BEADS OF COURAGE AS A PSYCHOSOCIAL INTERVENTION

FOR CHILDREN WITH CYSTIC FIBROSIS

A Research Grant Proposal

Presented to the faculty of the School of Nursing
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Submitted in partial satisfaction of
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Jennifer Spahr

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Abstract

of

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Cystic fibrosis is a fatal inherited autosomal recessive disorder associated with defective chloride transport resulting in abnormally thick secretions and ineffective clearance which causes alterations of the respiratory, gastrointestinal, integumentary, and reproductive systems (McCance et al., 2014). Cystic fibrosis affects approximately 30,000 children and adults in the United States and 70,000 worldwide (McCance et al., 2014). Median age of diagnosis is 6-8 months and the median age of survival is 37 years old (March & Schrub, 2013). As survival into adulthood becomes a reality, psychosocial interventions become an increasingly important aspect of medical care for these chronic illnesses.

The Beads of Courage Program is a frequently used resilience based psychosocial intervention for children with chronic illnesses and life-threatening conditions, yet there is little research demonstrating its effectiveness. Although Beads of Courage is used in pediatric hospitals worldwide, research on the program is limited to one study by the founder of the program pediatric cancer patients. There is an increasing need for psychosocial interventions that are theory and evidence based for children with chronic illnesses. The purpose of this study is to evaluate the Beads of Courage Program as a psychosocial intervention to increase resilience in children suffering from cystic fibrosis.

[Signature]
Dr. Denise Boren

April 29, 2015
Date
DEDICATION

I would like to dedicate this work to the two most important people in my life…

My husband Brian, “my rock”

My mom Bonnie, “my hero”

ACKNOWLEDGEMENTS

When I began this journey 3 years ago, I never imagined that in addition to a Masters degree, I would meet 4 amazing nurses and wonderful people, that I now call great friends. Thank you Kristin, Ella, Camila, and Jamila for your support and encouragement. And Jessica, can you believe our nursing school rollercoaster started 12 years ago? You have always been there for me through the ups and downs. I would not be the nurse I am today without you. These five ladies are the few that truly understood the “struggle was real”.

I would like to acknowledge my friends and family for the unconditional love and support throughout my educational journey.

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CHAPTER ONE: INTRODUCTION

Background and Significance

Advances in Western Medicine over the past century have dramatically increased disease-related survival rates and life expectancies. Today, more children are surviving cancer and battling what were considered childhood illnesses into adulthood. For that reason, many previously deadly childhood illnesses have evolved into chronic illnesses. For example, in the 1930s children with cystic fibrosis lived to an average age of 5 years old—elementary school age in the 1950s—and today have a life expectancy into their 30s, 40s, or even longer (Cystic Fibrosis Foundation, 2011). Cystic fibrosis affects approximately 30,000 children and adults in the United States and 70,000 worldwide (McCance et al., 2014). Median age of diagnosis is 6-8 months and the median age of survival is 37 years old (March & Schrub, 2013). As survival into adulthood becomes a reality, psychosocial interventions become an increasingly important aspect of medical care for these chronic illnesses. Psychosocial interventions should begin in childhood.

The most often recommended psychosocial intervention is counseling, which puts added time constraints and burdens on children and parents. Additional psychosocial interventions should be identified, “there is value in interventions that manipulate mediating variables, such as coping and hope, that have been found to influence resilience outcomes” (Peterson & Bredow, 2013, p.272). There is an increased need for proven psychosocial interventions that are theory-based and that promote positive outcomes in children with chronic illnesses.

An example of such intervention is the Beads of Courage Program. Jean Baruch, a pediatric oncology nurse, created the Beads of Courage Program in 2004. The beads provide children with something tangible to symbolize their journey, which encourages children to tell their story, thus lessening their illness-related distresses and increasing the use of positive coping
mechanisms (Beads of Courage, 2011). A child suffering from a chronic illness earns specific colored beads for treatments, procedures, accomplishments, and milestones. The Beads of Courage Program has grown substantially since 2004 and is now used by 250 pediatric hospitals within the United States (beadsofcourage.org, 2014).

**Problem**

Despite the overwhelming popularity of the Beads of Courage Program as a psychosocial intervention for pediatric illnesses, there is little research demonstrating the effectiveness of the program. Research on the Beads of Courage Program is limited to one study by the founder of the program amongst pediatric cancer patients (Baruch, 2010).

Research on similar bead programs is limited to two studies including the “Beaded Journey” for pediatric oncology patients and “The Heart Bead Program” for children with cardiac conditions (Penkman, Scott-Lane, & Pelletier, 2006; Redshaw, Wilson, Scarfe, & Dengler, 2011). In addition, there is a disproportionately small amount of published research over the past four years to support the extensive growth of the program. Further research on the Beads of Courage Program and its effectiveness as a psychosocial intervention is needed specifically related to pediatric chronic illness.

**Purpose**

The purpose of this study is to evaluate the Beads of Courage Program as a psychosocial intervention to increase resilience in children suffering from cystic fibrosis.
Research Question

The research question is “Will implementing the Beads of Courage Program as a psychosocial intervention on a medical pulmonary unit at a medical local medical center/clinic in southern California increase resilience in children ages 4-14 with cystic fibrosis?”

Research Variables

The dependent variable is resilience in children with cystic fibrosis. The independent variable is the Beads of Courage Program.
CHAPTER TWO: LITERATURE REVIEW

Review of Related Literature

After a thorough review of nursing, medical, and psychology literature, three published articles regarding bead programs for children coping with chronic illnesses were found. The three bead programs discussed in these articles are all related to one original program called “Bravery Beads”, which was developed by an oncology social worker. “Bravery Beads” was piloted at British Columbia Children’s Hospital with pediatric oncology patients (Baruch, 2010; Penkman et al., 2006; Redshaw et al., 2011).

