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# From worry, to warriors: an empowerment program for parents of infants diagnosed with a critical congenital heart defect (cCHD)

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BOSTON UNIVERSITY  
SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

**FROM WORRY, TO WARRIORS:  
AN EMPOWERMENT PROGRAM FOR PARENTS OF INFANTS DIAGNOSED  
WITH A CRITICAL CONGENITAL HEART DEFECT (cCHD)**

by

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Submitted in partial fulfillment of the  
requirements for the degree of  
Doctor of Occupational Therapy

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## **DEDICATION**

I would like to dedicate this doctoral project to all of the heart warrior families who have touched my heart and have shown me the true meaning of love, resilience and bravery.

## ACKNOWLEDGMENTS

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**ABSTRACT**

In the United States every year, approximately 7,200 infants are born with a critical congenital heart defect (cCHD), a life-threatening condition that often requires infant hospitalization and multiple surgeries after an infant's birth (CDC, 2020). A diagnosis of cCHD before birth, or prenatally, is almost always unexpected and leads to disruptions in parental occupations, or the everyday activities associated with being a parent. Current literature has revealed that parents are not equipped to navigate the challenges and barriers associated with parenting a hospitalized, critically ill infant. Lack of parent preparedness along with several other contributing factors have been associated with increased parent stress, difficulties with parent/infant bonding and a negative impact on parent mental health and quality of life.

Prenatal parent education programs often have positive effects on parent outcomes. However, they typically focus on the childbirth process rather than empowering parents and preparing them for the early stages of parenthood (Entsieh & Hallström, 2016). For decades, occupational therapy practitioners have supported critically ill infants and their parents through family education, health promotion and

advocacy, focusing on developmental, physical, and mental health. The following chapters provide an overview of current literature supporting the identified problem and a proposed solution; *From Worry, to Warriors*, a virtual parent empowerment program that utilizes key constructs from the profession of occupational therapy. Through participation in this program, parents will gain new knowledge, confidence, and a critical support network to navigate the challenges of becoming a parent to a critically ill infant.

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## LIST OF ABBREVIATIONS

BU .....	Boston University
cCHD .....	Critical Congenital Heart Defect
CHD .....	Congenital Heart Defect
ICU .....	Intensive Care Unit
NICU .....	Neonatal Intensive Care Unit
PCICU .....	Pediatric Cardiac Intensive Care Unit
RCT .....	Randomized Control Trials
SCT .....	Social Cognitive Theory
IRB .....	Institutional Review Board

## **CHAPTER ONE – Introduction**

### **Background**

Every year, nearly 40,000 babies in the United States are born with Congenital Heart Defects (CHDs), a variety of conditions that impact the structure and/or function of a baby's heart (March of Dimes, 2019). Approximately 1 in 4 infants with CHD are diagnosed with a Critical Congenital Heart Defect (cCHD). cCHD is considered life-threatening and typically requires a post-birth admission to a pediatric cardiac intensive care unit (PCICU) and/or one or more heart surgeries within the first year of life (Center for Disease Control, 2020). With advancements in medical care and technology, prenatal diagnosis of CHD has been increasing over the years (Ailes et al., 2013). In some cases, CHD can be identified during routine fetal ultrasounds (Children's Hospital of Philadelphia, 2021). Once transported to the pediatric cardiac intensive care unit (PCICU), infants are attached to intravenous lines, monitors, tubes and other life-sustaining equipment (Gibbs et al. 2010). Roughly 20% of infants hospitalized for cCHD management are admitted for 2 months or greater with some hospitalizations lasting a year or longer and followed by frequent re-admissions (Lisanti et al., 2019).

### **Identified Problem**

As a prenatal diagnosis of cCHD is unexpected, many expectant parents are not equipped to navigate the many challenges of caring for themselves and their family during an infant's PCICU admission. Parents find their anticipated parental occupations, or everyday activities associated with being a parent, to be significantly different from the reality they face after an infant with cCHD is born (Gibbs et al., 2016). This occupational

disruption, or disturbances that effects their ability to parent as initially expected, may impact their transition to the role of parenting a critically ill infant (Whitney & Walsh, 2020). In addition, there are several contributing factors such as medical fragility of an infant, PCICU environmental challenges, lack of parent knowledge, limited parent preparedness, parent/infant separation and limited early support for parent mental health & well-being. These contributing factors will be outlined further in Chapter 2. While in-hospital support is commonly available for parents of infants with cCHD, there is no documented evidence-based proactive programs available prenatally or post-birth that support the unique needs, skill building, and stress management of parents during a PCICU admission (Golfenstein et al., 2017).

### **Consequences to the Problem**

Parental stress begins with an infant's diagnosis and extends through the infant's hospitalization and beyond (Golfenshtein et al., 2017). Further, parental stress has been found to negatively affect parent quality of life, mental health, family function, child development, and child behavioral outcomes (Lisanti et al., 2019). According to Shorey et al. (2019) stressful adaptation to new parental roles and a lack of social support for parents can result in negative effects on parent/infant bonding and attachment. When surveyed, parents in the PCICU identified parental role alteration as one of the greatest sources of stress (Lisanti et al., 2017). Parental role alteration is experienced when parents are physically unable or feel that they are unable to care for their infant (Lisanti, et al., 2021). Additionally, up to 80% of parents with an infant diagnosed with cCHD experience psychological distress, including symptoms of depression, anxiety and trauma

(Woolf-king et al., 2017).

### **Domain of Occupational Therapy**

There has been extensive literature over the past decade presenting the importance of the occupational therapists' role in the neonatal intensive care unit (NICU). More specifically, the literature presents their unique ability to support and understand medical factors, human development, the complex relationship between environment and an infants' sensory system, and psychosocial strengths/needs (AOTA, 2018). Similarly, an occupational therapy practitioner in a pediatric intensive care setting plays an important role in supporting parent/infant engagement through co-occupations, also known as a caregiving activity that incorporates the participation of caregiver and the infant, which has a direct positive effect on parent/infant attachment (AOTA, 2018). However, the role of an occupational therapy practitioner extends far beyond the focus on occupations and includes a role in supporting education, health promotion, advocacy, and mental health (AOTA, 2020). In times of occupational disruption, or times when parents are unable to fulfill their parenting role as expected, an occupational therapy practitioner is distinctly qualified to help them to adapt (Whitney & Walsh, 2020).

### **Proposed Solution**

Early interventions that incorporate education have been found to have a positive impact on short term and long-term outcomes among infants and parents who are affected by cCHD (Shorey et al., 2019). Comprehensive support for parents, such as the formation of support groups and/or parent mentorship programs have been suggested to enhance parent quality of life as well as improve parent/infant physical, social and emotional

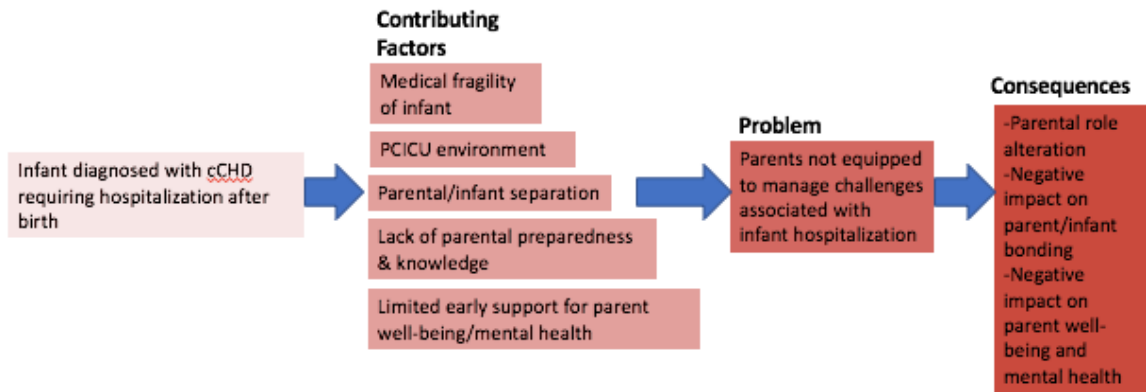
outcomes (Woolf-King, 2018). The following chapters will provide a detailed overview of the theories and current evidence to support the defined problem(s) and proposed solution. This dissertation will support the proposed program, a parent empowerment health promotion program that will encompass the holistic views from an occupational therapy lens.

