale, adolescent inventory of life events and changes, Posttraumatic stress index	Pediatric oncology mothers reported more PTSD symptoms than mothers of healthy children, survivors reported 36% more PTSD symptoms than healthy adolescents	No survivors met full PTSD criteria

Canning et al., 2014	N=74 5 year survivors across multiple UK hospitals	Cohort	Pediatric Index of Emotional Distress, Self-Description Questionnaire, Pediatric quality of life Inventory	Emotional distress connected to pain, illness worries, communication difficulties, relationships with parents and opposite sex, negative self-views	Limited diversity of participants
Cantrell & Posner, 2014	N=66 female survivors and 8186 females with no h/o cancer from National Longitudinal Study of Adolescent Health	Cohort	BSI-18, Center for Epidemiologic Studies-Depression Scale (CES-D), Mini International Personality Item Pool	Young adult female survivors have more depressive symptoms, but no difference in anxiety or somatization	Limited number of survivors. Anxiety rating based on International Personality Item Pool
Carney et al., 2019	18 articles	MS	Reciprocal translation	Commonly reported “forced enlightenment”, no longer the same, value family, social isolation, trying to adjust back into peer groups	Interpretation of meaning from various articles
Cetingul et al., 1999	N=19 in Turkey	Cohort	Cranial MRI, Evoked potentials, Beck depression inventory, Wechsler’s Intelligence Scale for Children-Revised.	For ALL survivors IQ scores were 18 points lower, 33.3% had abnormal MRI, 16.6% abnormal auditory test, 29.5% abnormal visual EP	Small cohort size at one location

Cook et al., 2020	N=196 survivors, 131 health counterparts St. Jude Children's Hospital	Cohort	Centrality of Events Scale	The degree that the cancer treatment was central to the patient's identity correlated to PTG and PTS	Limited expansion of the meaning between the connection of PTG and PTS
Cox et al., 2017	N=411 survivors, St. Jude Children's Research Hospital	Cohort	w/ or w/o telephone counseling and screening	Counseling increases survivor rates and intent to screen for secondary and long term complications, competency, autonomy, and perceived value of screening	Primarily white participants (89.3%)
Crochet et al., 2019	N=6844 from the Childhood Cancer Survivor Study	Cohort	Posttraumatic Stress Scale, Brief Symptom Inventory-18, Short-form 36 Health-related quality of life (HRQOL) survey, CCSS Neurocognitive Questionnaire, and questions about sociodemographics, physical health, health behaviors, and healthcare utilization	PTSS was connected to lower mental and physical QOL, decreased task efficiency, memory, organization, and emotional regulation, decreased PCP follow up, but also had increased Oncology appointment follow up	Lack of discussion about why patients do not go to PCP care

Cunningham et al., 2021	N=111 in Canada	Cohort	Symptom Worry Scale, Patient Reported Outcomes Measurement Information System, Cancer Worry Scale, Pediatric Quality of Life Inventory, Intensity Treatment Scale	Worry of relapse with pain or somatic symptoms. Symptom worry connected to QOL	Limited number of participants, mean age are adolescents
Cupit et al., 2018	NA	Expert Opinion	NA	Emotional challenges for survivors may stem from fear of relapse, that even in good times that fear can hang over their heads	Opinion based
Davies, 2007	N=14054 from Childhood Cancer Survivor Study	Cohort	Subsequent Malignant Neoplasm rates	10.8x increased overall mortality- particularly in females, dx before 5yo, leukemia, or CNS survivors. All cause excess risk of death 8.8 per 1000 persons per year. Primarily cause of death relapse, then SMN, then Cardiac dx, then pulmonary dx. Increased risk SMN in RT, high dose alkylators, or high dose epipodophyllotoxins.	No screening guidelines or breakdown of risk by subtype of cancer.
Demoor et al., 2020	N=2965 in France	Cohort	Height	Small height connected to younger at time of dx, small height at dx, pituitary irradiation, busulfan, >300mg/m2 lomustine, or irradiation of 7+ vertebrae.	Inclusion of individuals who were small at diagnosis, exclusion of those treated with growth hormone
Desaulniers et al., 2014	N=173 Children's	Cohort	Self-reported sleep and	Sleep problems were connected to adverse psychosocial outcomes,	Only adolescent survivors

	Healthcare of Atlanta Childhood, Adolescent, and Young Adult Cancer Survivor Study		psychosocial problems	difficulties in school, depression, memory problems, and anxiety. Highest sleep problems during treatment and immediately after treatment.	
Desjardins et al., 2019	N=91 from Canada	Cohort	Behavior Assessment System for Children, behavior Rating Inventory of Executive Function, The Global Executive Composite, and Emotional Control, Social Skills Rating System	Depression and social skill issues lead to social withdrawal, depression and anxiety and social withdrawal are positively connected	Mean age 11.21yo
Dsouza et al., 2019	N=57 survivors and 60 health peers, one large hospital	Cohort	Schedule for Affective Disorders and Schizophrenia for School-Age Children Epidemiologic —version 5,	No difference in self-reported depression or anxiety	Limited sample size, only English speaking, not CNS cancers
Erdman et al., 2019	NA	Expert Opinion	NA	LMIC and SEP impacted survival and outcomes for survivors	No breakdown of outcomes within specific

					cities in the United States
Erickson & Steiner, 2001	N=40	Cohort	Structured Interview for PTSD, Global Assessment of Functioning, Impact of Event Scale, Re- vised	88% has at least one trauma symptom to a significant level	Limited sample size
Ernst et al., 2021	N=633 from German Childhood Cancer Registry	Cohort	Patient Health Questionnaire	Loneliness 17.7% and predicted anxiety and SI, not connected to depression or somatic symptoms	Only 2.5y after treatment
Ernst et al., 2020	N=916 from German Childhood Cancer Registry	Cohort	Generalized Anxiety Disorder Scale, Patient Health Questionnaire-15, Mini-Social Phobia Inventory, Jenkins sleep scale	SI in 8%, previous suicide attempt 2.8%, SI connected to previous SI attempts, loneliness, living situation, and distress symptoms	Mean age 34.58yo
Freycon et al., 2019	N=71	Cohort	Height, infertility risk, pulmonary late effects, DM, and other severe late effects	TBI connected to SMN, chronic health disorders, educational underachievement, and depression. Chronic health conditions primarily affected the lungs, kidneys, heart, and reproductive organs.	Limited sample size
Friend et al., 2018	NA	SR	NA	Mental health disorders increased by HD anthracyclines, CNS tumors and cranial radiation therapy. Poor	Limited research on risks for mental health disorders

				physical health and chronic health conditions were also connected to increased rates of mental health disorders	
Ganz et al., 2010	N=70	Qual	Post-Traumatic Diagnostic Scale, Multidimensional Scale of Perceived Social Support	29% survivors met DSM criteria for PTSD, 50% has moderate to severe symptoms. Only 16% had no symptoms of PTSD.	Small sample at one site, no comparison to health peers
Geest et al., 2013	N= 652	Cohort	Hospital Anxiety and Depression Scale (HADS)	No increase in emotional distress in survivors compared to their cohort	Average of 15 years after treatment and average of 23 years old patients, meaning the patients completed treatment by an average of 8 years old which does not account for adolescent cancer patients or variation in severity of symptoms based on age of treatment or soon after treatment
Ghosh et al., 2021	N=25, 654 survivors of lung cancer from Childhood Cancer Survivor Study	Cohort	Hazard ratios, incidence rates	Increased rates of lung cancer, 0.16% SMN at 30y post diagnosis, chest RT were associated with lung SMN, greatest risk of lung SMN were Hodgkin lymphoma or bone cancer	No discussion about tobacco product use or occupational exposure in relation to SMN

Gianinazzi et al., 2013	N=407 survivors and 102 siblings	Cohort	BSI-18	Increased somatization, GSI, and anxiety among the distressed. Increased distress in females, and self-reported support and health concerns	Rates of distress did not vary significantly but the type of distress among survivors did vary from siblings
Ginsberg et al., 2006	NA	Expert Opinion	NA	Transition from pediatrics into adulthood and as an oncology patient into survivorship, focus on autonomy, responsibility, and education	Opinion based
Gandy et al., 2021	N=18, 5 survivors, 8 caregivers, 8 providers	Qual	Interview	Survivorship follow up important factors for patients are clinic environment, family presence, provider behavior. For caregivers they values clinic environment, resources, provider behavior, rapport.	Small sample size, mostly non-Hispanic white participants
Green et al., 2012	N=9,284	Cohort	BMI, demographics, treatment history	Obesity increased if diagnosed with cancer between 5-9 years old, abnormal Short Form-36 physical function, pituitary radiation 20-30 Gy, paroxetine use.	No discussion of family h/o obesity, corticosteroid treatment, or baseline obesity at time of diagnosis
Hayek et al., 2019	N= 10,899 survivors, 2,097 siblings	Cohort	Demographics, education, socioeconomic data, social history, BMI	Frailty increased in survivors, highest in CNS tumors and bone tumors, CRT, pelvic RT, abd RT, cisplatin >600mg/m2, amputees, or s/p lung surgery	No baseline BMI information before treatment
Ho et al., 2021	N=402	Cohort	Pittsburgh Sleep Quality Index	Lower PSQI scores in survivors than healthy, worst PSQI scores in children actively receiving chemotherapy, decreased PSQI related to PedsQL	No evaluation of causes of poor sleep quality
Hobbie et al., 2000	N=78	Cohort	Impact of Event Scale, Posttraumatic Stress Disorder	20% met criteria for PTSD, high intrusion and avoidance, perception more connected to PTSD rates than objective data	Small sample size from one location