The first study, A Psychosocial Program for Pediatric Oncology Patients: A Pilot Study of “The Beaded Journey” by Penkman et al. (2006), evaluated the effectiveness of a bead program that was developed to ease the psychosocial burden of cancer treatment for children and their families. The purpose of the Beaded Journey Program was to “help children and their families to tell their story, and provide a tangible reminder of what they have been through, thereby validating their feeling of being overwhelmed, fatigued, or scared” (Penkman et al., 2006, p. 105-106). Children enrolled in the Beaded Journey Program received a strand of beads that spelled out their name and a journal to record experiences (Penkman et al., 2006). Additional specific beads were given after procedures, tests, admissions, and chemotherapy (Penkman et al., 2006). The study evaluated both parent and child perceptions of the value of the bead program.

Fifty-eight families qualified to participate in the study. The data was obtained from 39 anonymous mail-out survey responses. The researchers developed the survey, which included 17 Likert-scale items and 4 open ended questions (Penkman et al., 2006). Parents were responsible for survey responses to all questions. Mean age of the children was 6.9 years, and mean time in
the program was 8.8 months (Penkman et al., 2006). Quantitative results of the study indicated that the program is valuable; however, parents endorsed higher values for themselves than for their children (Penkman et al., 2006). Value ratings for child and parent were correlated using Pearson r and were moderately correlated ($r = .455, p < .005$) in the positive direction (Penkman et al., 2006).

Qualitative results indicated that all families would recommend this program to others (Penkman et al., 2006). Quantitative data was collected from four open ended questions (Penkman et al., 2006). A main theme that emerged was the program served as a useful communication tool to help families share their story with other family and friends about what is happening in treatment (Penkman et al., 2006). Another theme that emerged was that parents thought the beads would become more valuable to their children as they grew older (Penkman et al., 2006). A limitation to this study was that it was based solely on parent’s perceptions and the child participant self-report data was not collected or included. The authors determined the Beaded Journey was a “creative and innovative way to provide psychosocial support to child-cancer patients and their families” (Penkman et al., 2006, p.114).

The second study was the “Narrative of the Heart: Telling the Story of Children with a Cardiac Condition through a Bead Program” by Redshaw et al (2011). The main focus of this study was to evaluate the significance of a bead program as a positive intervention to help children with a cardiac condition and their families develop a narrative of their experiences (Redshaw et al., 2011). Illness narratives can help facilitate the ability to talk about the illness, related experiences, and deal with stressors related to traumatic events (Redshaw et al., 2011). The program was called “The Heart Beads” and involved giving the child with a cardiac condition beads for procedures and processes they endure throughout hospitalization (Redshaw
et al., 2011). Similar to other bead programs, the enrolled child was given a string of beads that spelled out their first name and accumulated specific beads based on procedures and events as outlined by the program guide. The researchers theorized the beads would promote courage by rewarding achievements and the child and their families would have a tool to help narrate their journey (Redshaw et al., 2011). Eleven families (mother/child or father/child duos) participated in semi-structured interviews about their experiences with the program (Redshaw et al., 2011). Content analysis was used to interpret interviews. The major theme that emerged from this research was the importance of the beads in telling the child’s story (Redshaw et al., 2011). Participants described the many values of story telling including sharing their experiences with others, validation by the listeners of the stories, reflecting on the past, appreciating how much their child had endured, and a visual symbol of the length of the story (Redshaw et al., 2011). Other themes included symbolism, encouraging/uplifting, acknowledgment, connection with others, and imagining the future (Redshaw et al., 2011). The authors concluded that the bead program was a “significant way for children and families to comprehend their time in the hospital as part of the child’s life story” (Redshaw et al., 2011, p.2802). A limitation to this study was that only 4 of the 11 child participants were old enough to participate in the interview process with their parent. The remainder of the bead receivers were infants and conclusions were based on the parents’ interview alone.

The final study was a published doctoral dissertation entitled The Beads of Courage Program for Children Coping with Cancer (Baruch, 2010). The Beads of Courage Program is an art-in-health program that was developed by the researcher, and its aim is to strengthen resilience and alleviate suffering in children being treated for cancer (Baruch, 2010). As with other bead programs, children enrolled in this program receive a string of beads that spells out their name
and accumulated beads in specific colors or shapes representing procedures and milestones reached throughout treatment (Baruch, 2010). This study evaluated the Beads of Courage Program process, implementation, and outcomes (Baruch, 2010). A qualitative descriptive method was used where parents, children, clinicians, and bead artists were interviewed (Baruch, 2010). Data was analyzed using content analysis, and substantive codes were derived from data using open codes (Baruch, 2010). Results revealed the program was operating according to the design and the program rated high on overall satisfaction and perceived worth (Baruch, 2010). Themes that emerged from the content analysis included beads as a form of narrative medicine, a reflective tool, a symbol of accomplishment, joy, and encouragement for children receiving cancer treatment (Baruch, 2010). Most importantly the study data supported the Beads of Courage Program Theory; if resilience-based protective factors were supported including: positive coping, derived meaning, and social support then risk factors of uncertainty of illness than negative factors like defensive coping would decrease (Baruch, 2010). Limitations to this study include a possible bias because the researcher is the developer and founder of the program. Further research is recommended, specifically quantitative research that measures resilience factors over time while receiving the Beads of Courage (Baruch, 2010).

**Major Concepts and Variables Defined**

**Cystic Fibrosis**

Cystic fibrosis is a fatal inherited autosomal recessive disorder associated with defective chloride transport resulting in abnormally thick secretions and ineffective clearance which causes alterations of the respiratory, gastrointestinal, integumentary, and reproductive systems (McCance et al., 2014). Cystic fibrosis is the most common lethal genetic disease in Caucasians in the United States (March & Schub, 2013). The incidence of cystic fibrosis varies among
ethnicities. It affects approximately 1 in 3,200 Caucasians, 1 in 15,000 African Americans, 1 in
9,500 Hispanics, and 1 in 31,000 Asian Americans (March & Schub, 2013; McCance et al.,
2014). Cystic fibrosis results from a mutation in the cystic fibrosis transmembrane conductance
regulator (CFTR) gene, which is located on the long arm of chromosome 7, resulting in
abnormal chloride transport (McCance et al., 2014). A diagnosis of cystic fibrosis in a child
requires inheritance of two CFTR mutations (one from the mother and one from the father).
When both the mother and father are carriers, the child has a 25% chance of inheriting the
disease and a 50% chance of becoming a carrier of the mutation (March & Schub, 2013). More
than 1,900 cystic fibrosis causing CFTR mutations have been identified and 1 in 29 whites in the
United States are carriers (March & Schub, 2013; McCance et al., 2014).