## **CHAPTER TWO – Project Theoretical and Evidence Base**

Expectant parents who receive a prenatal diagnosis of a critical congenital heart defect (cCHD) are quickly propelled into a whirlwind of emotions, decisions, and planning. The reality of giving birth to a baby with a serious health condition is difficult to process and is understandably associated with grief and loss of a “healthy baby” (Bruce et al., 2013). With stress often beginning immediately after a prenatal diagnosis, it is not uncommon for expectant parents to face reductions in physical and psychological well-being, as well as quality of life (Harris et al., 2020). As expectant parents transition into the pediatric cardiac intensive care unit (PCICU) after an infant's birth, more novel challenges present themselves disrupting typical parental roles and family function.

A close examination of the literature has revealed several factors that contribute to parents' being poorly equipped to manage the challenges associated with their infant's PCICU hospitalization. These factors include the medical fragility of the infant, the PCICU environment, parent/infant separation, lack of parental preparedness, and knowledge and limited early support for parent well-being/mental health. The first portion of this chapter (Part One) will include an explanatory model of the problem, an overview of supporting evidence related to the contributing factors, and a theoretical lens that can be utilized to understand the problem. The second portion of this chapter (Part Two) will provide an overview of existing literature of interventions that can support expectant parents.

## Part One: Overview of the Problem



**Figure 2.1** Explanatory Model

Figure 2.1 is a visual representation of the contributing factors to the problem described in this chapter.

### Clinical Questions & Summary of Evidence

- What evidence exists to support the claim that parents are not equipped to manage the challenges associated with an infants' hospitalization for management of cCHD?

A search of the literature was conducted using primarily PUBMED, AJOT, Google Scholar and CINAHL. Several search terms were utilized in combination with one another, including: “congenital heart defects”, “critical congenital heart defects”, “parent”, “pediatric intensive care unit”, “intensive care unit”, “parental role alteration”, “mental health”, “stress”, “prepared”, “critically ill infant”, “infant”, “medically fragile infant”. Search criteria included articles written in English, full text availability and literature published within the past 10 years (i.e. 2011-2021). Eighteen articles were chosen for review based on their relevance to the clinical question; quasi-experimental

designs (Uhm & Kim, 2019); non-randomized secondary analysis (Lisanti et al., 2021); mixed methods articles (Sweet & Mannix, 2012); pilot study (Lisanti et al., 2020); descriptive/qualitative studies (Ames et al., 2011; Bruce et al., 2013; Dahav & Sjöström-Strand, 2017; Feeley et al., 2013; Feeley et al., 2016; Golfenshtein et al., 2017; Harris et al., 2020; Kosta et al., 2015; Lisanti et al., 2017; Sood et al., 2018; Vainberg et al., 2019); historical comparison study (Lee et al., 2013) & expert opinion/literature reviews (Cockcroft, 2012; Lisanti et al., 2019; Miller et al., 2020).

### **Review of the Evidence: Medical Fragility of Infant & PCICU Environment**

In the PCICU, the medical fragility of infants typically requires the placement of many life-sustaining lines and tubes. This includes, but is not limited to, feeding tubes, invasive lines and mechanical ventilators. After surgery, infants may face significant medical setbacks such as delayed chest closures, prolonged placement of chest tubes/drains, and the unexpected need for life sustaining machines, such as Extracorporeal Membrane Oxygenation (ECMO). Cumulatively, these interventions and medical challenges are associated with increased infant pain levels. Pharmaceutical management of pain in infants has been associated with diminished responsibility to parents as well as signs and symptoms of withdrawal (Lisanti et al., 2019). Infant appearance and behavior was identified to be the most significant source of stress for parents during their infants' hospitalization (Lisanti et al., 2017).

Parents additionally reported the PCICU environment itself to be a significant stressor. Constant activity, frequent alarming of equipment/monitors and the lack of privacy are factors that increase parent stress (Lisanti et al., 2017). Bright lights, variable

noise levels, and interruptions from medical staff have a significant impact on sleep for both infants and their parents. Developmental care practices such as parent engagement, cue-based care, and interventions to promote a healing environment have been found to be inconsistently implemented across PCICU's (Miller et al., 2020). Further, standards of care, or guidelines for medical professionals, often do not include protocols for parent involvement and developmental care practices. This has led to inconsistent support for developmental care practices such as infant holding, which negatively affects parent/infant bonding and parent participation (Lisanti et al., 2020).

### **Review of the Evidence: Parent/Infant Separation**

Environmental and medical factors place restrictions on parents regarding how and when they can touch, feed, comfort and care for their infant (Lisanti et al., 2021). Parents with PCICU experiences have reported being almost immediately separated from their infants, impacting potential opportunities to hold and/or bond with them during their first few weeks of life (Vainberg et al., 2019). Nursing staff have been considered 'gatekeepers' by many parents, as nurses have some control and decision making on how/when parents are able to interact with their medically fragile infant (Cockcroft, 2012; Feeley et al., 2016; Feeley et al., 2013). In addition to perceived and physical separation within the intensive care unit (ICU), fathers reported unique challenges with separation resulting from their need to return to work. As a result, the amount of time they were able to spend with their infant in the intensive care unit (ICU) was negatively affected (Cockcroft, 2012). Parents have reported longing for alone time with their infant during a hospital admission, but for many reasons this time alone is limited (Lisanti et al.,

2017). Delays in parents' ability to care for and/or have unlimited access to their infant have been associated with increased feelings of guilt, parental role alteration, and issues with parent/infant bonding (Cockcroft, 2012).

### **Review of the Evidence: Lack of Parental Preparedness & Knowledge**

Parents expressed the desire to gain information and guidance on what they were 'allowed to do' with their infant while they were hospitalized (Kosta et al., 2015). However, evidence suggests this limited knowledge and guidance negatively impacts parent participation. A lack of information, particularly related to an infants' hospitalization, has been noted to be a significant stressor for parents (Sweet & Mannix, 2012). In a study by Sood et al. (2018), parents with previous PCICU experiences reported feeling unprepared and without adequate knowledge related to caring for an infant with cCHD. Parents also reported feeling unprepared for the emotional impact of a cCHD diagnosis and how a hospital admission would affect them and their families (Sood et al., 2018). To cope with the uncertainties of having an infant with cCHD, parents often seek guiding information (Harris et al., 2020). While parents reported wanting to be involved in caring for their infant in the PCICU, they often felt unsure about how to touch, hold, or interact with them safely (Ames et al., 2011). Additionally, fathers of hospitalized infants have reported limited knowledge about their infants' needs, leading to feeling unsure of how to interact with them (Lee et al., 2013).

### **Review of the Evidence: Limited Early Support for Parent Well-Being & Mental Health**

Evidence surrounding psychosocial support programs for parents of infants

diagnosed with cCHD, prenatally or during a hospitalization, is lacking. According to Golfenshtein et al. (2017), an early intervention program following a prenatal diagnosis of cCHD could be highly beneficial for parents' health and well-being, but no such programs have been identified in the literature. Parents with PCICU experiences reported suffering feelings of isolation and loneliness as a result of limited support (Vainberg et al., 2019). In one study by Bruce et al. (2013), it was found that even in the early stages of having an infant diagnosed with cCHD, mothers felt psychologically unwell, overwhelmed by worry, and uncertainty.