			Reaction Index, State-Trait Anxiety Inventory, Structured Clinical Interview for DSM III, Assessment of Life Threat and Treatment Intensity Questionnaire, Brief Symptom Inventory, Intensity of Treatment Rating, Medical sequalae rating		
Huang et al., 2013	N=1,667	Cohort	physical/mental component summary and six domain scores of the Medical Outcomes Study 36-Item Short-Form Health Survey	Decreased QOL with pain (other than head, neck, and back) and disfigurement	No detailed discussion of the other symptoms which were reported in the study, such as learning problems, sensation abnormalities, or pain in back/neck
Katzman & John, 2018	NA	SR	NA	There was significant increase in PTSD and PTSS in survivors in the 9 articles reviewed	Discussion of nine articles

Kelada et al., 2019	N=404	Cohort	Interview	Unmet needs for managing pain and fatigue, pain and fatigue led to increased fear of relapse	Lack of recommendations for managing these symptoms
Kinahan et al., 2012	N=4,023	Cohort	HRQOL, reported scarring and disfigurement, demographics	Cranial RT increased risk of head/neck disfigurement. Hair loss led to anxiety. Head/neck disfigurement led to depression.	Limited discussion of survivor reports of why these issues caused distress
Klosky et al., 2014	N=6,162	Cohort	Posttraumatic Growth Inventory, Posttraumatic Stress Diagnostic Scale	No robust connection between PTSS and PTG	There is a connection revealed in their data
Koutna et al., 2021	N=167	Cohort	University of California at Los Angeles Posttraumatic Stress Reaction Index	No significant correlation between PTG or PTSS, fear or relapse connected with PTG	Possible connect between fear or relapse and intrusive thoughts
Laage et al., 2016	N=348	Cohort	Brief Symptom Inventory-18, the Impact of Event Scale, and the Illness Worry Scale, Mini-International Neuropsychiatric Interview	High anxiety and mood disorders even in very long term adult survivors	No comparison to non-oncology peers

Langeveld et al., 2004a	N=500	Cohort	Impact of Event Scale	12% severe PTSS, 20% females had severe vs. 6% male.	Further investigation into why females had higher PTSS
Langeveld et al., 2004b	N=400	Cohort	Medical Outcome Study Scale, a Worry questionnaire consisting of three scales, and the Rosenberg Self-Esteem Scale	No significant difference in self-esteem, more worries about fertility, unemployment, late effects/health problems, which impacted QOL	Higher worry ratings in female patients- meaning
Leclerc et al., 2019	N=138	Cohort	BRIEF-SR and CAARS-S:L, BSI-18, PANAS, PedsQL-MFS	Decreased working memory, attention	Poor reliability of self-reports
Lee et al., 2006b	N=45	Cohort	investigator-developed demographic and disease form, the Mishel Uncertainty in Illness Scale-Community, the Post-traumatic Stress Disorder Index and the Health Promoting Lifestyle Profile II	Higher uncertainty and PTS symptoms in survivors, lower PCP interaction and fewer cognitive resources increased unhealthy behavior	Small sample size

Lee, 2006a	N=45	Cohort	Mishel Uncertainty in Illness Scale-Community Form, University of California at Los Angeles Post Traumatic Stress Disorder Index	Uncertainty was correlated to PTSS	Small sample size
Lewis et al., 2021	N=579	Cohort	Questionnaire	Gastrointestinal, psychological, and neurologic symptom clusters. GI most common among all groups	No non-oncology peer comparison
Li et al., 2012	N=137	Cohort	Center for Epidemiologic Studies Depression Scale for Children, Chinese version of the State Anxiety Scale for Children, Rosenberg Self-esteem Scale, Coping Behaviour Checklist for Chinese Children, Pediatric Quality of Life Inventory version	Low self-esteem and depression which connected to anxiety and decreased QOL	No non-oncology peer comparison

Lindell et al., 2015	N=174	Cohort	Demographics, charts, and patient interviews	Survivorship clinics increased knowledge in survivors	No non-oncology peer comparison
Ljungman et al., 2015	N=169	Cohort	PTSD Checklist Civilian Version	Bereaved parents experience high levels of PTSD, PTSS stable for 3 months after treatment	Reasons for difference in PTSS between mothers and fathers
Lown et al., 2013	N=3,034 siblings, 10,398 survivors	Cohort	Brief Symptom Inventory, Global Severity Index	Siblings more likely to drink heavily or be risky drinkers. Heavy drinking connected to depression, anxiety, global psychiatric distress	Need for sibling support in survivor care
McCarthy et al., 2013	NA	Expert opinion	NA	Decreased survivor knowledge of risks of treatment and need for follow up	Opinion based
McDonnell et al., 2017	NA	SR	NA	Possibility of increased anxiety in adolescent survivors	Limited data sources for anxiety
Meeske et al., 2001	N=51	Cohort	BSI and RAND SF-36	PTSD led to poor QOL and distress, functional limitations and psychological comorbidity	Small sample size
Michel et al., 2010	N=1,076	Cohort	BSI	Survivors have less distress overall than the population, but the proportion with distress have more severe symptoms	Significance that when distress occurs it is more severe, but is also less common at the same time
Miller et al., 2017	N=18,882	Cohort	Interview	Preference for follow up from oncologist instead of PCP	Further investigation needed into survivorship clinic follow up
Moor et al., 2011	N=374	Cohort	Surveys	93% of survivors smoked in the last 7 days	Further studies to verify these results
Ozono et al., 2010	N=247	Cohort	Family Relationship Index,	Supportive types, conflict types, and intermediate types. Conflict types had highest PTSS, depression, and state-trait anxiety	Ways to help change conflict type personality traits to reduce distress

Patton et al., 2021	N=140	Cohort	Pain Questionnaire, Pain Catastrophizing Scale, Pediatric Quality of Life Inventory, Patient-Reported Outcome Measurement Information System (PROMIS)–Pain Interference, Anxiety, and Depression scales, Child Posttraumatic Stress Scale, the Posttraumatic Stress Disorder Checklist for the DSM-V, and the Cancer Worry Scale	26% chronic pain, increased chronic pain with higher PTSS, older age, increased pain catastrophizing, female	Increased discussion of other causes for their chronic pain
Phipps et al., 2014	N=255 survivors, 101 peers	Cohort	Clinician-Administered PTSD Scale for Children and Adolescents, University of California, Los Angeles PTSD	0.4% met PTSD criteria and not significantly higher in survivors compared to population, decreased PTSS by half by 5 years from treatment	Discussion of improved distress symptoms over time distance from treatment

			Reaction Index for DSM-IV, Benefit Finding/Burden Scale for Children, Life Events Scale		
Prasad et al., 2015	N=2,589	Cohort	Brief Symptom Inventory-18 and a Neurocognitive Questionnaire	Higher depression, anxiety, problems with task efficiency, emotional regulation, and memory. Less s/s from lymphoma or sarcoma patients	Compared to siblings instead of non-oncology peers
Rai et al., 2008	N=424	RCT	BMD	Most had BMD deficits, only 34% had BMD at mean or greater	Most participants were white, needs guidance on improving BMD in leukemia patients
Ranft et al., 2017	N=618	Cohort	Toronto Extremity Salvage Score, Short-Form Health Survey (SF-36), Brief Symptom Inventory (BSI), and Rosenberg Self-Esteem Scale questionnaires and by the accelerometric StepWatch 3 Activity Monitor	Survivors less physically active, pelvic tumors or female sex were connected to less physical activity	Method to increase physical activity or limit physical disabilities

Recklitis et al., 2010	N=2,968	Cohort	BSI and current medical conditions	Increased SI in survivors, related to relapse, CNS tumors, depression, poor health, chronic pain	Identify rates of SI attempts in survivors
Recklitis et al., 2006	N=8,945	Cohort	BSI	Survivors had fewer s/s of psychological distress compared to non-oncology peers	Analysis about if there is truly a lower rate of distress in survivors, population demographics of compared peers
Santacroce & Lee, 2006	N=45	Cohort	Mishel Uncertainty in Illness ScaleVCommunity Form, the Posttraumatic Stress Disorder Index, and the Health Promoting Lifestyle Profile II	PTSS is connected to levels of uncertainty	Small sample size
Schultz et al., 2007	N=2,979 survivors and 649 siblings	Cohort	Parent-reported behavior problem index	1.5x more likely to have anxiety/depression, antisocial behaviors, attention deficit. Highest deficits with neuroblastoma, cranial RT, or IT MTX	Methods to reduce antisocial behaviors, and connection of psychosocial distress to antisocial behavior
Schwartz, 2020	NA	Expert Opinion	NA	Lack of formal education for survivors on long term effects of their treatments, Need for education on importance of long term primary care follow up	Opinion Based