Since 2009, screening for cystic fibrosis is included in newborn screening in all 50 states
(Nicholson, 2013). Newborn screening has dramatically reduced the average age of diagnosis
and increased the prognosis for individuals with cystic fibrosis. A positive newborn screen is an
indicator for sweat chloride testing (Nicholson, 2013). Requirements for a diagnosis of cystic
fibrosis are positive genetic testing or a positive sweat chloride and one of the following: chronic
pulmonary disease, pancreatic insufficiency, or positive family history (often a sibling) (Sharma,
2014). Most children now (75%) are diagnosed by the age of 2 (Cystic Fibrosis Foundation,
2011). The median age of diagnosis is 6-8 months (Sharma, 2014).

Onset of symptoms, involvement of systems, and disease severity varies on an individual
level depending on the class of genetic mutation, environment, and treatment compliance; most
commonly affected systems are the respiratory and the gastrointestinal (McCance et al., 2014).
Signs and symptoms of cystic fibrosis are all related to, or adverse effects of, abnormally thick
secretion build up and ineffective clearance of secretions in various organ systems.
Manifestations may be multiple and complex depending on stage and progression of the disease, and may include meconium ileus in newborns, increased salty sweat, increased chest diameter, clubbing, respiratory failure, productive cough, nasal polyps, wheezing, constipation, fatty foul-smelling stools, recurrent pneumonia, failure to thrive, and infertility (March & Schub, 2013).

Treatment is lifelong and primarily supportive, focused on maintaining optimal pulmonary and nutritional health. Pulmonary treatment involves multiple therapies and medications to decrease viscosity of secretions, increase secretion clearance, and delay bacterial colonization (McCance et al., 2014). Nutritional treatment includes pancreatic enzymes, fat-soluble vitamins, insulin, and high calorie intake is required to meet nutritional demands as poor nutrition is correlated with worse outcomes and additional complications (McCance et al., 2014). Secondary treatment is focused on promoting physical activity and positive quality of life for both the child and family (Hockenberry & Wilson, 2007).

Cystic fibrosis is a chronic, progressive disease with no known cure, requiring lifelong daily treatment and frequent hospitalizations. As the disease progresses towards end stage, organ transplantation of the lungs, liver, and/or pancreas may be necessary (March & Schub, 2013). The primary cause of death in cystic fibrosis is respiratory failure at an average age of 40 years (March & Schub, 2013; McCance et al., 2014).

**Psychosocial Interventions**

The primary focus of cystic fibrosis research has been on medical therapies and cures. With the gains medical research has made in increasing life expectancy, there is a crucial need for frequent and proper psychosocial interventions for children suffering from cystic fibrosis. Literature frequently highlights this need with minimal recommendations. Most often counseling or group therapy for the child and family is recommended. Counseling is an effective
psychosocial intervention; however, it can put additional pressure and burden on children and families who are already struggling with time constraints from frequent appointments and daily treatment routines.

Various other psychosocial interventions are used, both inpatient and outpatient, but many lack formal review for effectiveness or theoretical backgrounds. Beads as a psychosocial intervention is based upon two overarching themes, arts-in-medicine and narrative medicine. This section will discuss the two themes, both of which are well researched, have shown effectiveness, and are based in theory.

**Arts in medicine.** Art is used in healthcare to promote health and lessen suffering; art and making art has been shown to promote self-efficacy, reduce boredom, lower anxiety, decrease depression, improve immune functioning, and promote coherence between the person and the world (Sonke et al., 2009). The use of expressive art as a therapeutic intervention started in the 1950s after World War II (Sonke et al., 2009). In the 1970s, a new popularity began for art-based hospital programs that included visual, literary, and performing art as “healthy distractions” (Sonke et al., 2009). Art in medicine became widely used in the 1980s primarily as aesthetics to create a healing environment (Sonke et al., 2009). In the 1990s, art in healthcare evolved into a more hands-on approach, as artist’s started working with patients. Today arts-in-medicine is limitless from simple bedside arts and crafts projects to enormous outdoor healing gardens.

Arts-in-medicine is derived from several theoretical approaches including psychoanalytical, cognitive-behavioral, and humanistic (Sonke et al., 2009). Evaluation of arts in medicine began with outcome and patient satisfaction surveys. These studies were primary qualitative and revealed benefits including: improved patient coping, communication, and
attitude (Sonke et al., 2009). Rigorous control group research on arts in medicine is fairly limited; however, the results of the few completed studies have been significant for increased cognitive and psychosocial well-being of the treatment group versus the control (no treatment) groups (Sonke et al., 2009). Due to the evolution, popularity, and supportive research “arts in healthcare has emerged as a significant field and as a recognized component of the healthcare systems in the United State in the past half century” (Sonke et al., 2009, p.132). Given the economic climate of healthcare organizations and increasing need for cutting costs and meeting budgets, importance of continued quality research of arts in medicine is critical. Future research should include cost-effectiveness as well as the impact on the well-being of the individual (Sonke et al., 2009).

**Narrative medicine.** Historically narratives have been an important part of medical care, but they were pushed aside as modern medicine grew and began to favor scientific facts and findings over patient narratives (Kalitzkus & Matthiessen, 2009). Once again narratives are gaining momentum and an era of narrative-based medicine has emerged. These narratives include sharing illness related stories between the patient and the health care provider, as well as between the patient and their family (Kalitzkus & Matthiessen, 2009). Narrative medicine is “medicine practiced with the narrative competencies to recognize, absorb, interpret, and be moved by the stories of illness” (Charon, 2005, p.261). Narrative medicine is derived from the medical humanities and literary theories (Charon, 2005).