### **Limitations & Quality**

Several limitations were identified while examining the included studies. The perspectives of mothers were a primary focus in many of the articles (Bruce et al., 2013; Golfenshtein et al., 2017; Lisanti et al., 2017; Lisanti et al., 2020), with limited focus on fathers or the collective perspective from two parents. Rigor could be seen as a limitation due to the high percentage of qualitative articles utilized in this review. However, the inclusion of qualitative articles which included quotes directly from parents provides a truthful raw perspective of parents' feelings as it relates to the contributing factors (Bruce et al., 2013; Dahav & Sjöström-Strand, 2017; Feeley et al., 2013). Small sample sizes (Golfenshtein et al., 2017; Lisanti et al., 2020) and studies including countries with differing visiting policies (Feeley et al., 2013) are limitations that may have affected the generalizability.

## **Future Implications & Recommendations**

Occupational therapy practitioners play a critical role in working with parents of medically fragile infants. Within an ICU environment, occupational therapy practitioners can support parent learning of new skills and empower them to participate in meaningful parental roles (AOTA, 2018). Many articles have been identified within the field of nursing, supporting their role with parents in the ICU environment. However, little research has established the relationship between occupational therapy practitioners and parents of infants with cCHD. This is a gap in the literature that must be explored in future studies. The inclusion of future studies with stronger reliability and rigor, for example through randomized control trials (RCT), would provide valuable insight and support for the identified population. It is apparent neonatal intensive care units (NICU) research is widely available and it is possible that some aspects can be transferable to support families with cCHD. However, families of infants with cCHD face unique challenges. With at least 35 pediatric cardiac care centers identified in North America, research focusing on this specific population is needed (Sood et al., 2016).

### **Theoretical Framework: Social Cognitive Theory**

Developed by Albert Bandura, Social Cognitive Theory has been utilized for many years in a variety of disciplines, including areas within health promotion, health education and public health. According to Social Cognitive Theory, human behaviors can be explained by the causal interaction between personal cognitive factors, behavioral factors and socio-environmental factors (Kedler et al., 2015).

- Personal cognitive factors include three important constructs; self-

efficacy, outcome expectations and knowledge (Kedler et al., 2015). Self-efficacy, or a person's belief that they can be successful in a particular situation and/or environment, is a concept at the core of Social Cognitive Theory (Kim & Lee, 2012). Knowledge related to health risks and benefits is a precondition for change, playing an important role in health promotion (Kedler et al., 2015).

- Behavioral factors, which have a direct impact on health, include a person's current coping skills, health behavior capabilities and their intentions. Performing behaviors is dependent on whether or not a person has knowledge of behavior components and its importance, as well as the skills to perform the behavior (Kedler et al., 2015).
- Socio-environmental factors are perceived or physical aspects of the environment that can facilitate or discourage certain behaviors (Kedler et al., 2015). Two important constructs related to socio-environmental factors are social support and barriers/opportunities. During challenging life circumstances, social support, or interpersonal relationships, act as a protective factor, contributing to self-efficacy as well as aiding in the promotion of human well-being (Kedler et al., 2015). For personal change to occur, individuals need access to opportunities, support and resources.

Based on the research supporting the problem outlined above, parents of infants diagnosed and hospitalized with cCHD are at a significant disadvantage. Social Cognitive Theory provides a critical basis for what is needed to support personal changes related to

individual health and well-being. However, it is clear that parents of infants with cCHD are negatively affected by a lack of crucial personal cognitive, behavioral and socio-environmental factors that could support positive health behaviors during an extremely challenging time.

## **Part Two: Intervention**

### **Clinical Questions & Summary of Evidence**

- What evidence exists that supports an effective education intervention for expectant parents of infants diagnosed with cCHD?
- What evidence exists related to interventions that support cCHD parent confidence and well-being?

A search of the literature was conducted using primarily PUBMED, AJOT, Google Scholar and CINAHL. Initial searches focused on parents with infants diagnosed with cCHD, however, results were limited. A broader search was conducted and a variety of search terms were utilized in combination with one another to examine existing literature related to the above clinical questions. These search terms included: “congenital heart defects”, “critical congenital heart defects”, “parent”, “education”, “workshops”, “trainings”, “program”, “classes”, “prenatal”, “antenatal”, “self-efficacy”, “confidence”, “mental health”, “well-being”. Search criteria included articles written in English, full text availability and literature published within the past fourteen years (i.e. 2006-2021). Seventeen articles were chosen for review based on their relevance to the clinical question; systematic reviews including RCT (Panter-Brick et al., 2014), systematic review/meta-analysis of qualitative/mixed-methods literature (Entsieh & Hallström,

2016; Nightingale et al., 2015), randomized control trials (RCT) (Jamalivand et al., 2017; Maliheh et al., 2016; Melnyk et al., 2006; Petteys & Adoumie, 2018; Shorey et al., 2019), quasi experimental designs (Tsai et al., 2018), cross-sectional designs (Abbass-Dick et al., 2020; Bishop et al., 2020; Sira et al., 2014) descriptive and/or qualitative research studies (Feeley et al., 2016; Golfenshtein et al., 2017; Kovala et al., 2016; Vainberg et al., 2019; Woolf-king et al., 2018).

### **Review of Evidence: Parent Education Needs & Preferences**

Antenatal parent education programs, or education programs carried out before birth, have been associated with positive effects on parent self-efficacy (Jamalivand et al., 2017; Shorey et al., 2019; Tsai et al., 2018) and stress levels (Tsai et al., 2018). An RCT study conducted by Jamalivand et al. (2017), studied the effects of prenatal education on pregnant mothers' self-efficacy related to infant care. Compared to a control group, mothers who received education (i.e., either booklet or software based), demonstrated increased levels of maternal self-efficacy (Jamalivand et al., 2017). Maliheh et al. (2016) studied the effects of infant care education via video training on mothers' self-efficacy within a NICU. Results of the RCT showed an increase in maternal self-efficacy as compared to a control group, indicating a positive change during a challenging time (Maliheh et al., 2016). Theory-based parent education programs within the early stages of parenthood have also been associated with many positive outcomes. These include stronger parental beliefs, reduced parental anxiety/depressive symptoms, more positive parenting interactions and reduced hospital length of stay, when utilized with families of premature infants (Melnyk et al., 2006).

Antenatal parent education programs often focus on the childbirth process rather than empowering parents and preparing them for the early stages of parenthood (Entsieh & Hallström, 2016). Kovala et al. (2016) identified that expectant parents place importance on learning about parent/infant attachment and postnatal infant care during antenatal education. Healthcare providers can facilitate parent-infant closeness by providing parents with information, coaching, and access to resources supporting knowledge and skills relevant to infant care within an ICU (Feeley et al., 2016). When parents are able to care for their infant, it promotes a sense of normalcy, fosters closeness, and promotes parent well-being and competence (Feeley et al., 2016). Evidence supporting the needs of fathers, their involvement in prenatal education and targeted interventions remains limited. To facilitate the success of fathers, Panter-Brick et al. (2014) suggests the importance of early involvement and the inclusion of interventions that support flexibility, consistent communication, education on the benefits of father/infant relationship, and navigating barriers to engagement.

Several studies have examined how to best create and implement antenatal education programs that will suit both parents' needs and learning styles. It was determined that parents prefer technology-based education programs (Abbass-Dick et al., 2020; Shorey et al., 2019; Kovala et al., 2016) and programs that incorporate face-to-face interaction (Kovala et al., 2016), as well components of simulation/demonstration (Maliheh et al., 2016). A systematic review of 23 studies conducted between 1990-2013 provided insightful information on parents' learning needs and preferences. It was identified that parents learned best with the use of various teaching methods and tools,

incorporating written, verbal and audio-visual methods (Nightingale et al., 2015).