Sedmak et al., 2020	N=83	Cohort	Impact of Event Scale-Revised Questionnaire (IES-R), Quality of life scale (QOLS) and Social Adjustment Scale (SAS-SR)	Association between WOL, PTG, PTS, health conditions, and social adjustment after treatment	Lack of comparison to non-oncology peers
Simard et al., 2013	NA	SR	NA	Fear of relapse one of the top reported concerns. Many reported this need was not addressed by health care providers. Increased fear of relapse in younger, severe physical symptoms, low QOL, and distress	Measures for fear of relapse are not consistent
Taieb et al., 2003	NA	SR	NA	Wide range of rates of PTSD in survivors and their parents based on included studies	Studies prior to 2001
Taskiran et al., 2016	N=27 survivors and 28 healthy peers	Cohort	Child Posttraumatic Stress Disorder—Reaction Index (CPTSD-RI) Clinician-Administered PTSD Scale (CAPS)	Significantly higher PTSD rates in BMT survivors and their mothers	Small sample size
Taylor et al., 2012	N=118 survivors	Cohort	Post-traumatic stress disorder: PTSD Checklist – Civilian Version,	Higher PTSD in females who had more late effects, significant numbers report PTSS but not connected to treatment or diagnosis	No comparison to non-oncology peers

			Chronic Disease Self-Efficacy scales, questionnaires		
Tutleman & Heathcote, 2020	NA	Expert opinion	NA	Understanding of illness based on age, autobiographical memory of treatment, metacognition, parent relationship, identity issues all play a role in fear of relapse	Discussion based
Vestch et al., 2018	NA	SR	NA	13 studies showed worse QOL, 8 showed no difference in QOL, and 3 found improved QOL in ALL survivors compared to non-oncology patients	Further discussion about the possible causes for the different results of these studies
Vuotto et al., 2017	N=1,714	Cohort	BSI, Posttraumatic Stress Disorder Checklist, Body Image Scale, survey,	Distress can be treated through treatment of body image dissatisfaction, BID connects scarring and disfigurement of the head and distress	No BID rates based on type on cancer
Wilson et al., 2016	N=61	Cohort	CRIES-13, ICPS-FFS, SDM-Q-9, PHQ-4,	PTG connected to PTSS	Small sample size
Yan et al., 2020	N=2,146	Cohort	American Cancer Society (ACS) cancer screening guidelines adherence rates	Low adherence to breast, cervical, and colorectal screening, only 27% had PCPs and a survivorship care plan	Need to create survivorship care plans to increase adherence to cancer screenings
Yuen et al., 2014	N=89	Cohort	Chinese Cancer-related Rumination	Hope related to PTG, Hope decreased depression, anxiety, and negative rumination	Methods to increase hope in patients

			Scale; depression symptoms were measured by Beck Depression Inventory; and anxiety symptoms were measured by Beck Anxiety Inventory.		
Zebrack et al., 2004	N=2,817	Cohort	Questionnaire, Global Severity Index, BSI-18,	Distress equivalent to the general population, survivors had higher distress than their siblings. Higher distress with females, low income, lower education, unmarried, unemployed, poor health	Discussion if sociodemographic factors that caused increased distress were also equal to their non-oncology peers with the same demographics
Zhang et al., 2012	N=1,248	Cohort	SMN rates, death records, demographics	Increased mortality excess risk and SMN compared to health counterparts	Possible causes of excess deaths among survivors apart from SMN
Zheng et al., 2018	N=859	Cohort	BPI, Demographics, chronic health conditions, and treatment records	Neuroblastoma survivors has more mental health concerns and social withdrawal. Having 2+ chronic health conditions caused impairment, endocrine and peripheral neuropathy diseases also predicted impairment	Further discussion about screening and intervention to reduce poor outcomes in neuroblastoma survivors

Note. RCT, randomized controlled trial; MA, Meta-analysis; SR, Systematic Review; Qual, qualitative study. CCS, Childhood cancer survivor; PTSS, posttraumatic stress syndrome; PTG, post traumatic growth; PA, physical activity. (Melnyk & Fineout-Overholt, 2019)

Appendix H: Survey

Table H1

Family-Centered Psychosocial Care of Pediatric Oncology Patients

Knowledge and Confidence Survey

How many years have you worked in pediatric oncology as a nurse? 0-11 months, 1-4 years, 5-9 years, 10+ years

1. I feel confident in my ability to assess and care for patients with anxiety and/or PTSD:
   1. Strongly Disagree **2.** Disagree **3.** Neutral **4.** Agree **5.** Strongly Agree

2. I feel confident in my ability to assess and care for patients with depression and/or SI:
   1. Strongly Disagree **2.** Disagree **3.** Neutral **4.** Agree **5.** Strongly Agree

3. I feel confident in my ability to assess and care for patients at the end of life period:
   1. Strongly Disagree **2.** Disagree **3.** Neutral **4.** Agree **5.** Strongly Agree

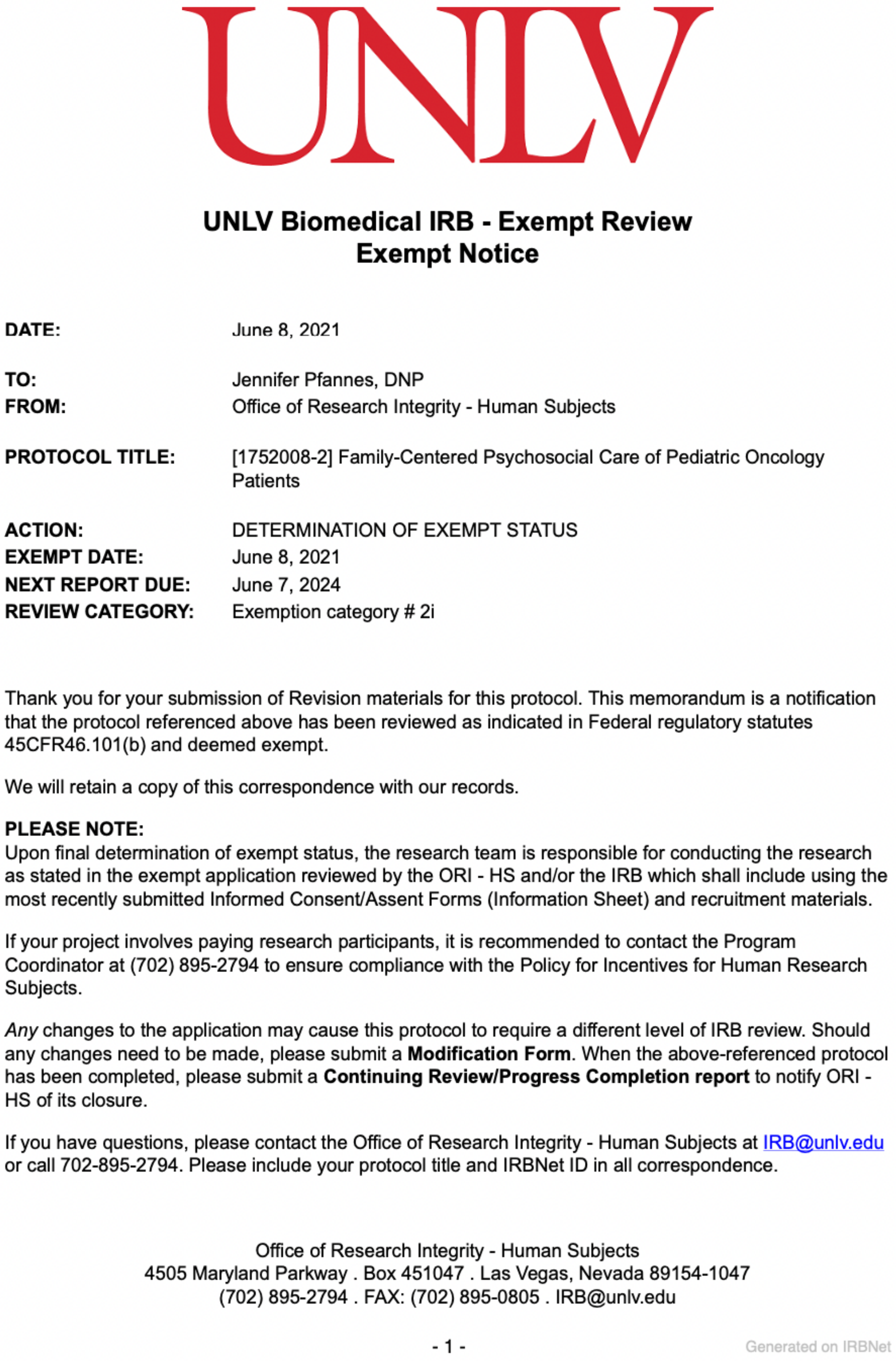
4. I feel confident in my ability to assess and care for psychosocial side effects of therapy:
   1. Strongly Disagree **2.** Disagree **3.** Neutral **4.** Agree **5.** Strongly Agree