An important benefit to narrative medicine is giving the patient and their families a voice to their suffering in order to comprehend what they endure in their sickness (Charon, 2005). Narrative medicine allows more than a pathological description of illness; it allows a subjective approach where the listeners, including healthcare professionals, can understand how illness
affects the person on an individual basis (Kalitzkus & Matthiessen, 2009). In addition, narrative medicine has an important healing potential for both the listener and the patient teller. Studies have shown significant changes in physiologic parameters when the sufferer of a traumatic event or illness was able to document personal stressful experiences (Kalitzkus & Matthiessen, 2009). Constructing a narrative of traumatic experiences allows the person to acknowledge their trauma and positively impacts their sense of well-being (Redshaw et al., 2011).

The process of storytelling has emotional healing potential and provides a vehicle for self-reflection (Kalitzkus & Matthiessen, 2009). Narrating illness can allow a child to make sense of and take control of illness-related events (Redshaw et al., 2011). Children living with a chronic illnesses experience countless traumatic events throughout treatment. Encouraging children to tell their illness story can empower them by allowing them to reflect on what they have been through and how far they have come. The use of beads as symbols encourages children to share their narrative.

**Beads**

Beads are the “earliest known expression of the creativity of the human soul” (Francis, 1999). Beads are the oldest form of art dating back to 108,000 B.C.; they even precede cave paintings and carved figures (Dubin, 2009). The relationship between beads and people has evolved for over 40,000 years; beads have impacted the history of every culture and country over time (Francis, 1999).

The definition of the bead alone, in various languages, demonstrates its power. In Egyptian, the word for *bead* is sha-sha and sha means, “luck” (Dubin, 2009). In Anglo-Saxon languages, *bead* is derived from *bidden* “to pray” and *bede* “prayer” (Dubin, 2009). Over the centuries beads have been made of bones, shells, metals, and glass. Beads have served many
purposes including as decorations, jewelry, trade, symbols of wealth, mnemonic devices, calculations, tools, currency, magic, social status symbols, superstition, religion, and healing (Francis, 1999). Beads have been linked to strength and were worn by warriors for courage and protection from both natural and supernatural enemies (Dubin, 2009). In many societies beads were and are used with the concept that “an object that is part of something or resembling something else can influence the course of events” (Francis, 1999). For example, a hunter would wear claws or teeth of an animal to transmit the animal’s attributes to himself (Francis, 1999). Because beads have been long been used to protect warriors from enemies and lend special magical protection during long journeys, they are an excellent artifact to symbolize the courage it takes for a child to face illness. No matter what the bead is made of or where it came from, every bead has a story and it is up to the collector to give it a voice.

**Beads of Courage Program**

The Beads of Courage program is a non-profit organization founded in 2004 by Jean Baruch, a pediatric oncology nurse. The idea stemmed from her experience at a summer camp. She noted that children beaded constantly to pass time and make wearable items to show off, give away, and trade. The program is based on arts-in-medicine to support children and families facing chronic illness.

“The Program is a resilience-based intervention designed to support and strengthen children and families coping with serious illness. Through the program children tell their story using colorful beads as meaningful symbols of courage that commemorate milestones they have achieved along their unique treatment path” (beadsofcourage.org, 2013).
Once enrolled in the program a child (or parent if the child is too young) is given a bead journal, and a strand of beads that spells the child’s name (beadsofcourage.org, 2013). The child then receives a specific bead for every procedure, treatment, and milestone to add to his or her collection. For example, a yellow bead signifies an overnight hospital stay, and a glow in the dark bead symbolizes radiation (Weinstein Kaplan, 2012). The beads are handmade by collaborating artists. The Beads of Courage Program and guides are available for cancer and blood disorders, cardiac conditions, burn injuries, neonatal ICU families, and chronic illness (beadsofcourage.org, 2013). Written information about the program supports the benefits, which include: helping to decrease illness-related distress, increasing the use of positive coping strategies, helping children find meaning in illness, and restoring sense of self in children coping with serious illness (beadsofcourage.org, 2013).

The Beads of Courage Program is being used by 250 hospitals worldwide and has touched the lives of 60,000 children (beadsofcourage.org, 2014). The color and shape of each bead provides tangible evidence of the bravery and courage the wearer has demonstrated to receive the bead (Weinstein Kaplan, 2012). The visual evidence of the beads promotes strength for future procedures. The idea is if the child sees the bead from the last time they had a certain procedure they will acknowledge they have the strength to endure it again (Weinstein Kaplan, 2012). Once the beads begin to form a strand, the child and family can reflect on and narrate their journey with friends, family, and members of the health care team. Not only does it provide the child with a visual reminder of what they overcome, but also others can understand the lengths of what the child has been through.
**Resilience**

The definition of resilience varies widely throughout literature. Windle (2011), explored this complexity with a concept analysis and developed a robust comprehensive definition of resilience. Resilience is defined as “the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma” (Windle, 2011, p.152). Resilience is frequently described as an individual’s ability to ‘bounce back’. Each person has unique internal assets and resources to facilitate this; however, external factors assist their capacity to adapt in the face of adversity (Windle, 2011). Resilience is a unique concept in illness and health because it focuses on healthy development and strengths rather than weaknesses and deficits (Windle, 2011).

Research related to resilience is primarily psychology driven, focused around children and adolescents. The purpose of recent research on resilience has focused on detecting what factors contribute to developing or maintaining resilience and how resilience can be stimulated to improve health and well-being (Windle, 2011). The Beads of Courage Program is advertised as a resilience-based intervention. The author theorizes that the bead program provides an external asset to offset the effects of adversity and promotes positive adaptation.

**Conceptual Framework: Resilience**

The theory of resilience was designed to explain positive psychosocial adjustment to illness (Peterson & Bredow, 2013). Resilience is broadly defined as the phenomenon of positive adjustment in the face of adversity (Peterson & Bredow, 2013). It is warned that the term resiliency must not be substituted for resilience because resiliency describes a personality trait that cannot be altered (Peterson & Bredow, 2013). The three requirements that are needed for resilience include: the need for significant adversity/risk, the need for assets or resources to offset the effects of the adversity, and positive adaptation or avoidance of a negative outcome.
(Windle, 2011). Defining attributes of resilience are adversity, resistance, and adaptation (Windle, 2011). Closely-related attributes necessary for resilience to be achieved are assets, resources, or strength (Windle, 2011).