### **Review of Evidence: Inclusion of Social Support Component**

When interviewed, parents expressed appreciation for social support (Vainberg et al., 2019). The most-commonly reported suggestion by parents to improve psychosocial support was offering opportunities to connect with other CHD families, which they felt was an unmet need (Woolf-king et al., 2018). Positive coping techniques, such as connecting and interacting with parents who are or have gone through similar experiences, have the potential to reduce feelings of parent isolation and improve quality of life (Sira et al., 2014).

### **Review of Evidence: Incorporating Mindfulness**

Petteys & Adoumie (2018) describe mindfulness as bringing awareness to an experience by being present, moment by moment, without judgement. Approximately 85% of surveyed expectant parents reported having an interest in learning more about mindfulness (Abbass-Dick et al., 2020). The majority of mothers with infants hospitalized for management of CHD reported overall positive thoughts on mindfulness after a brief education and self-practice session (Golfenshtein et al., 2017). Mothers expressed value in utilizing short sessions due to time and space constraints while in the PCICU and reported optimal timing for mindfulness interventions to be immediately after a prenatal diagnosis (Golfenshtein et al., 2017).

Preliminary evidence supports mindfulness as a protective factor, having a positive effect on illness-related parenting stress and maladjustment in parents with children diagnosed with CHD (Bishop et al., 2020). Parents who are able to incorporate

mindfulness may be better equipped to handle illness-related stressors. With increased awareness and acceptance of a present experience, mindfulness can allow parents to actively cope with stress and more easily adapt (Golfenshtein et al., 2017). In turn, reducing parental stress levels (Petteys & Adoumie, 2018) and positively influencing parent mental health (Bishop et al., 2020).

### **Limitations & Recommendations**

Several limitations have been identified among the articles included in this synthesis. Of the seventeen reviewed, only five studied the effects of interventions on parents with infants hospitalized for CHD management and/or diagnosed with CHD (Bishop et al., 2020; Golfenshtein et al., 2017; Petteys & Adoumie, 2018; Sira et al., 2014; Vainberg et al., 2019). Generalizability was a limitation for a majority of the studies. The location and participant ethnicities varied across the articles however, a majority focused on western cultures and individuals who were English speaking (Abbass-Dick et al., 2019; Kovala et al., 2016; Melnyk et al., 2006; Entsieh & Hallström, 2016; Golfenshtein et al., 2017; Tsai et al., 2018). A few studies reported participant characteristics as a concern as many were white, highly educated and of higher socioeconomic status (Golfenshtein et al., 2017; Kovala et al., 2016). Many of the studies included small sample sizes (Abbass-Dick et al., 2019; Golfenshtein et al., 2017; Petteys & Adoumie, 2018; Woolf-king et al., 2018), which could also have had an effect on study generalizability and reliability. Most of the studies either didn't include fathers (Golfenshtein et al., 2017; Jamalivand et al., 2017; Tsai et al., 2018) or had very few included (Abbass-Dick et al., 2019; Bishop et al., 2020; Kovala et al., 2016; Sira et al.,

2014; Woolf-king et al., 2018). Although many of the studies included standardized outcome measures, one study utilized a researcher made questionnaire (Jamalivand et al., 2016) and others relied on self-report (Abbass-Dick et al., 2019; Bishop et al., 2020; Sira et al., 2014), which could have impacted reliability. One study reported concerns about attrition due to missed paperwork and early patient discharges (Petteys & Adoumie, 2018).

### **Future Implications & Recommendations**

Current studies related to the utilization of antenatal education and/or mindfulness interventions with parents whose infant is hospitalized with cCHD are close to non-existent. Therefore, future research focusing on this unique population is crucial, including understanding parent needs and learning preferences. Entsieh & Hallström (2016) captured fathers' feelings of exclusion and unmet needs, which highlights the importance of identifying father specific concerns and providing interventions that include fathers equally. There was no mention of same-gender couples in the studies reviewed, which demonstrates the need for inclusion of research related to parents within the LGBTQ community. Learning styles varied amongst parents included in the above studies therefore, it is important to incorporate different forms (example: video, brochure, 1:1 interaction) of education to increase the likelihood for success of antenatal programs (Entsieh & Hallström, 2016; Nightengale et al., 2015).

Parents identified the importance of having access to a healthcare professional (Entsieh & Hallström, 2016; Abbass-Dick et al., 2019), as well as social interaction with other CHD families throughout the duration of a program (Kovalala et al., 2016; Shorey et

al., 2019; Sira et al., 2014; Woolf-king et al., 2018). These components would be important to include in future antenatal education programs. Melnyk et al. (2006) examined the effects of a parent education program on infant length of stay in an intensive care unit and identified that there are possible cost-savings associated with the implementation of such a program. However, to make this determination, long-term follow up is needed.

### **Theoretical Framework: Transactional Model of Stress and Coping**

When a person faces a stressful experience, the way in which they manage that experience is dependent on their evaluation (primary appraisal) of the stressor, the resources available to them (i.e., psychological, social and material) and their ability to cope with the stressor (secondary appraisal). Positive coping techniques, such as information seeking, social support and benefit finding, can have a positive impact on the way individuals process stress and outcomes of stressful experiences (Wethington, 2015).

## **CHAPTER THREE – Description of the Program**

### **Basis of the Program**

According to Lisanti et al. (2019), parents of infants diagnosed with a critical congenital heart defect (cCHD) experience stress from the time of diagnosis through their hospitalization and beyond. Parents easily become overwhelmed by their new reality and the unknowns they face during the months following a cCHD diagnosis. Infant medical fragility and the pediatric cardiac intensive care unit (PCICU) environment act as barriers to parent engagement in important co-occupations with their infant, resulting in parental role alteration (Lisanti et al., 2019). Parent/infant separation results in limited opportunities for early attachment and bonding which have detrimental effects on parents and infant mental & physical health (Lisanti, 2018).

Preparation and knowledge are both factors that have been found to positively enhance transitions faced by new parents (Entsieh & Hallstrom, 2016). Existing literature supports the notion that prenatal education is especially effective in improving parental stress and self-efficacy. However, prenatal education does not often include information about infant care or other parenting resources (Ateah, 2013). Studies suggest that parent education needs include education in a small group setting to allow for opportunities to interact with peers, as well as ask questions to healthcare providers (Kovala et al., 2016). It has also been determined that parents prefer education that is face-to-face (Kovala et al., 2016) and web-based preferably through use of their smartphones (Orr et al., 2017). Based on an extensive literature review, no prenatal programs exist that provide support for parents of infants diagnosed with cCHD.

## **Program Purpose**

*From Worry, to Warriors* was designed to be the first known virtual empowerment program for parents of infants diagnosed with cCHD. This program will serve expectant parents whose infant has been prenatally diagnosed cCHD that will require hospitalization and/or surgical intervention after birth. Parents whose infant receives an unexpected post-birth diagnosis of cCHD within the first month of life will also have access to the program. This program utilizes constructs within the occupational therapy scope of practice to support parental roles and well-being during the transition to becoming a parent of a critically ill infant.

## **Program Components**

Each program component included in the program was chosen based on evidence-based recommendations discovered during the extensive literature review outlined in Chapter 2.

## ***Program Website***

The program website will be the central access point for program participants once they are formally enrolled in the program. On the program's website, participants can connect with other parent participants, access multi-modal forms of education, locate other helpful community resources and directly contact an occupational therapy practitioner. Pages from the draft of the *From Worry, to Warriors* website can be viewed in Appendix A.