5. The treatment for a patient with acute Ifosfamide neurotoxicity is:
   A. Glucarpidase
   B. Leucovorin
   C. Mesna
   D. Methylene Blue
6. Treatment for a patient with acute Methotrexate neurotoxicity includes:
   A. Glucarpidase
   B. Lorazepam
   C. Furosemide
   D. Mesna
7. Symptoms of Cytokine Release Syndrome include:
   A. Hypertension, Hypothermia, Headaches
   B. Constipation, Jaundice, Small Bowel Obstruction
   C. Fever, Hypotension, Hypoxia, risk of Neurologic changes
   D. Diarrhea, Neuropathy, Tinnitus
8. Which of these medications does NOT cause central nervous system toxicity?
   A. Vincristine
   B. Cisplatin
   C. Cytarabine
   D. Mercaptopurine
9. Which medication can cause confusion and altered mental status?
   A. Thiotepa
   B. Topotecan
   C. Melphalan
   D. Doxorubicin

10. What do you feel would help you to implement psychosocial care principles to care for your patients?

11. What do you feel would prevent you from using psychosocial care principles to care for your patients?

Appendix I: IRB Permissions



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UNLV Biomedical IRB - Exempt Review
Exempt Notice

DATE:	June 8, 2021
TO:	Jennifer Pfannes, DNP
FROM:	Office of Research Integrity - Human Subjects
PROTOCOL TITLE:	[1752008-2] Family-Centered Psychosocial Care of Pediatric Oncology Patients
ACTION:	DETERMINATION OF EXEMPT STATUS
EXEMPT DATE:	June 8, 2021
NEXT REPORT DUE:	June 7, 2024
REVIEW CATEGORY:	Exemption category # 2i

Thank you for your submission of Revision materials for this protocol. This memorandum is a notification that the protocol referenced above has been reviewed as indicated in Federal regulatory statutes 45CFR46.101(b) and deemed exempt.

We will retain a copy of this correspondence with our records.

PLEASE NOTE:
Upon final determination of exempt status, the research team is responsible for conducting the research as stated in the exempt application reviewed by the ORI - HS and/or the IRB which shall include using the most recently submitted Informed Consent/Assent Forms (Information Sheet) and recruitment materials.

If your project involves paying research participants, it is recommended to contact the Program Coordinator at (702) 895-2794 to ensure compliance with the Policy for Incentives for Human Research Subjects.

Any changes to the application may cause this protocol to require a different level of IRB review. Should any changes need to be made, please submit a **Modification Form**. When the above-referenced protocol has been completed, please submit a **Continuing Review/Progress Completion report** to notify ORI - HS of its closure.

If you have questions, please contact the Office of Research Integrity - Human Subjects at IRB@unlv.edu or call 702-895-2794. Please include your protocol title and IRBNet ID in all correspondence.

Office of Research Integrity - Human Subjects
4505 Maryland Parkway . Box 451047 . Las Vegas, Nevada 89154-1047
(702) 895-2794 . FAX: (702) 895-0805 . IRB@unlv.edu

Appendix J: SPSS Data

Table J1
Paired Samples Statistics

		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	Score Pre	3.21	28	.917	.173
	Score Post	4.82	28	.390	.074
Pair 2	Likert Score	14.21	28	2.872	.543
	Likert Post Score	17.07	28	2.372	.448

Table J2
Paired Samples Correlations

				Significance	
		N	Correlation	One-Sided p	Two-Sided p
Pair 1	Score Pre & Score Post	28	.111	.287	.574
Pair 2	Likert Score & Likert Post Score	28	.694	<.001	<.001

Table J3

Paired Samples Test

		Paired Differences							Significance	
					95% Confidence Interval of the Difference					
		Mean	Std. Deviation	Std. Error Mean	Lower	Upper	t	df	One-Sided p	Two-Sided p
Pair 1	Score Pre - Score Post	-1.607	.956	.181	-1.978	-1.236	-8.895	27	<.001	<.001
Pair 2	Likert Score - Likert Post Score	-2.857	2.103	.397	-3.673	-2.042	-7.189	27	<.001	<.001

Table J4
Paired Samples Effect Sizes

			Standardizer[a]	Point Estimate	95% Confidence Interval	
					Lower	Upper
Pair 1	Score Pre - Score Post	Cohen's d	.956	-1.681	-2.254	-1.095
		Hedges' correction	.984	-1.634	-2.191	-1.064
Pair 2	Likert Score - Likert Post Score	Cohen's d	2.103	-1.359	-1.869	-.835
		Hedges' correction	2.164	-1.320	-1.816	-.812

Table J5
Wilcoxon Ranks

		N	Mean Rank	Sum of Ranks
Likert Post Score - Likert Score	Negative Ranks	0[a]	.00	.00
	Positive Ranks	25[b]	13.00	325.00
	Ties	3[c]		
	Total	28		

a. Likert Post Score < Likert Score
b. Likert Post Score > Likert Score
c. Likert Post Score = Likert Score

Table J6
Wilcoxon Test Statistics

	Likert Post Score - Likert Score
Z	-4.392^b
Asymp. Sig. (2-tailed)	.000

a. Wilcoxon Signed Ranks Test
b. Based on negative ranks.

Table J7
Likert Question Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.905	.923	8

Table J8
Race/Ethnicity

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Asian	7	25.0	25.0	25.0
	Hispanic White	3	10.7	10.7	35.7
	Indian	1	3.6	3.6	39.3
	non-Hispanic White	17	60.7	60.7	100.0
	Total	28	100.0	100.0	

Table J9
Nursing Degree

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Bachelors Degree	25	89.3	89.3	89.3
	Associates Degree	3	10.7	10.7	100.0
	Total	28	100.0	100.0	

Table J10

Years Working in Pediatric Oncology

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0-11 months	3	10.7	12.5	12.5
	1-4 years	9	32.1	37.5	50.0
	5-9 years	9	32.1	37.5	87.5
	10+ years	3	10.7	12.5	100.0
	Total	24	85.7	100.0	
Missing	System	4	14.3		
Total		28	100.0		

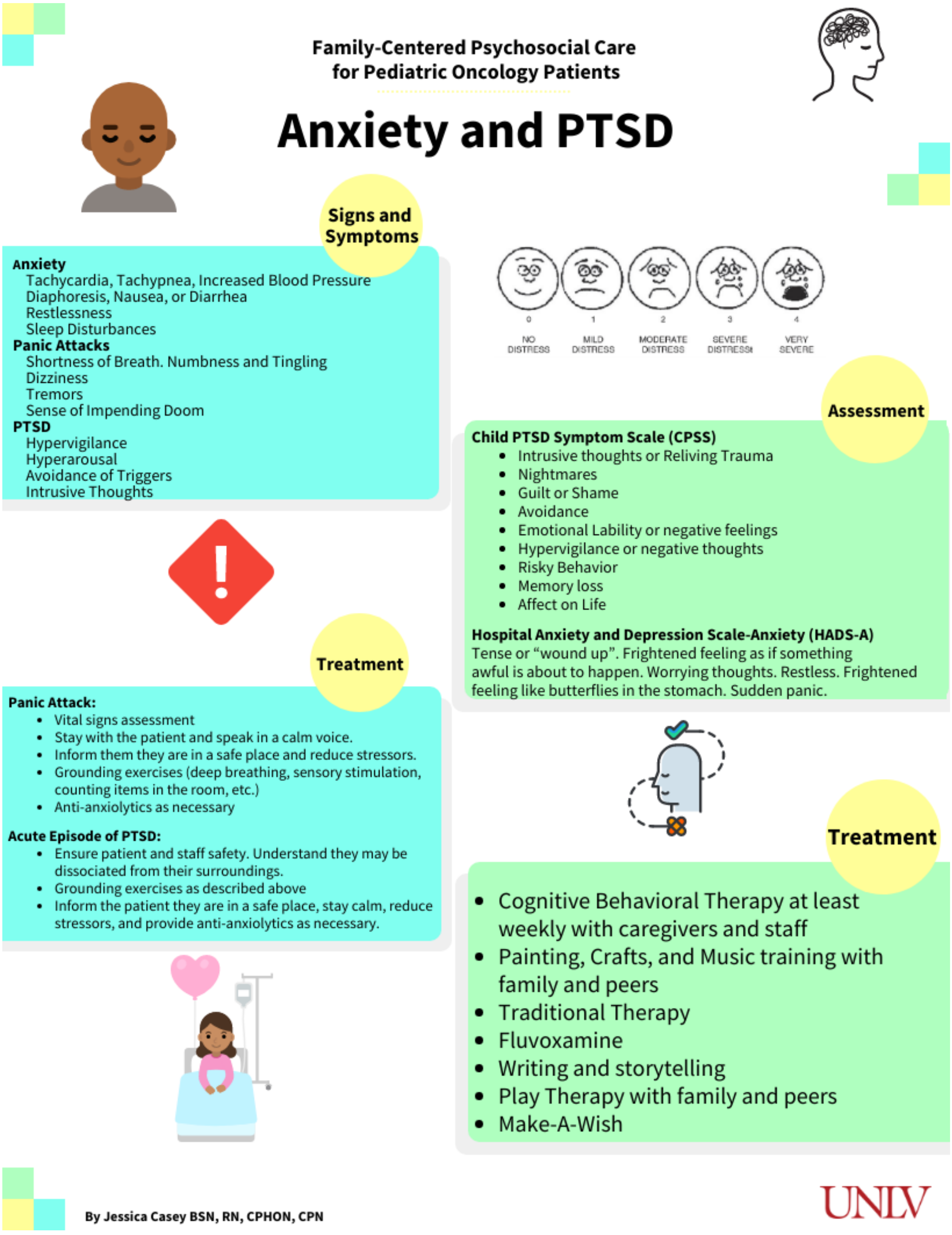
Table J11

Sex of Participants

Female	27	96.4%
Male	1	3.6%

Appendix K: Resource Infographics

Figure K1: Anxiety and PTSD



Family-Centered Psychosocial Care for Pediatric Oncology Patients

Anxiety and PTSD

Signs and Symptoms

Anxiety
- Tachycardia, Tachypnea, Increased Blood Pressure
- Diaphoresis, Nausea, or Diarrhea
- Restlessness
- Sleep Disturbances