Antecedents are events that must occur prior to the occurrence of the concept (Windle, 2011). With resilience the antecedent that must occur is “the experience of a risk or adversity that carries a significant threat for the development of a negative outcome” (Windle, 2011, p.158). Consequences are the outcomes or end point that occurs as a result of the combination of the antecedents and attributes (Windle, 2011). Consequences of resilience demonstrate maintenance of normal mental or physical health or better than expected functioning (Windle, 2011). Some other positive outcomes of resilience include: increased confidence, better self-esteem, more self-efficacy, higher self-worth, enhanced quality of life, positive coping, global psychosocial adjustment, and a sense of having overcome that fosters mastery (Peterson & Bredow, 2013). In other words, positive adaptation or adjustment is achieved despite adversity.
CHAPTER THREE: METHODOLOGY

Introduction

The Beads of Courage Program is a frequently used resilience based psychosocial intervention for children with chronic illnesses and life-threatening conditions, yet there is little research demonstrating its effectiveness. Although Beads of Courage is used in pediatric hospitals worldwide, research on the program is limited to one study by the founder of the program pediatric cancer patients. The purpose of this study is to evaluate the Beads of Courage Program as a psychosocial intervention to increase resilience in children suffering from cystic fibrosis. There is an increasing need for psychosocial interventions that are theory and evidence based for children with chronic illnesses. Evidence of program value is necessary to prevent the program from being eliminated from institutions for financial reasons.

Research Question

It is hypothesized that the beads will increase resilience in a population that experiences frequent stressful events and procedures as a result of their disease. Will implementing the Beads of Courage Program as a psychosocial intervention on a medical pulmonary unit at a medical local medical center/clinic in southern California increase resilience in children ages 4-14 with cystic fibrosis?

Sampling Plan

The target population for this research study is children ages 4 to 14 with the diagnosis of cystic fibrosis. Qualifying participants will be selected from a local pediatric pulmonary clinic. Sample selection will be a consecutive, convenience, sample; it will be non-probability and non-random sample. Enrollment period will be over three months to achieve sample size.
The desired sample size for this study is 70 participants. This sample size was calculated for a one tailed dependent t-test using the following parameter: a power of 0.80 and an effect size of 0.50 (Keller & Kelvin, 2013). The logic behind the selection of these parameters was that the power of 0.80 suggests there is an 80% chance of rejecting a false null hypothesis; and a power of 0.80 is appropriate for behavioral scientists (Keller & Kelvin, 2013). A moderate effect size of 0.50 was chosen and was based upon the previous similar research; in which, similar research with the same research tool averaged an effect size of 0.49 (Wang et al., 2010). The Effect Power table recommends a minimum of 50 participants. Due to the longtime frame of the study and possibility of high attrition 40%, or 20 participants, were added to the recommend sample size.

To be eligible to participate in the study, participants must meet the inclusion criteria: diagnosis of cystic fibrosis, age 4-14, average of at least one two-week inpatient “tune up” per year, pulmonary clinic patient, parental consent, and child assent. Children at least 7 years of age can give verbal assent or agreement to participate in the study and if the participant is at least 12 years of age a written assent will be obtained (Polit & Beck, 2012). Sole exclusion criteria includes currently or previously enrolled in the Beads of Courage Program or similar bead program. Upon enrollment all participants will be given a string of beads that spells their first name and a bead guide.

**Research Design**

The research design is mixed method concurrent triangulation design. With this design both quantitative and qualitative data will be collected concurrently with equal importance. A mixed method design was chosen because neither quantitative nor qualitative design alone can address the complexity of resilience in children (Polit & Beck, 2012). The goal of this design is to gather separate but complementary and supporting data related to the phenomenon and to
determine the effectiveness of the intervention (Polit & Beck, 2012). Quantitative research
design is a quasi-experimental one group pre-test/post-test design. This design will allow for the
collection of data at baseline (pre-intervention) and post-intervention within one group in order
to determine the effectiveness of the intervention. The sample will be identical and nested
meaning the same subjects will provide data at both points in time (Polit & Beck, 2012). In this
study resilience will be a proxy measure of “effectiveness”. The dependent variable is resilience
in children with cystic fibrosis. The independent (intervention) variable is The Beads of Courage
Program.

Data Collection

After obtaining informed parental consent from all participants and written assent from
children 5 years and older, quantitative resilience data will be collected—pretest. Demographic
data to be collected includes age, gender, grade in school, ethnicity, socioeconomic status,
language and average number of hospitalizations per year. Throughout the intervention period
participants will receive specific colored or shaped beads each representing a procedure,
treatment, or milestone as outlined by the daily bead guide provided by the Beads of Courage
Program (Appendix B). Resilience data, number of beads accumulated, and number of hospital
stays will then be collected 1 year after enrollment period ended. Qualitative data will be
obtained using a semi structured joint (dyadic) interview at the completion of the intervention
period with child and parent. All interviews will be recorded and transcribed. Any audio and
paper records will be stored in a locked file cabinet. Data will be initially placed in Excel and
then transferred to SPSS computer software systems. Electronic systems will be encrypted and
password secured.
Quantitative Instrument

Resilience will be measured by participant self-report using the 10-item Connor-Davidson Resilience Scale (*Appendix A*) (Wang et al., 2010). The scale adequately operationalizes the concept of resilience or the phenomenon of positive adjustment in the face of adversity. Questionnaire items are measured using a Likert-type scaling with 5 rankings from 0-4, 0 being “not true at all” to 4 being “true nearly all of the time”. Faces representing the 0-4 options were added to the original instrument. An example question from the scale is “Thinks of myself as a strong person” (Wang et al., 2010). The higher the score on each item and the higher the overall score indicate higher resilience. Total possible score 0-40.