## ***Multimodal Education***

Educational components will be provided in a variety of formats to support varied

parent learning preferences with the goal of supporting parent preparation, increased knowledge and ultimately, parent well-being. The program's primary educational component will be provided through Zoom workshops (live and/or recorded workshops available). Based on the recommendations of Bastable & Rabbia (2019), Zoom workshops will include no more than 30 minutes of structured/semi-structured teaching to support parent learning. For live workshops, parents will have the opportunity to participate in group discussions and ask questions. Group discussions will support a deeper understanding of education, increased social support and a more active role in learning (Fitzgerald & Jacobs, 2019). Live workshops will allow for no more than five couples to ensure a small group environment. In order to include the elements described above, live and recorded workshops will be approximately 30-60 minutes in length.

An introductory workshop will be available for parents to assist with orientation to the program. Additional workshops will incorporate topics found during the literature review that either parents deemed to be important and/or a gap in parent education was identified. Listed below are a few examples of topics that would be covered during program workshops:

- Strategies for parent/infant bonding in the hospital (Kovalala et al., 2016)
- Mindful parenting in the hospital
- Supporting an environment for healing
- Importance of self-care in the hospital
- Advocating for you and your baby's needs
- Things you may want to bring to the hospital

In addition to workshops, other educational resources will be available to parents on the program website. This includes but is not limited to printable handouts, external website links and video/audio recordings (examples: podcasts, flipgrid).

### *Support*

As mentioned above, group discussions and activities will be facilitated through Zoom during live workshops. This will provide parents with the opportunity to interact with parents experiencing similar challenges and feelings, which will ultimately increase the social support network for parents. In addition, scheduled support groups will be advertised on the program's website and be carried out through Zoom. Beyond support from other parents, participants will have access to an occupational therapy practitioner and other experienced professionals as needed. Access to the expertise and knowledge from skilled healthcare professionals will facilitate parents feeling supported (Bruce et al., 2013).

### **Program Delivery**

The program will be carried out entirely online to support ease and convenience for parents. Once parents are enrolled in the program, they will have access to a variety of online resources through the program's website. Parents will have the ability to attend live virtual workshops with other parents whose infant received an early diagnosis of cCHD. If parents prefer, they have the choice of watching recorded workshops at a time that is convenient for them. This is meant to support parents with varied availability and emotional readiness.

## **Program Personnel**

### ***Primary Occupational Therapy Practitioner***

The primary occupational therapy practitioner will be the primary facilitator of the program. It is required that they have at least three years of experience working with parents and infants in a PCICU. Their role includes facilitating, organizing and/or creating workshops. They will provide verbal and written education within the scope of occupational therapy to support parent's self-efficacy, knowledge and well-being. They will also create evaluation surveys utilized in the program.

### ***Secondary Occupational Therapist***

The secondary occupational therapy practitioner will be recruited, interviewed and trained by the primary occupational therapy practitioner. It is required that they have at least five years of experience working in the occupational therapy profession, preferably with some research experience and/or experience working within a PCICU. Their responsibilities include co-facilitation of workshops, website management and evaluation data collection.

### ***Experienced Professionals***

In addition to occupational therapy practitioners, other experienced professionals will be invited to become involved with the program. Social workers, mental health counselors and child life specialists can provide valuable information to parents prenatally to prepare and support them during their infants first few months of life. Experienced professionals will be recruited, interviewed and trained. Their role is to assist with providing relevant education to parents either during workshops and/or

through resources available on the website. They may assist with facilitation of support groups offered virtually to parents through the program with a focus on parent support. For questions that arise related to in hospital medical care, parents will be encouraged to discuss with medical providers.

### ***Peer Advocates***

Peer advocates are important co-facilitators and supporters within the program. Peer advocates will likely be someone who had a past experience of having a hospitalized infant diagnosed with cCHD and is interested in helping other parents going through a similar experience. Peer advocates are recruited and interviewed to ensure they are a good fit for the program. Peer advocates will be required to go through a brief training before participation in the program. They will assist with providing social support during group activities and workshops. They will assist with answering parent questions when relevant. For questions that arise related to in hospital medical care, parents will be encouraged to discuss with medical providers.

### **Recipients of the Program and Recruitment**

This program was created for parents whose infant receives a prenatal diagnosis of cCHD. The program specifically targets parent participants between the ages of 18 and 55 years old and its content and features support both mothers and fathers, as they each have unique roles and needs. Once a prenatal diagnosis is given, parents can be recruited to the program through several routes. They can be referred to the program by medical providers (i.e. a physician in obstetrics/gynecology, cardiac surgeon, physician assistant and/or nurse practitioner), a social worker and/or a member of a community organization

that supports families with infants diagnosed with cCHD (example: Mended Little Hearts).

### **Desired Outcomes of the Program**

Immediately after parent completion of both introductory workshop segments, short term outcomes are expected. These short-term outcomes include increased knowledge, feeling of being supported, empowerment, and decreased stress as it relates to their infants' hospitalization. Continued engagement in the program, including participation in additional workshops and use of provided resources will allow for long term outcomes. These long-term outcomes will be similar to the short-term outcomes, including those mentioned above, as well as increased parent-infant attachment and perceived self-efficacy. Long term outcomes will continue to be achieved within 3-8 months following participation in the program based on parent continued use of the program as a resource.

## Potential Barriers and Challenges

**Table 3.1** *Potential barriers and challenges*

*Potential barriers and challenges related to the proposed program and how they will be addressed. related to the proposed program and how they will be addressed.*

<b>Potential barrier/challenges</b>	<b>How it will be addressed</b>
<p>Attendance- Parents may feel the program will not benefit them. Parents may be unsure if they can commit time to participating in the program.</p>	<ul style="list-style-type: none"> <li>• Adequate promotion of the program through various sources such as non-profit organizations (i.e., email, online), doctors' offices (i.e., word of mouth, flyers) and social media (i.e., parent support groups)</li> <li>• Inclusion of topics that parents want and need (based on needs assessment)</li> <li>• Availability of recorded workshops for parents to access on their own time if schedule does not allow them to attend live</li> </ul>
<p>Access to technology- Parents may not have their own phone/computer/IPAD.</p>	<ul style="list-style-type: none"> <li>• Resource list of places families can access computers for free</li> <li>• Work with hospitals to allocate an IPAD or computer that parents may be able to access</li> </ul>
<p>Varied response based on readiness- Parents may feel that the program will make them more stressed or upset.</p>	<ul style="list-style-type: none"> <li>• Parents to be offered the ability attend a live workshop where active participation is encouraged or watch the recording of a previously recorded workshop</li> <li>• Resources for parents related to mental health for parents who are struggling</li> </ul>
<p>Parent advocate engagement- Parent advocates may feel participation in the program is too big of a time commitment.</p>	<ul style="list-style-type: none"> <li>• Inclusion of small monetary incentive to parent advocates (i.e., Wegmans or amazon gift card) for participation</li> </ul>
<p>Funding- It may be difficult securing funding.</p>	<ul style="list-style-type: none"> <li>• Work with non-profit organizations who can assist with funding</li> <li>• Search and apply for scholarships and/or grants that may apply</li> </ul>

<p>Difficulty recruiting staff for referrals- It may be difficult securing support for the program.</p>	<ul style="list-style-type: none"> <li>• Education to be provided to healthcare staff that would be referring to improve understanding of importance via presentation and/or handouts including sharing parent stories to support need</li> </ul>
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Expectant parents whose infant has been diagnosed with cCHD requiring hospitalization and/or surgery will face many challenges during their child’s first few months of life. Prenatal education does not often include topics that are important to parents and there is not currently evidence to support prenatal education programs for this at-risk group. The literature supports the idea that preparation and knowledge can positively support parents through a difficult transition and that prenatal education can help to improve parent and infant outcomes. *From Worry to Warriors* will be a guiding light for parents facing many unknowns by supporting, empowering and educating them through a virtual prenatal education program.