Panic Attacks
- Shortness of Breath. Numbness and Tingling
- Dizziness
- Tremors
- Sense of Impending Doom

PTSD
- Hypervigilance
- Hyperarousal
- Avoidance of Triggers
- Intrusive Thoughts

Treatment

Panic Attack:
- Vital signs assessment
- Stay with the patient and speak in a calm voice.
- Inform them they are in a safe place and reduce stressors.
- Grounding exercises (deep breathing, sensory stimulation, counting items in the room, etc.)
- Anti-anxiolytics as necessary

Acute Episode of PTSD:
- Ensure patient and staff safety. Understand they may be dissociated from their surroundings.
- Grounding exercises as described above
- Inform the patient they are in a safe place, stay calm, reduce stressors, and provide anti-anxiolytics as necessary.

Assessment

Child PTSD Symptom Scale (CPSS)
- Intrusive thoughts or Reliving Trauma
- Nightmares
- Guilt or Shame
- Avoidance
- Emotional Lability or negative feelings
- Hypervigilance or negative thoughts
- Risky Behavior
- Memory loss
- Affect on Life

Hospital Anxiety and Depression Scale-Anxiety (HADS-A)
Tense or "wound up". Frightened feeling as if something awful is about to happen. Worrying thoughts. Restless. Frightened feeling like butterflies in the stomach. Sudden panic.

Treatment

- Cognitive Behavioral Therapy at least weekly with caregivers and staff
- Painting, Crafts, and Music training with family and peers
- Traditional Therapy
- Fluvoxamine
- Writing and storytelling
- Play Therapy with family and peers
- Make-A-Wish

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Figure K2: Depression and Suicide

Family-Centered Psychosocial Care for Pediatric Oncology Patients

Depression and Suicide

Signs and Symptoms

- Social Withdrawal
- Flat affect or Mood Lability
- Dysphoria
- Sleep Disturbances
- Eating Pattern Changes
- Self-harm or History of Suicide Attempt
- Feelings of Hopelessness
- Low Self-esteem or Feeling Worthless
- Anhedonia (lack of joy)
- Suicidal Ideation (SI) or Aggression

Treatment

After Suicide Attempt or Voiced SI:

- Ensure safety- remove any items which could be used to attempt suicide. Consider continuous visual monitoring by staff while actively suicidal and hospitalized.
- Provide a safe environment and complete suicide risk assessments such as C-SSRS.
- Talk to the patient about their triggers and symptoms.
- Provide anti-depressants as indicated. Risk for SI when starting anti-depressants in children.
- Create a safety plan for the patient for when they go home. The safety plan would include what they can do when they feel SI at home, including support systems, warning signs, positive things about themselves, reasons to keep living, and removing safety risks such as guns.

Assessment

Children's Depression Inventory (CDI): Sadness, Guilt or Shame, Self-hatred, SI, Irritability, Enjoyment in Life, Crying, Interaction with others, Worry

Columbia Suicide Severity Rating Scale (C-SSRS)

- Wish to be dead
- Non-specific active suicidal thoughts
- Active SI with any method without intent to act
- Active SI with some intent to act without a plan
- Active SI with specific plan and intent
- Frequency, Duration, Deterrents, Reasons for Ideation, Controllability
- Risk factors and protective factors

Treatment

- Cognitive Behavioral Therapy at least weekly with caregivers and staff
- Painting, Crafts, and Music training with family and peers
- Traditional Therapy
- Escitalopram, Fluoxetine, Fluvoxamine
- Writing and storytelling
- Play therapy with family and peers
- Make-A-Wish

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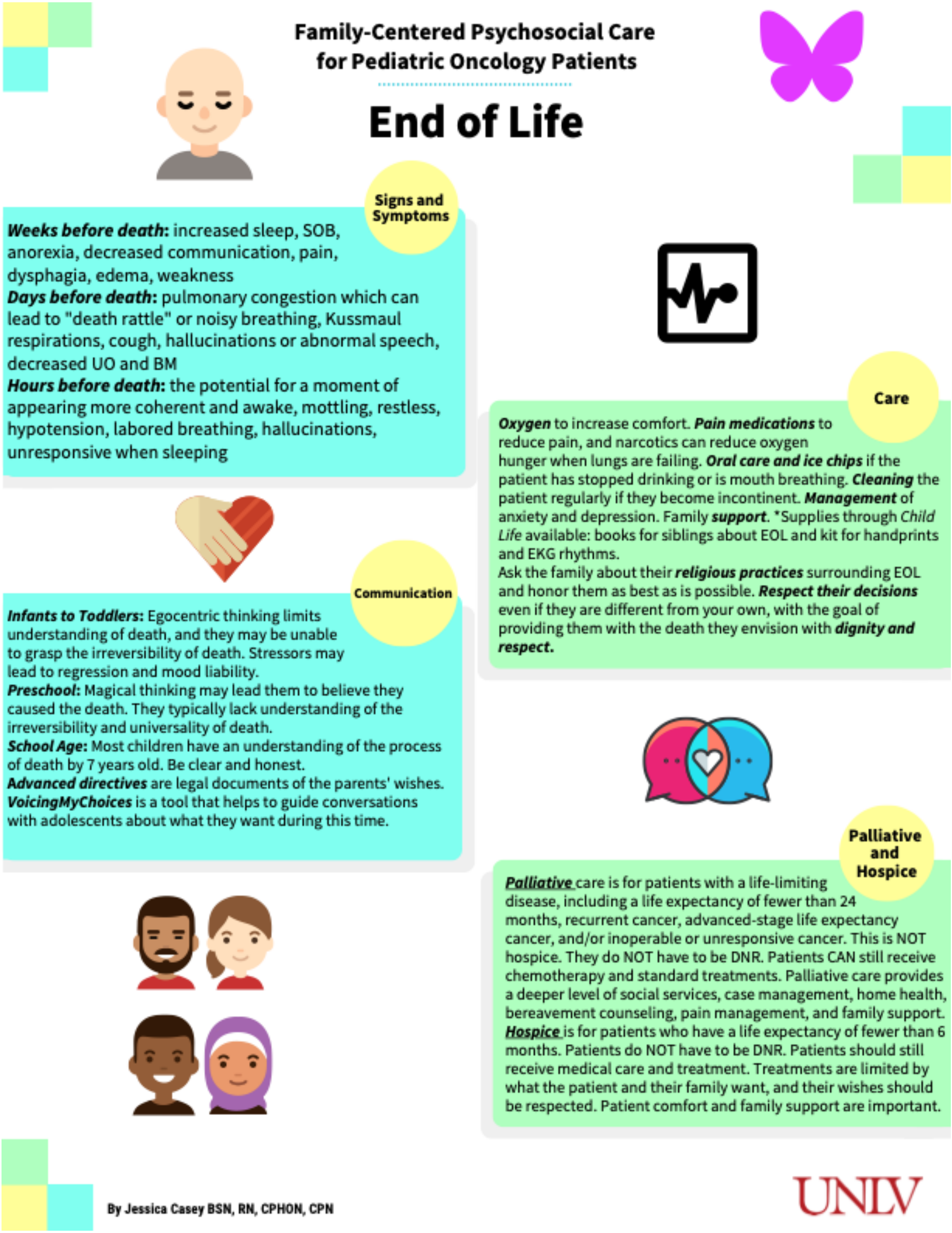
Figure K3: End of Life



Family-Centered Psychosocial Care for Pediatric Oncology Patients

End of Life

Signs and Symptoms

Weeks before death: increased sleep, SOB, anorexia, decreased communication, pain, dysphagia, edema, weakness
Days before death: pulmonary congestion which can lead to "death rattle" or noisy breathing, Kussmaul respirations, cough, hallucinations or abnormal speech, decreased UO and BM
Hours before death: the potential for a moment of appearing more coherent and awake, mottling, restless, hypotension, labored breathing, hallucinations, unresponsive when sleeping

Care

Oxygen to increase comfort. ***Pain medications*** to reduce pain, and narcotics can reduce oxygen hunger when lungs are failing. ***Oral care and ice chips*** if the patient has stopped drinking or is mouth breathing. ***Cleaning*** the patient regularly if they become incontinent. ***Management*** of anxiety and depression. Family ***support***. *Supplies through *Child Life* available: books for siblings about EOL and kit for handprints and EKG rhythms.
Ask the family about their ***religious practices*** surrounding EOL and honor them as best as is possible. ***Respect their decisions*** even if they are different from your own, with the goal of providing them with the death they envision with ***dignity and respect.***

Communication

Infants to Toddlers: Egocentric thinking limits understanding of death, and they may be unable to grasp the irreversibility of death. Stressors may lead to regression and mood liability.
Preschool: Magical thinking may lead them to believe they caused the death. They typically lack understanding of the irreversibility and universality of death.
School Age: Most children have an understanding of the process of death by 7 years old. Be clear and honest.
Advanced directives are legal documents of the parents' wishes.
VoicingMyChoices is a tool that helps to guide conversations with adolescents about what they want during this time.