This scale has been tested in the general population in multiple age groups and in clinical settings (Wang et al., 2010). It has sound psychometric properties and distinguishes between those with lesser and greater resilience (Wang et al., 2010). Reliability is demonstrated by internal consistency or Cronbach’s alpha score of 0.91 (Wang et al., 2010). Cronbach’s alpha is rated on a scale of 0-1.00, 1.00 indicating higher reliability (Polit & Beck, 2012). The instrument has high test-retest reliability indicated by the correlation coefficient of 0.90 (Wang et al., 2010). The correlation coefficient is ranked on a scale of 0-1.00, 1.00 indicating higher stability (Polit & Beck, 2012). The instrument demonstrates concurrent validity (Wang et al., 2010). It has high construct validity where at least 75% of the items are appropriate for what is being measured (Polit & Beck, 2012; Wang et al., 2010). A limitation to the scale is there are no reversed scored items. Another possible limitation is young children may not be able to understand the concepts on the scale or how to use a ranking scale. Because the scale was altered, post hoc testing will be completed following analysis.
Analysis

Interpretive integration will be used for this mixed methods study in which quantitative and qualitative data will be analyzed separately; findings of each will be synthesized to develop an overall interpretation (Polit & Beck, 2012).

Data analysis will begin with an evaluation of all variables for measures of central tendency. The inferential analytic technique to be used is the one-tailed paired t-test. This test will compare the mean of the participants at two separate times (pre-test/post-test). The one-tailed paired t-test is a parametric test (Keller & Kelvin, 2013). To use this analytic technique, data must meet the following assumptions: same person takes a test at two different points in time (pre-test/post-test), data is ideally interval/ratio (can be ordinal), and normal distribution (Keller & Kelvin, 2013). If the data is not normally distributed, there must be at least 30 pairs of data (Keller & Kelvin, 2013). In the event that the data does not end up meeting the assumptions, a non-parametric analytic technique, Wilcoxon Matched-Pairs Signed Rank Test, will be used. Assumptions of the Wilcoxon Matched-Pairs Signed Rank Test include: same person pre-test/post test; scale can be ordinal, interval, or ratio; and sample size must have at least 5 pairs (Keller & Kelvin, 2013).

Analysis of qualitative data will begin with transcription of interviews. Based on the interviews, category schemes will be determined then data will then be coded into corresponding categories (Polit & Beck, 2012). Once coded, the data will be entered into computer assisted qualitative data analysis software (CAQDAS), ATLAS/TI, which will be used to display and analysis relationships between codes (Polit & Beck, 2012).
**Limitations & Bias**

Threats to internal validity of the study include the long timeframe. Over time there is a greater chance that other external variables can cause change instead of the intervention. Even the progression of the disease or disease treatment, or maturation, could influence outcomes. The timeframe allows for attrition, participant dropout or mortality. Using a self-report tool can cause limitations including: answering untruthfully and answering the socially acceptable way. Age or developmental level may cause a limitation to the study, if the child does not comprehend the questions. Another limitation that may be encountered is participation. Parents may choose not consent to research or the child may not give assent. A limitation to the research design is not having a control group and not having a random sample. There may be an investigator bias in this design because the researcher has a relationship with the facility and possible participants. Children may have a bias due to the novelty of the bead.

**Ethical Considerations**

Permission to conduct this study will be obtained from the hospital and California State University San Marcos Institutional Review Board before approaching potential research participants. Participation in this study will be voluntary and every effort will be made to ensure confidentiality is maintained (i.e., encrypted computer, locked file cabinets, and locked office). Participants in this study are considered a vulnerable population due to their age and health status; both parental consent and child assent (ages 5 and older) will be obtained. Minimum age limit of 4 years complies with the Consumer Product Safety Commission (CPSC). The CPSC monitors and regulates toys in the United States; they have banned small toy or small parts of toys to children 3 years and under due to the choking risk (Kids Health, 2013).
## CHAPTER FOUR: BUDGET

### Budget

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<td>Administrative overhead (10%)</td>
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<tr>
<td><strong>Project total</strong></td>
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**Budget Justification**

**Personnel Cost: $72,655**

Jennifer Spahr RN, MSNc, will serve as the principle investigator (PI) on this research project. Jennifer Spahr is a Masters’ prepared Registered Nurse with 5 years of pediatric nursing experience. The PI will devote 10 hours per week for 2 years to the research project. The PI will be responsible for the overall direction of the project including: Institutional Review Board applications; coordinating participant enrollment and enrollment data collection; overseeing intervention period (1 year); end of study data collection and interviews; directing research assistant; overseeing the proposed budget; and preparing dissemination reports. The PI will devote 25% of her time for 2 years to this project, annual salary of $80,000. Total payment calculated: $80,000 x 0.25(%) x 2 (years) = 40,000 x 0.10 (fringe) = **$44,000**.

Statistician (to be determined) duties: inputting data into SPSS & ALTAS/TI, analyzing data, assisting with transcription and interpretation of quantitative and qualitative data. Once the data has been collected and coded, the statistician will provide 15 hours a week for two weeks at an hourly rate of $175. Total payment calculated: 15 (hours) x 175 ($) x 2 (weeks) = 5,250 x 0.10 (fringe) = **$5,775**.

Research assistant (to be determined), the ideal candidate for research assistant will be a Master’s student, with experience in research. The research assistant will assist the PI with: participant enrollment, record keeping, intervention monitoring, assisting quantitative data collection, scheduling, interviewing, and assisting with coding of qualitative data. The research assistant will devote 50% of his/her time or 20 hours per week for 2 years on this project. Total payment calculated: 10 ($) x 20 (hours) x 104 (2 years) = $20,800 x 0.1 (fringe) = **$22,880**
Other than Personal Services: $8,050

Cost to implement the Beads of Courage program at the research facility is $5,000 this includes supplies (initial set of beads, strings, bead guides) and staff training. The cost for a 1-year supply of beads is $1,500. Total cost: $5000 + $1500 = $6500.

Supplies and equipment will be needed for the research project. The PI and research assistant will have use a password secured, encrypted computer for the research project, total cost $1,000. Audio recorder will be needed to record interviews, $50. Estimated cost of office supplies: paper, photocopying, and pens $500. Total cost: $1000 + $50 + $500 = $2,000.