## **CHAPTER FOUR – Evaluation Plan**

### **Program Scenario and Stakeholders**

The proposed program entitled *From Worry, to Warriors* is a health promotion program designed to empower parents utilizing education, peer support and components of mindfulness. Incorporating key concepts from the Occupational Therapy Practice Framework: Domain and Process (4<sup>th</sup> edition), this program aims to support parent engagement in meaningful occupations, advocacy, well-being and quality of life (AOTA, 2020). The priority population that this program aims to serve is expectant parents whose infant has been prenatally diagnosed with a critical congenital heart defect (cCHD) that will require hospitalization after birth.

The program will be facilitated online where parents will be able to participate in various components of the program when and where they are able. Parents may attend program workshops in real time or access a recorded version at their convenience. Parents will additionally have access to various educational and resources, as well as support from peers and health professionals.

An important component of any program is the program evaluation, which identifies areas of successes, challenges and outcomes of a program. Information gathered throughout the evaluation process will be utilized to share with stakeholder groups. The purpose of this paper is to provide a detailed overview of the evaluation plans, including important stakeholders, research methods, data collection/analysis and dissemination of results.

## **Vision for Program Evaluation Research**

Parents of infants diagnosed with cCHD face unique challenges that, based on a literature review, appear to have a negative impact on individual and family health and well-being. However, a significant gap has been identified demonstrating limited research and literature supporting successful interventions for this unique population. The launch and evaluation of the proposed empowerment program would be a significant step towards improving the lives of families affected by cCHD. The audience for evaluation results are the author, other occupational therapists, parents, medical professionals/administrators and community advocates. A short-term and long-term vision for the proposed programs evaluation research has been created and are described below.

***Short-term vision:*** The short-term vision will be the successful launch of a virtual pilot program. The pilot program, or phase 1, will run over the course of two years. During this time, the program will recruit participants twice per year, including no more than forty participants in the program throughout the pilot phase. The pilot phase evaluation will aim to examine the usefulness of the program and whether or not the program is meeting the needs of parent participants. It will identify successes and challenges in order to make any changes needed to improve program effectiveness. The pilot phase will also be helpful in identifying preliminary outcomes.

***Long-term vision:*** The long-term vision will be a successful launch of the full virtual program, or phase 2, and dissemination of results. The full launch evaluations will aim to demonstrate the intermediate and long-term effects of the program, which will be

imperative for propelling future research related to this unique population.

### **Engagement of Stakeholders and Stakeholder Program Evaluation**

The involvement and continued support from key stakeholders is imperative for the success of the program. Stakeholders will provide important guidance and support related to the programs' implementation and evaluation, which will ensure the program is indeed meeting anticipated needs and objectives. Key stakeholders identified by the author will be invited to scheduled meetings with the goal of coming together to discuss the components and processes of the program. Identified key stakeholders are provided in Table 4.1.

One to two individuals from each stakeholder group will be invited to participate in either virtual and/or in person meetings, determined by stakeholder preferences. The first meeting with identified stakeholders will include a brief presentation carried out by the author. This will include a program overview, providing details on current literature related to the problem and proposed solutions outlined in this dissertation. After the presentation and during future meetings, open discussions with stakeholders will be carried out and recorded to assist in program planning and implementation.

Each stakeholder group will bring distinct value to their participation in supporting this proposed program. Unique stakeholder interest in why they've decided to become involved with the program will bring about varying questions related to the value this proposed program holds specific to their group. Outlined in Table 4.1 is a list of questions each stakeholder group may be interested in finding out in the program evaluation process.

**Table 4.1. Example Questions for Stakeholders**

*Below are examples of questions that stakeholders involved in the program evaluation process may be seeking.*

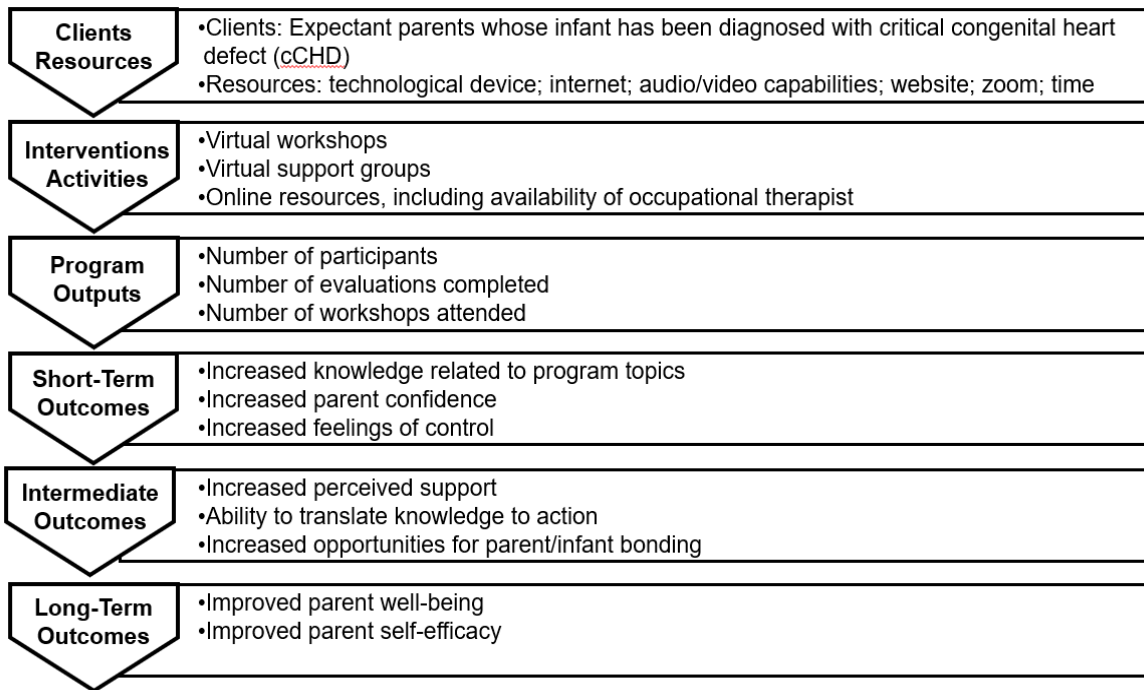
<b>Stakeholder or Stakeholder Group</b>	<b>Types of Program Evaluation Research Questions</b>	<b>How will this be measured?</b>
<p><b>Researcher (Author)</b></p>	<p><u>Quantitative questions:</u></p> <ul style="list-style-type: none"> <li>*Will the program increase parent self-efficacy related to the topics covered in the education?</li> <li>*Will the program increase perceived level of attachment (parent/infant)?</li> <li>*Will the program have a positive effect on feelings of worry, sadness, lack of control?</li> </ul> <p><u>Qualitative question:</u></p> <ul style="list-style-type: none"> <li>*What parts of the program supported parent learning?</li> <li>*Did the program meet the needs of parents? If not, what could have been included to meet the needs?</li> <li>*What parts of the program did parents feel were helpful/not helpful?</li> </ul>	<p><u>Quantitative questions:</u></p> <ul style="list-style-type: none"> <li>*Questions related to self-efficacy, knowledge, attachment and wellbeing will be answered with Likert style questions on pre- and post-surveys</li> </ul> <p><u>Qualitative questions:</u></p> <ul style="list-style-type: none"> <li>*Feedback related to what parents found to be helpful/not helpful, parent learning and parent needs will be answered through open-ended questions on post surveys</li> </ul>