Palliative and Hospice

Palliative care is for patients with a life-limiting disease, including a life expectancy of fewer than 24 months, recurrent cancer, advanced-stage life expectancy cancer, and/or inoperable or unresponsive cancer. This is NOT hospice. They do NOT have to be DNR. Patients CAN still receive chemotherapy and standard treatments. Palliative care provides a deeper level of social services, case management, home health, bereavement counseling, pain management, and family support.
Hospice is for patients who have a life expectancy of fewer than 6 months. Patients do NOT have to be DNR. Patients should still receive medical care and treatment. Treatments are limited by what the patient and their family want, and their wishes should be respected. Patient comfort and family support are important.

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Figure K4: Psychosocial Side Effects of Treatment

Family-Centered Psychosocial Care
for Pediatric Oncology Patients

Psychosocial Side Effects of Treatment

Side Effects of Treatments

Confusion: 5FU, procarbazine, retinoic acid, carmustine, thiotepa, rare- arsenic, fludarabine, ifosfamide, imatinib, interferon-alpha, irinotecan, nelarabine, paclitaxel, dasatinib, temozolomide, busulfan, cyclophosphamide, CRS, clofarabine, docetaxel, lomustine, teniposide, methotrexate, etoposide

Delirium/hallucinations: procarbazine, rare- ifosfamide, retinoic acid, thiotepa, busulfan, hydroxyurea, clofarabine, carmustine

Encephalopathy: arsenic, cytarabine, 5FU, thiotepa, rare- gemcitabine, fludarabine, ifosfamide, methotrexate, nelarabine, oxaliplatin, paclitaxel, retinoic acid, cyclophosphamide, etoposide, cisplatin, cladribine, thalidomide, carmustine, busulfan, carboplatin

Depression: arsenic, imatinib, procarbazine, retinoic acid, thalidomide, vinblastine, busulfan, rare- corticosteroids, fludarabine, nelarabine, dasatinib, temozolomide, thiotepa, cladribine, mitoxantrone, carmustine

Insomnia: arsenic, imatinib, irinotecan, oxaliplatin, procarbazine, retinoic acid, busulfan, melphalan, ATG, rare- corticosteroids, fludarabine, nelarabine, dasatinib, temozolomide, cladribine, carmustine

Seizures: busulfan, procarbazine, temozolomide, thiotepa, vinblastine, rare- arsenic, corticosteroids, hydroxyurea, ifosfamide, imatinib, methotrexate, nelarabine, oxaliplatin, retinoic acid, CRS, cisplatin, doxorubicin, docetaxel, idarubicin, mitoxantrone, thalidomide, vincristine, etoposide, fludarabine, cyclophosphamide

Agitation: clofarabine, rare- arsenic, corticosteroids, busulfan, fludarabine, thiotepa

Memory changes: temozolomide, rare- ifosfamide, imatinib, nelarabine, thiotepa

Anxiety: arsenic, imatinib, procarbazine, retinoic acid, busulfan, ATG, clofarabine, thalidomide, thiotepa, rare- corticosteroids, temozolomide, cladribine, mitoxantrone, carmustine, methotrexate

Stroke: rare- pegaspargase, fludarabine, gemcitabine, irinotecan, nelarabine, retinoic acid, dasatinib, thiotepa, busulfan, carboplatin, bleomycin, cisplatin, clofarabine

Personality changes: cytarabine, rare- corticosteroids, methotrexate, dasatinib, thalidomide, carmustine

Neurotoxicity: cytarabine, 5FU, ifosfamide, procarbazine, carmustine, cisplatin, carboplatin, docetaxel, mechlorethamine, vinblastine, vinorelbine, rare- fludarabine, hydroxyurea, methotrexate, thiotepa, busulfan, cyclophosphamide, cladribine, teniposide, vincristine

Other Treatments

Cytokine Release Syndrome (CRS):
Due to the release of cytokines secondary to the administration of immunotherapy. Can cause hypotension, hypoxia, fevers, and neurological changes such as AMS and seizures.

Cranial Radiation: Potential to cause decreased IQ, decreased attention span, memory changes.

Posterior Fossa Syndrome: After cranial surgery. Can last for months or leave permanent changes. SE: Speech changes, agitation, emotional lability, cognitive decline.

Benzodiazepines, Narcotics, Benadryl, and other medications administered can potentially cause altered mental status and side effects listed above.

Toxicity

Ifosfamide- Acute encephalopathy with hallucinations, psychiatric changes, seizures, and confusion potentially due to build-up of metabolites. Treat with Methylene Blue which acts to clear the metabolites by accepting electrons. 1-2mg/kg or 50mg IV Q4-8 hours until resolution of symptoms.

Methotrexate- Acute encephalopathy which can cause somnolence, confusion, hemiparesis, psychiatric changes, seizures, and decreased protein synthesis. Leucovorin (folinic acid- bypasses MTX inhibition of folic acid). Treat with Glucarpidase, 50 units/kg IV Once, within 48-60 hours. If IT MTX toxicity, possible to give 2000 units IT once.

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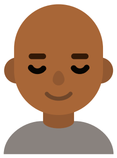
Figure K5: Cognitive Behavioral Therapy

Family-Centered Psychosocial Care for Pediatric Oncology Patients



Cognitive Behavioral Therapy (CBT)

Cognitive Behavioral Therapy (CBT) involves identifying cognitive distortions, learning effective ways to approach situations, and reframing thinking and behaviors to improve mental health.

Cognitive Distortions:
Illogical or Negative Thinking Patterns

Exaggeration
- Belief worst-case scenario will occur
- Belief that if something is difficult it is impossible to overcome or cope with
- Belief that everything must go exactly as one wishes
- Attributing terms to oneself or others based on singular events

Avoidance/Negativity
- If one thing is not what one wants to happen, it is all bad
- If one thing is good/bad then all others like it are good/bad
- Ignoring anything which does not fit one's narrative
- Belief that any good thing that happens must have negative purposes

Magical Thinking
- Making negative predictions about the future
- Belief that others are thinking negatively about oneself
- Belief that everything is based on one's worldview or relates to oneself
- Belief that feelings are the truth

CBT Steps:
1. Assess emotions and causes of the unwanted reaction
2. Identification of possible cognitive distortions and alternative thinking patters which may be more based in truth and logic.
3. Apply new thinking patter when situation occurs again and evaluate if reactions changed.

Trauma-Focused CBT
Incorporates Trauma Informed Care into the CBT process.
Validate their experience and emotions. Provide a safe environment. Encourage relaxation techniques to decrease anxiety. Identify positive coping mechanisms. Help find ways to react differently to events in the future.

Motivational Interviewing (MI)
Helping patients to make positive changes in their behaviors.

The patient already has the capacity for change within themselves. Encourage the patient when they are considering making a change. Support them and their autonomy. Reflect and validate their emotions about the change.