Administrative Overhead

An administrative overhead of 10% will be added to the total cost of the project. Total cost $80,705 x 0.1 = $8,071

In-kind

Childlife Specialists at the research facility will be included in the Beads of Courage implementation and training. In addition to the researcher and research assistant, the Childlife Specialists can assist in handing out beads according to the journals. The Childlife Specialists will be trained and used in-kind. The Childlife Specialist will spend no more than 1 hour per day. Total in kind: 1 (hour) x 5 (days) x 20 ($/hour) x 52 (weeks) = $5,200
Appendix A

Altered 10-item Connor-Davidson Resilience Scale

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<th>Statement</th>
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<td>Able to adapt to change</td>
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<tr>
<td>Can deal with whatever comes my way</td>
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</tr>
<tr>
<td>Tries to see the humorous side of problems</td>
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<tr>
<td>Coping with stress can strengthen me</td>
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<tr>
<td>Tend to bounce back after illness</td>
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<tr>
<td>Can achieve goals despite obstacles</td>
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<tr>
<td>Can stay focused under pressure</td>
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</tr>
<tr>
<td>Not easily discouraged by failure</td>
<td><img src="image" alt="Rating" /></td>
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<tr>
<td>Thinks of self as a strong person</td>
<td><img src="image" alt="Rating" /></td>
</tr>
<tr>
<td>Can handle unpleasant feelings</td>
<td><img src="image" alt="Rating" /></td>
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0: not true at all 1: sometimes not true 2: neither true or not true 3: sometimes true 4: true nearly all the time
A Simple String becomes a Story of your Strength and Courage

BEad YOU... because nothing can change who you are. No matter what happens, no matter how your body changes as you go through your treatment, YOU will always be YOU. Like your parents, brothers, sisters, friends, nurses, child life specialists, and doctors, Beads of Courage will be here to help you through. You have courage... Bead YOU!

Be Proud of your String of Strength

Use this bead journal to keep track of your treatment journey. On the backside of the journal, you will see a column for each day of treatment. You can place the date at the top and then color in each bubble as you go thru your treatments OR you can place a number showing how many of each you have received. This journal will help remind your healthcare provider how many beads you need to receive. As your Beads of Courage collection grows, it will be something you can use to remember and re-tell your unique story of courage. Your story isn’t just about what is happening to you, it is about how you are taking control of a tough situation.

With each procedure or milestone in your treatment, you will receive a special bead. Each one will be your way of saying, “This may have been hard, but I DID IT!”

Remember to take your Beads of Courage collection with you to show your friends, classmates and family and tell your story of courage!

beads of COURAGE Providing innovative, arts-in-medicine programs to help families RECORD, TELL, and OWN their stories of COURAGE.

www.beadsofcourage.org
<table>
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<th>Daily Bead Journal</th>
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Bone Marrow Aspirate | Biopsy | Aspirations | Joint Injections | EVD | Beige
Chemotherapy | Immune Therapy | Infusions | Immunizations | White
Clinic Visit | Home Health Visit | Blue
Dressing Change | Skin Care | Gray
Emergency | Unusual Occurrence | Ambulance Ride | Magenta
Hair Changes (Hair Loss) | Hair Growth | Brown & Face Bead
Infusions (Antibiotics) | PCA | Pressor Support | Others | Purple
Inpatient Admission | Sleepover at Hospital Per Day | Yellow
Isolation | Neutropenia | Lime
Line Placement & Removal (Port) | Central Line | PICC | Orange
Medication Challenge (Taking/Learning) | Self Infusion | Bumpy
Mobility Challenge (Remain Lying Flat) | Bed Rest | Crutches | Splints | Other | Bumpy
Procedures (Cardiac Cath, Casting) | IPL Scope | Shunt Tap | Wound Care | Tortoise
Pokes (IV Starts) | Blood Draws | SC & IM Injections | Port Access | Black
Radiation | Echocardiogram | EEG | Ultrasound | Glow In The Dark
Respiratory Support | Pink
Stem Cell Harvest | Dialysis | TPN | NPO | Dark Green
Surgery | Glass Star
Test | Scans (CT Scan) | EKG | PFT | MRI | X-ray | Others | Light Green
Transfer to Intensive Care Unit | Square Heart
Transfusions | Blood Products | Red
Tube Placement & Removal (NG) | Chest Tube | Foley | Aqua
Transfer Units or Facilities | Long Distance Travel for Care | Fish Bead
Visits from Care Team (PT) | OT | RT | Others | Rainbow

**milestones**

Act of Courage | Glass Selection
Special Accomplishments | Recognition | Ceramic Special Selection
Independent in Self Infusions & Procedures | Ceramic Special Selection
Transplant | Transplant Glass Selection
Transfer to Adult Services | Completion of Treatment | BOC | Signature Heart
Discharge from Lengthy Hospitalization | Member's Choice Selection
References


Pathophysiology: the biologic basis for disease in adults and children. (7th ed).
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for pediatric oncology patients: a pilot study of "the Beaded Journey". Journal of
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Connor-Davidson resilience scale in Chinese earthquake victims. Psychiatry and Clinical
Neurosciences, 64(1), 499-504.