<p><b>Persons actively involved in program delivery (i.e. parent co-facilitators, occupational therapists)</b></p>	<p><u>Qualitative questions:</u></p> <ul style="list-style-type: none"> <li>*Was the information presented in a way parents of varying education levels can understand?</li> <li>*Was the education provided at an optimal pace?</li> <li>*Are the workshops too long? Too short?</li> <li>*Were some aspects of the program more or less useful or effective?</li> <li>*Is there anything that should be changed to improve program content or delivery?</li> <li>*What barriers/challenges were faced by parents participating in the program?</li> </ul> <p><u>Quantitative questions:</u></p> <ul style="list-style-type: none"> <li>*Did parents gain knowledge related to program content?</li> <li>*Did participants gain perceived confidence in their ability to advocate? Participate in infant care?</li> <li>*Did parent participants demonstrate competence to carry over skills/knowledge they learned?</li> </ul>	<p><u>Qualitative questions:</u></p> <ul style="list-style-type: none"> <li>*Information related to parent learning will be gathered via open-ended question on post-test survey</li> <li>*Feedback related to length, pacing and aspects of program, including barriers and changes needed will be collected by open ended questions on surveys</li> </ul> <p><u>Quantitative questions:</u></p> <ul style="list-style-type: none"> <li>*Questions related to self-efficacy, knowledge and carryover will be answered via Likert style survey questions on pre-&amp; post surveys</li> </ul>
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<p><b>Facility, educational institution or organization (i.e., advocacy organizations)</b></p>	<p><u>Qualitative questions:</u></p> <ul style="list-style-type: none"> <li>*Did the parents feel that the program was helpful/supportive?</li> <li>*Did the parents face any barriers to participating in the program?</li> <li>*Do parents enjoy participating in the program?</li> </ul> <p><u>Quantitative questions:</u></p> <ul style="list-style-type: none"> <li>*Did the research data show that the intervention led to desired change?</li> <li>*Can the research be utilized to prepare parents with similar experiences?</li> <li>*Is delivery of the program more costly than other means of delivery?</li> <li>*What were the rates of program withdrawal?</li> <li>*Does the education support parents from different educational backgrounds and financial status?</li> </ul>	<p><u>Qualitative questions:</u></p> <ul style="list-style-type: none"> <li>*All will be answered through open ended questions on post-test survey</li> </ul> <p><u>Quantitative questions:</u></p> <ul style="list-style-type: none"> <li>*Change will be measured through statistical analysis of data collected via pre-test/post-test</li> <li>*Can be determined based on demographic information collected and sample size, can this be generalized to others?</li> <li>*Withdrawal can be determined by pre-test completed vs post-test completed, as well as program viewers/participants</li> <li>*Demographic information will provide information on education and financial status</li> </ul>
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<p style="text-align: center;"><b>Medical professionals &amp; Administrators</b></p>	<p><i>Qualitative questions:</i></p> <ul style="list-style-type: none"> <li>*Do parents feel more prepared for the experience of having a newborn infant who may have to be hospitalized?</li> </ul> <p><i>Quantitative questions</i></p> <ul style="list-style-type: none"> <li>*Does the program positively affect parent self-confidence?</li> <li>*Does the program positively affect parent stress levels and overall well-being?</li> <li>*Do parents have increased self-advocacy following involvement in the program?</li> <li>*How many parents fully complete the program?</li> </ul>	<p><i>Qualitative questions:</i></p> <ul style="list-style-type: none"> <li>*Answered through open ended question on post-test survey</li> </ul> <p><i>Quantitative questions:</i></p> <ul style="list-style-type: none"> <li>*Questions about self-efficacy, stress and well-being will be answered through Likert-style questions on pre-test/post-test surveys</li> <li>-*Questions related to advocacy will be answered through Likert style questions on pre &amp; post surveys</li> <li>*Number of participants that participated in program will be determined through registration/completion of post surveys</li> </ul>
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To represent the planning that has taken place for the proposed program a simplified logic model has been created. The simplified logic model is intended to assist stakeholders in being able to quickly and easily review the resources, intervention activities, program outputs and outcomes associated with this empowerment program. Please see Figure 4.1 for a representation of the simplified logic model for *From Worry, to Warriors*.



**Figure 4.1.** *Simplified logic model for the From Worry, to Warriors program evaluation research showing expected program inputs, outputs short term, intermediate and long-term outcomes. Short term outcomes will be measured immediately after parent participation in the program. Intermediate outcomes will be measured 1 month after parent participation in the program. Long-term outcomes will be measured 3-6 months after parent participation in the program.*

### **Research Design**

To provide an in-depth evaluation of this program, both formative and summative components will be utilized. During the first two years of the program, a pilot phase will be launched (phase 1). The results received during phase 1 will provide important information on the successes/challenges of the program, as well as preliminary outcome information. The information gathered during the pilot phase will be utilized to make

modifications as needed prior to the next phase. After the completion of phase 1, the full program launch (phase 2) can begin.

### **Methods**

Institutional Review Board (IRB) approval will be needed prior to the launch of this proposed program since it will involve human subjects (parents). To ensure confidentiality of participants, each parent participant will receive a randomized code that will be later used for data analysis, which will be kept in a secure folder on the researchers' computer.

#### **Formative Data Collection Methods**

Data collection methods completed during the proposed program evaluation will vary in nature. Formative evaluations will be included during the pilot launch and will be conducted online/virtually. The pilot launch will include no more than forty parent participants (20 participants per year) who will be recruited via referral from medical professionals, advocacy organization staff and/or interest in the program after viewing online marketing strategies. Inclusion criteria will consist of parents of any gender and/or sexual orientation, parents who are able to read/speak English and parents whose infant has been prenatally diagnosed with cCHD.

Exclusion criteria consists of parents who do not have access to a technological device with the internet and parents who live outside of New York. Directly after the parents complete the program, an electronic survey will be distributed via Survey Monkey and will include both quantitative and qualitative questions. Questions regarding individual demographic information will also be included. Quantitative questions will be

in the form of a Likert scale. Qualitative information will be gathered via open-ended questions with a word limit. Sample qualitative questions include:

- Are there changes we could make to better support you and your learning during this program?
- What did you find to be most helpful when taking part in this program? What did you find to be the least helpful when taking part in this program?

After the last year of the pilot phase (year two), a full launch of the program will begin. The full launch of the program is expected to support up to 50 parent participants per year, with approximately 10 parents per quarter. Inclusion/exclusion criteria will be the same as in the pilot launch, however can be expanded outside of New York.

### **Formative Data Management and Analysis**

All responses, including open-ended responses, will be added to an excel file kept on the researchers' computer and additionally on a secure USB backup drive. Every survey will be marked with a randomized code to ensure confidentiality. Descriptive statistics will be gathered related to demographic data (i.e. mean, median, mode, range) to provide a summary of this information in order to better understand participants included in the study. Survey Monkey will be utilized to identify themes among the qualitative responses. A triangulation method will be utilized to ensure consistency/accuracy of themes. Triangulation will be completed by peers who are aware of the project but are not directly involved in carrying out program interventions (example: academic mentor, peer mentor through Boston University). Survey Monkey will also be utilized for sentiment analysis to identify whether responses received by participants were positive, neutral or

negative.

### **Summative or Outcome Data Collection Methods**

The research design that best fits this program is a quasi-experimental, one-group pretest/posttest design. This research design will assist in determining the effects of the program on the dependent variables proposed in the logic model. Data collection for summative or evaluations will continue to occur online/virtually. The independent variable for this proposed program is primarily parent education however, peer support and as needed access to an occupational therapist are also considered independent variables. The dependent variables related to this proposed program are self-efficacy/confidence, acquired knowledge, perceived parent/infant bonding and well-being as described in the logic model. Dependent variables will be measured using Likert-style surveys created by the researcher. Due to the unique nature of this population and program needs, no current reliable and valid outcome measurement have been identified. Questions regarding individual demographic information will be included in all surveys.

### **Summative or Outcome Data Management and Analysis**

Summative evaluation data will be added to an excel file kept on the researchers' computer and additionally on a secure USB backup drive. Descriptive statistics will be gathered related to demographic data (i.e., mean, median, mode, range) to provide a summary of this information in order to better understand participants included in the study. Inferential statistics will be utilized for this one-group pre/post study to determine the relationship between the intervention and outcomes, most specifically the chi-square test will be utilized for analysis.