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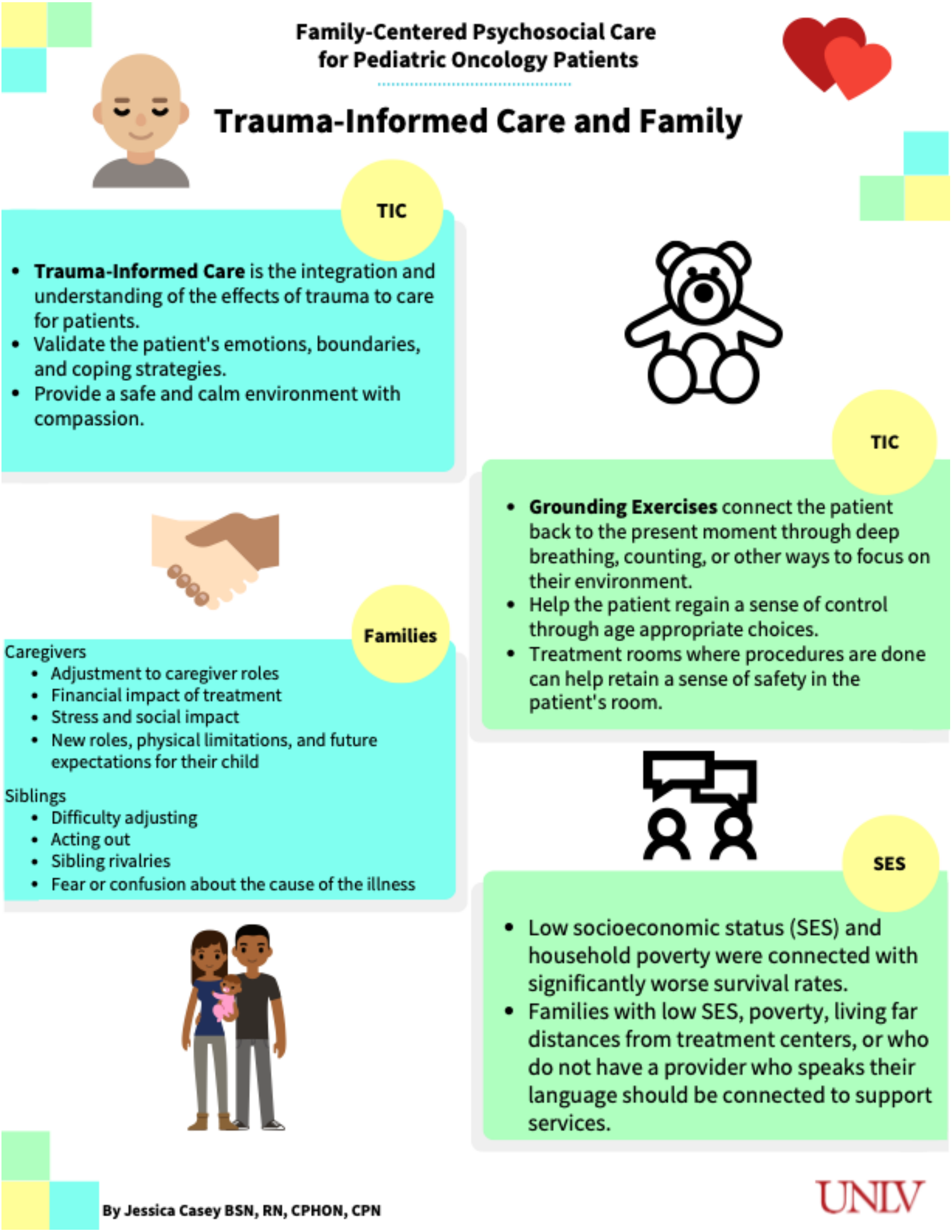
Figure K6: Trauma-Informed Care and Family



Family-Centered Psychosocial Care for Pediatric Oncology Patients

Trauma-Informed Care and Family

TIC

- **Trauma-Informed Care** is the integration and understanding of the effects of trauma to care for patients.
- Validate the patient's emotions, boundaries, and coping strategies.
- Provide a safe and calm environment with compassion.

TIC

- **Grounding Exercises** connect the patient back to the present moment through deep breathing, counting, or other ways to focus on their environment.
- Help the patient regain a sense of control through age appropriate choices.
- Treatment rooms where procedures are done can help retain a sense of safety in the patient's room.

Families

Caregivers

- Adjustment to caregiver roles
- Financial impact of treatment
- Stress and social impact
- New roles, physical limitations, and future expectations for their child

Siblings

- Difficulty adjusting
- Acting out
- Sibling rivalries
- Fear or confusion about the cause of the illness

SES

- Low socioeconomic status (SES) and household poverty were connected with significantly worse survival rates.
- Families with low SES, poverty, living far distances from treatment centers, or who do not have a provider who speaks their language should be connected to support services.

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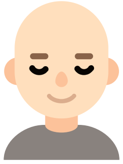
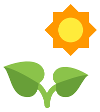
Figure K7: Developmental and Behavioral Disorders



Family-Centered Psychosocial Care
for Pediatric Oncology Patients



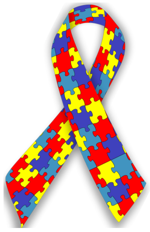
Developmental and Behavioral Disorders

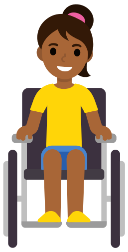
ADHD, ODD, Conduct Disorder

- **ADHD** (Attention Deficit Hyperactivity Disorder)- hyperactivity/impulsivity or inattention for at least 6 months in two different settings. Tx-Behavioral therapy and stimulant medications.
- **ODD** (Oppositional Defiant Disorder)- defies authority figures and rules. Tx-Behavioral therapy and calm consistent rules.
- **Conduct Disorder**- aggressive disobedience. Tx-Behavioral therapy and clear rules.

Down Syndrome

- **Down Syndrome** occurs when a child has a three copies of Chromosome 21.
- Symptoms- developmental delays, protruding tongue, learning difficulties, increased respiratory infections, hyperextensibility, possible hearing loss or increased risk of leukemia.
- Tx- Caregiver support. Support the patient to attain personal goals and independence. Physical therapy. Speech therapy. Occupational therapy.





Cerebral Palsy

- **Cerebral Palsy** is caused by a brain injury from the time of gestation up to 2 years old.
- Symptoms- Delayed development, muscle tone changes, abnormal movements, potential learning difficulties.
- Tx- Occupational therapy. Speech therapy. Physical therapy. Mobility devices. Anti-seizure medications if necessary. Caregiver support.

Autism

- **Autism** involves a spectrum of social and behavioral difficulties.
- Assessment by pediatrician at 18 and 24 months old.
- Symptoms- social interaction difficulties, repetitive behaviors, sensory sensitivities, possible verbal difficulties.
- Tx- Behavioral therapy, support of routines, respect of boundaries and sensory challenges, and potential for medications such as lorazepam during emotional outbursts.

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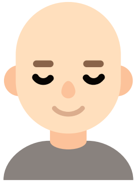
Figure K8: Long Term Survivorship



Family-Centered Psychosocial Care for Pediatric Oncology Patients

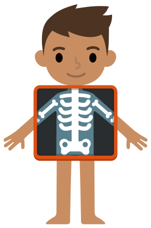
Long Term Survivorship

From Treatment Into Relapse

- Education and discussion about the adjustment from patient with cancer receiving treatment into survivor
- Adjustment into new roles and out from the identity of cancer and illness into an identity of health
- Social engagement and school reentry
- Personal goals and adjustments based on new physical capabilities

Screening

- Screening for relapse, secondary malignant neoplasm, organ damage, development, psychological conditions, and adjustment after treatment.
- Importance of establishing a primary care relationship.
- Cardiovascular, neurological development, and pulmonology assessment.



Fear of Relapse

- Importance of screening for relapse. Patient's may fear results and resist follow up.
- Education to address expectations and symptoms which may cause fear of relapse.
- Importance of medication adherence.
- Provide patients with a plan of care and treatment that they can provide to doctors in the future

The Future

Potential to have lower educational and socioeconomic attainment than peers.

Support patient success through:

- Support groups
- Career development
- Psychological care
- Social support and involvement
- Education to address fears

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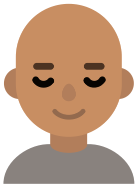
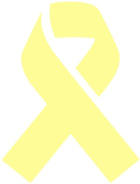
Figure K9: New Diagnosis



Family-Centered Psychosocial Care for Pediatric Oncology Patients

New Diagnosis

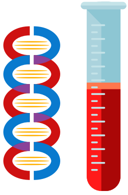


At Time of Diagnosis

- Likely are feeling intense fear
- Respect their Stages of Grief
- Ensure all caregivers are present.
- Prevent interruptions during discussion with the provider.
- Use age appropriate and relatable terminology and descriptions.
- Be truthful and supportive

Needs Assessment

- Social work referral for financial and social support
- Provide information on charities that can help pediatric oncology patients
- Connect to patient and caregiver support groups
- Discussion of supplies that the family may find useful, such as mints for nausea



Education

- Prepare before entering the patient's room by being ready for possible questions and printing educational information.
- Ensure the education is not done during a highly emotional moment to improve retainment.
- Provide education in a quiet and uninterrupted room.
- Allow participants and the patient to ask questions. Correct any misconceptions.
- Validate their emotions and reactions. Let them know they can ask questions any time, and are not expected to remember everything.

Preparation

Provide a copy of information on:

- Treatment roadmap
- Side effects of treatment
- Pathophysiology of their cancer
- Complications during treatment
- Infection prevention
- Support services
- Common terminology
- When to call the physician

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Figure K10: PEDIATRIC

PEDIATRIC: A resource for family education

PEDIATRIC is intended to guide nurses in providing education to families after a pediatric patient is newly diagnosed with cancer.

Prepare

Study the patient's treatment plan and medications. Print available educational handouts on the diagnosis, medications, side effects, home care, common disorders, complications to treatment, and basic pathophysiology related to treatment. This may include information on CBC results, infection prevention, bleeding prevention, neutropenia, and anemia. Prepare for questions the family and patient may have. Ensure education is provided in the patient and caregiver's preferred language.