**Cystic Fibrosis Foundation**

**Pilot and Feasibility Award with LOI**

**Grant Application**

---

**APPLICANT NAME:** Spafr, Jennifer

**POSITION TITLE:** Clinical Nurse II

**ACADEMIC RANK:** MSN

**DIVISION:**

**DEPARTMENT:** Medical-Pulmonary

**E-MAIL ADDRESS:** jenzleh84@yahoo.com

**Tel:**

**Fax:**

---

**TITLES OF PROJECT** (Titles exceeding 81 characters, including spaces and punctuation, will be truncated.)

Beads of Courage as a Psychosocial Intervention for children with CF

**APPLICANT NAME:** Spafr, Jennifer

**POSITION TITLE:** Clinical Nurse II

**ACADEMIC RANK:** MSN

**DIVISION:**

**DEPARTMENT:** Medical-Pulmonary

**E-MAIL ADDRESS:** jenzleh84@yahoo.com

**Tel:**

**Fax:**

---

**PROGRAM ELIGIBILITY INFORMATION: (Responses to selected fields displayed below. For some grant programs this section may be blank.)**

**New CF Investigator?** Yes

---

**DATES OF PROPOSED PROJECT (MM/DD/YYYY)**

From 1/1/2016 Through 12/31/2017

**PROPOSED BUDGET**

87162.00

**Name:** Rady Children’s Hospital - San Diego

**Address:**

7910 Frost Street, Suite 200
San Diego CA 92123
United States

**Tel:** 858-966-8108
**Fax:**

**EIN:** 95-1691313

---

**SIGNING OFFICIAL FOR**

**Name:**

**Title:**

**Address:**

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**HUMAN SUBJECTS**

**Human Subjects Assurance No.:**

**IRB Status:**

**IRB Date:**

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**VERTEBRATE ANIMALS**

**Animal welfare assurance no.:**

**IACUC Status:**

**IACUC Date:**

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**RECOMBINANT DNA**

**Status:**

**Date:**

**BIOHAZARDS**

**SIGNATURE OF APPLICANT**

*(In ink. “Per” signature not acceptable.)*

**SIGNATURE OF SIGNING OFFICIAL**

*(In ink. “Per” signature not acceptable.)*

**ADDITIONAL SIGNATURE (follow guidelines for required signatures):** I certify that the statements herein are true, complete and accurate to the best of my knowledge.

**DATE**

**ADDITIONAL SIGNATURE (follow guidelines for required signatures):** I certify that the statements herein are true, complete and accurate to the best of my knowledge.

**DATE**

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**SIGNATURE OF APPLICANT**

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**SIGNATURE OF SIGNING OFFICIAL**

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**DATE**

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**ADDITIONAL SIGNATURE (follow guidelines for required signatures):** I certify that the statements herein are true, complete and accurate to the best of my knowledge.

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ABSTRACT

Cystic fibrosis is a fatal inherited autosomal recessive disorder associated with defective chloride transport resulting in abnormally thick secretions and ineffective clearance which causes alterations of the respiratory, gastrointestinal, integumentary, and reproductive systems (McCance et al., 2014). Cystic fibrosis affects approximately 30,000 children and adults in the United States and 70,000 worldwide (McCance et al., 2014). Median age of diagnosis is 6-8 months and the median age of survival is 37 years old (March & Schrub, 2013). As survival into adulthood becomes a reality, psychosocial interventions become an increasingly important aspect of medical care for these chronic illnesses.

The Beads of Courage Program is a frequently used resilience based psychosocial intervention for children with chronic illnesses and life-threatening conditions, yet there is little research demonstrating it's effectiveness. Although Beads of Courage is used in pediatric hospitals worldwide, research on the program is limited to one study by the founder of the program pediatric cancer patients. There is an increasing need for psychosocial interventions that are theory and evidence based for children with chronic illnesses. The purpose of this study is to evaluate the Beads of Courage Program as a psychosocial intervention to increase resilience in children suffering from cystic fibrosis.
TECHNICAL ABSTRACT

Cystic fibrosis is a fatal inherited autosomal recessive disorder associated with defective chloride transport resulting in abnormally thick secretions and ineffective clearance which causes alterations of the respiratory, gastrointestinal, integumentary, and reproductive systems (McCance et al., 2014). Cystic fibrosis affects approximately 30,000 children and adults in the United States and 70,000 worldwide (McCance et al., 2014). Median age of diagnosis is 6-8 months and the median age of survival is 37 years old (March & Schrub, 2013). As survival into adulthood becomes a reality, psychosocial interventions become an increasingly important aspect of medical care for these chronic illnesses.

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Advances in Western Medicine over the past century have dramatically increased disease related survival rates and life expectancies. Today, more children are surviving cancer and battling what were considered childhood illnesses into adulthood. For that reason, many previously deadly childhood illnesses have evolved into chronic illnesses. For example, in the 1930s children with cystic fibrosis lived to an average age of 5 years old—elementary school age in the 1950s—and today have a life expectancy into their 30s, 40s, or even longer (Cystic Fibrosis Foundation, 2011). Cystic fibrosis affects approximately 30,000 children and adults in the United States and 70,000 worldwide (McCance et al., 2014). Median age of diagnosis is 6-8 months and the median age of survival is 37 years old (March & Schrub, 2013). As survival into adulthood becomes a reality, psychosocial interventions become an increasingly important aspect of medical care for these chronic illnesses.

Psychosocial interventions should begin in childhood. The most often recommended psychosocial intervention is counseling, which puts added time constraints and burdens on children and parents. Additional psychosocial interventions should be identified, "there is value in interventions that manipulate mediating variables, such as coping and hope, that have been found to influence resilience outcomes" (Peterson & Bredow, 2013, p.272). There is an increased need for proven psychosocial interventions that are theory-based and that promote positive outcomes in children with chronic illnesses.

An example of such intervention is the Beads of Courage Program. Jean Baruch, a pediatric oncology nurse, created the Beads of Courage Program in 2004. The beads provide children with something tangible to symbolize their journey, which encourages children to tell their story, thus lessening their illness-related distresses and increasing the use of positive coping mechanisms (Beads of Courage, 2011). A child suffering from
## PROPOSED BUDGET

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<tr>
<td>Travel (North Amer)</td>
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<tr>
<td>Patient Care In-Pat</td>
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<tr>
<td>Patient Care Out-P.</td>
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<tr>
<td>Alterations and Rer</td>
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<tr>
<td>Other Expenses</td>
<td>250.00</td>
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<td>Consortium &amp; Cont</td>
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<td>Sub Total: Non-Per</td>
<td>6300.00</td>
<td>1750.00</td>
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<tr>
<td><strong>TOTAL DIRECT COSTS</strong></td>
<td>42628.00</td>
<td>38078.00</td>
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**Indirect Costs (i.e. overhead costs, facilities and administrative costs)**

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<td>INDIRECT COSTS</td>
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<td>TOTAL COSTS</td>
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<td>41124.00</td>
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