Environment

Ensure that the education occurs during a period of time where there will be minimal interruptions. Education will ideally be completed in the patient's room. Make sure that all primary caregivers and the patient will be present. It is best to choose a time where the patient and their caregivers are not in emotional distress, such as immediately after diagnosis or emergency medical situation.

Describe

Inform the family that you want to provide new diagnosis education about the diagnosis, medications, treatment, side effects, home care, and expectations. Let them know that they may not remember everything covered, but printed educational information will be provided for them to review.

Invite

Invite the patient and caregivers to ask questions. Tell the family that it is okay for them to ask the same question multiple times if they need to, and provide them writing supplies that they can use to write down questions they may think of later.

Assess

Assess the patient and family's understanding of the education by asking them to "teach-back" what was covered and by asking questions. Before asking questions let the caregivers and children know that this is not a "test" and there is no judgment on their answers.

Time

Give realistic time frames based on the treatment plan. Inform the patient of how long the chemotherapy or immunotherapy will run over, and when they will be started. Let the family and patient know what days during their admission they will be receiving treatment.

Reflect

Allow the family and patients to express their fears, emotions, concerns, and needs. Reflect upon their emotions and concerns to clarify if the educator's interpretation is correct. Also let the caregivers and patient know that the diagnosis is not their fault if they voice feelings of guilt or confusion. Provide empathetic responses to their emotions, validation, and let them know their response is understandable.

Intervene

If the caregivers or patient have any misconceptions, incorrect expectations, or misunderstandings from the education provide correction through repetition of correct information. Provide additional written information if necessary.

Close

Reiterate that the caregivers and patients are not expected to remember everything covered. Let them know they can ask any and all questions. Provide them with information for support groups, and let them know that they have the support of the nursing staff.

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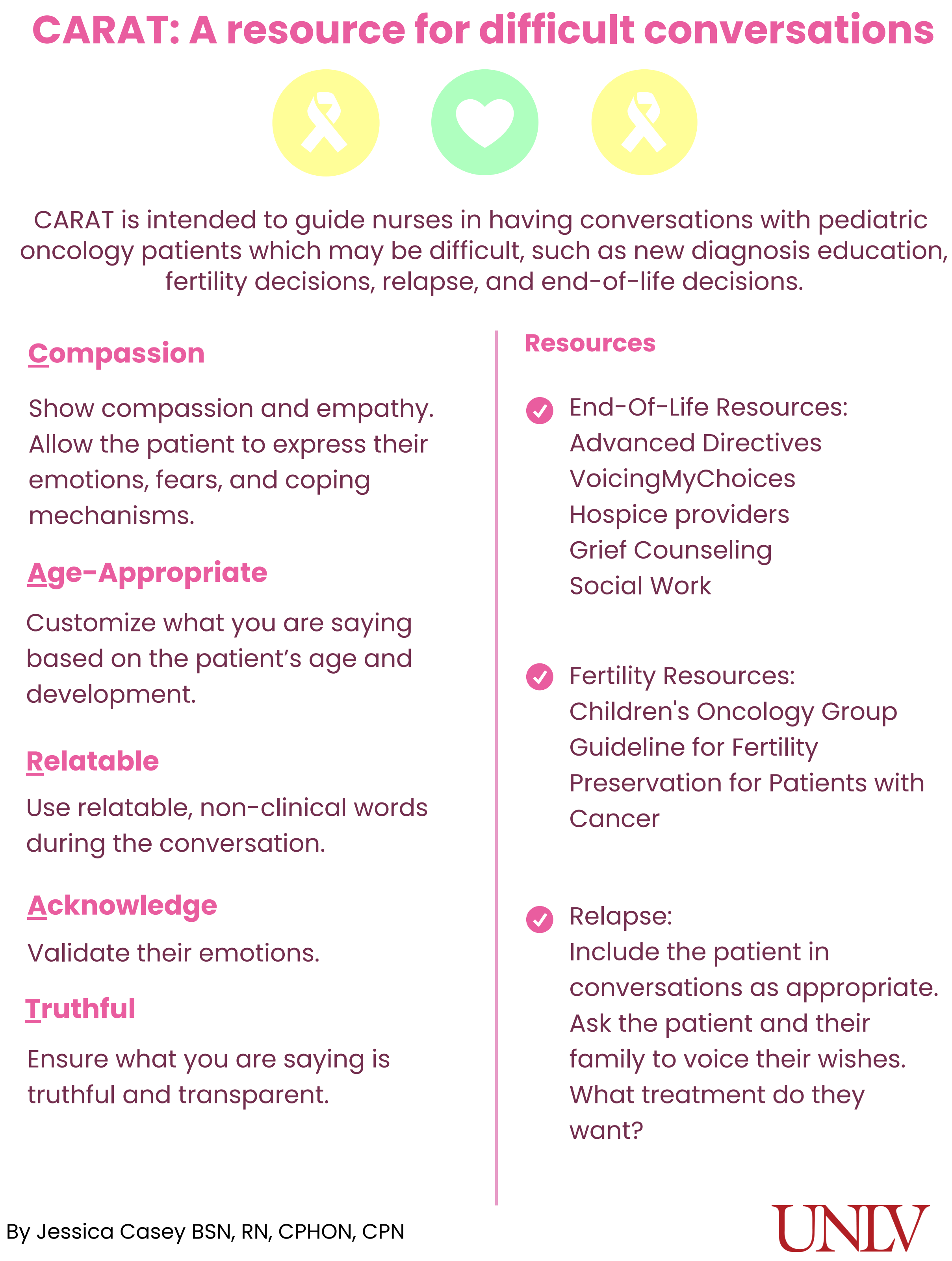
Figure K11: CARAT



CARAT: A resource for difficult conversations

CARAT is intended to guide nurses in having conversations with pediatric oncology patients which may be difficult, such as new diagnosis education, fertility decisions, relapse, and end-of-life decisions.

Compassion

Show compassion and empathy. Allow the patient to express their emotions, fears, and coping mechanisms.

Age-Appropriate

Customize what you are saying based on the patient’s age and development.

Relatable

Use relatable, non-clinical words during the conversation.

Acknowledge

Validate their emotions.

Truthful

Ensure what you are saying is truthful and transparent.

Resources

✓ End-Of-Life Resources:
Advanced Directives
VoicingMyChoices
Hospice providers
Grief Counseling
Social Work

✓ Fertility Resources:
Children's Oncology Group Guideline for Fertility Preservation for Patients with Cancer

✓ Relapse:
Include the patient in conversations as appropriate. Ask the patient and their family to voice their wishes. What treatment do they want?

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Curriculum Vitae

Jessica Casey BSN, RN, CPHON, CPN

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Education

Bachelor of Science in Nursing. University of Nevada, Las Vegas. Las Vegas, NV. December 2016

Training

- Optum/Southwest Medical AAP Internship. Las Vegas, NV. October 2020-December 2021.
- New Graduate RN Residency. Valley Health System. Las Vegas, NV. January 2017-October 2017.

Professional Experience

Pediatric RN II. Pediatric Hematology/Oncology, IMC, PICU, and Pediatrics. Float to SCN NICU.
Summerlin Hospital Medical Center - Las Vegas, NV **January 2017-Present**

- Newborns – 21 year old patients
- Ports, PowerFlow apheresis ports, Vortex ports, PICCs, Broviacs, and PIV care
- Chemotherapy and immunotherapy administration, including on-study patients. IV therapy, PCA pumps, IVIG, and transfusions
- Preparing and assessment: exchange transfusions, LPs, seizures, stem cell harvest, and bone marrow biopsy
- Oxygenation (blow-by to NIMV)
- Chest Tube care
- Pre/post-op and wound care
- Diabetes care and education
- OD and psychiatric treatment
- Care of patients with ESRD, peritoneal dialysis, hemodialysis, and HTN treatment
- Kangaroo pumps, G tubes, G-J tubes, nasogastric tubes, and gavage feeds.
- Urinary catheters and ostomies
- Family centered care, treatment, and education
- Writing Standards of Practice policies
- Training of RNs and students
- Accurate and complete charting

Licenses and Certifications

- Certified Pediatric Oncology and Hematology Nurse (CPHON)— Expires December 2023
- Certified Pediatric Nurse (CPN)—Expires February 2023
- APHON Pediatric Chemotherapy and Biotherapy Provider—Expires December 2022
- Basic Life Support (BLS)—Expires February 2023
- Advanced Cardiovascular Life Support (ACLS)—Expires February 2022
- Pediatric Advanced Life Support (PALS)—Expires February 2022
- Neonatal Resuscitation Program (NRP)—Expires August 2022

Professional Memberships

- American Association of Nurse Practitioners—Student Member
- Association of Pediatric Hematology/Oncology Nurses
- Oncology Nursing Society

Achievements and Projects

- Service Excellence Award from Summerlin Hospital—May 2019
- Outstanding BSN Leadership Project from UNLV—December 2016

Volunteer Work

- Make a Wish (Wish Discovery Team, Wish Story Writer, Wishmaker Club, Donations, 2018-present)
- Beads of Courage Ambassador for my hospital (2019-present)
- Knots of Love (knit hats for veteran drive and hospitalized patients, 2015-present)
- Wounded Warrior Project (2020-present monthly donations)