### **Disseminating Findings of the Program Evaluation**

Upon the completion of both phases of the program evaluation important findings will be disseminated to key stakeholders and other community groups (local and national). Advocacy organizations and medical systems will be the target audience of the most in depth findings report. An electronic presentation will be created to include an overview of findings, recommendations and key descriptive/inferential statistics. A paper copy and/or electronic copy of a more comprehensive technical report including the information will be available to these stakeholders. Along with this information, powerful quotes and/or pictures from parent participants will be included to highlight the emotionality, passion and human impact surrounding this program.

Additional groups and stakeholders will benefit from the dissemination of the findings of this program evaluation. For example, parents who may be interested in participating in this program should have access to the valuable information related to the impact and findings. A clear and simple explanation of findings through a one-page summary will be available on the program website. In addition, flyers will be created that could be posted on social media platforms and/or sent out via E-mail. The dissemination of this information would also be helpful for healthcare professionals, such as occupational therapists, social workers, psychologists or other researchers interested in studying this area. An electronic presentation and/or poster presentation including methodology, findings, recommendations and impact could be utilized at local, state, national or international conferences. The long-term vision for the dissemination of this information is to expand the reach across the United States in hopes that it will have a

positive impact on families lives/futures as well as aid in providing important research that can be utilized on a global scale.

The establishment of a parent empowerment program offered to this unique population will have short- and long-term positive implications for parents, occupational therapists, medical professionals and other key stakeholders. Current research related to parents and infants diagnosed with cCHD is much needed but currently lacking. The evaluation and dissemination of this program and its findings will be imperative for its success.

## **CHAPTER FIVE – Funding Plan**

*From Worry, to Warriors* is a virtual empowerment program available to expectant parents of infants with a critical congenital heart defect (cCHD), incorporating evidence-supported components such as multi-model education, mindfulness, peer support and support from skilled professionals. All portions of the program will be carried out virtually to support parent participation and autonomy. This proposed program provides parents with opportunities to interact with other cCHD parents and prepares them for parenting their infant in a hospital setting. Anticipated outcomes following participation in this program are improved parent knowledge, self-efficacy and well-being.

The first and second year of the proposed program implementation will be considered a pilot phase. Following the pilot phase, a program evaluation will be completed to determine future program needs and direction. The following chapter will provide an overview of the funding plan for the pilot phase providing details related to available resources needed, budget items and potential funding sources to assist with the implementation and dissemination of the proposed program.

### **Available Resources**

In order for the proposed program to be successful, both in-kind and monetary support are needed. Connections have been established by the author to various professionals, as well as organizations in the Rochester New York area, that support families affected by cCHD. In addition to these connections, other available resources have been identified both in the local Rochester community and in other communities

within the United States. Table 5.1 provides a list of available resources and a brief description of how the resources can assist in the implementation and dissemination of the program.

**Table 5.1**  
*Local and Other Available Resources with Description*

Local Resources	Description
Local Organizations	<p>There are several organizations in the area that support patients and families affected by CHD. Organizations and/or non-profits may be interested in adopting the proposed parent empowerment program, supporting the program with resources they have available. Other ways local organizations can assist is by providing free marketing for the program and/or referrals. They may also collaborate with the program and/or provide volunteer support (example: teaming up for a virtual event or support group)</p> <p>Potential Organizations:</p> <ul style="list-style-type: none"> <li>• Mended Little Hearts of Rochester</li> <li>• Ronald McDonald House Charities of Rochester</li> <li>• American Heart Association of Rochester</li> </ul>
Professional Volunteers	<p>By networking with professionals known to the writer, it is possible to recruit professional input, time and services on a volunteer basis. This may include occupational therapy practitioners, social workers, mental health professionals, parents and/or other health care workers in Rochester New York.</p>
Donated Gift Cards	<p>Many local companies look for opportunities to donate to programs, organizations and/or charities. Through local community business donations, it would be possible to receive gift card donations to support parent advocate participation.</p>
Marketing, Website Design and Video Professional	<p>With many colleges in Upstate New York, finding interns to volunteer their time to assist with these areas is possible. Utilizing volunteer assistance from the author's sister, who has a master's degree in marketing, is another resource available.</p>

**Note:** Local resources that can support program implementation

### **Needed Resources: Budget**

To accommodate for additional items needed for program implementation and dissemination, a list of budget items was compiled and are described below in Table 5.2. An estimated cost for the program's first and second years (pilot phase) are included. The first-year cost is slightly higher than the second year due to one-time program needs (i.e. equipment). The hours allotted to the primary and secondary occupational therapy practitioners are based on the anticipated average number of hours needed to manage multiple aspects of the program and they may vary. Inflation of costs related to services (i.e., Wix, Zoom, YouTube, Microsoft) from year one to year two is anticipated. Needed budget items are dependent on whether or not the program is supported by an established non-profit, as they may have many of the listed resources already available. If needed, there is the option to apply to be a non-profit however, this will be an additional cost (~\$700).

**Table 5.2***Budget Item Description and Estimated Cost*

Budget Item	Description	Estimated Expense Year 1	Estimated Expense Year 2
Wix Website	A Wix website will allow parents to have access to resources, upcoming virtual events and connect with other parents through a forum. A premium website through Wix costs \$23/month. <a href="https://www.wix.com/upgrade/website?referralAdditionalInfo=HelpCenter">https://www.wix.com/upgrade/website?referralAdditionalInfo=HelpCenter</a>	\$276/ year	\$276/ year
Zoom Pro Account	Support groups and virtual workshops will be attended through zoom, which is a HIPPA compliant platform. A zoom pro account costs \$250/year. <a href="https://zoom.us/pricing">https://zoom.us/pricing</a>	\$250/ year	\$250/ year
YouTube	YouTube allows for video storage and streaming. YouTube links will be included on the Wix website to view recorded videos.	Free	Free
Microsoft Package (Word, PowerPoint, Excel)	A Microsoft package will be needed to create course materials, course presentations, and data management. Microsoft requires a yearly fee of \$69.99 to use these products. <a href="http://www.microsoft.com/en-us/microsoft-365">www.microsoft.com/en-us/microsoft-365</a>	\$69.99/ year	\$69.99/ year
Occupational Therapy Practitioner Rate	The primary and secondary occupational therapy practitioners are responsible for creation, facilitation, maintaining program tasks and collection/analysis of evaluation data. Their hourly rate (\$50/hour) is based on the per diem pay for an occupational therapist in Rochester NY. The estimated hours allotted for the primary occupational therapy practitioner is 10 hours/week. The estimated hours allotted for the secondary occupational therapy practitioner is 5 hours/week.	\$36,000/ year	\$36,000/ year

Social Worker OR Mental Health Counselor Contractor Rate	Social workers and/or mental health counselors will assist with content creation, facilitation of workshops and facilitation of support groups. Their hourly rate (\$30/hour) is based on an average per diem pay. It is anticipated two professionals would be assisting during a given month at 5 hours/month.	\$14,400/ year	\$14,400/ hour
IT equipment	IT equipment will be utilized mainly by primary and secondary occupational therapy practitioners. Provided is the approximate cost of IT equipment. Two Laptops Two Wireless Mouse Two USB drives Two Wireless Headset Internet package	\$1,600 \$20 \$15 \$100 \$600/ year	\$600/ year
Survey Monkey	Surveys will be utilized before and after the program, as well as for program evaluation. Survey Monkey is an online tool for creating surveys and analyzing survey responses. The monthly cost is \$75.00 for a pro account. <a href="https://www.surveymonkey.com/pricing/">https://www.surveymonkey.com/pricing/</a>	\$900/ year	\$900/ year
Marketing	Marketing will mainly take place online and marketing tools will be created through Microsoft Word & PowerPoint. However, some flyers will be given during dissemination and can be handed out by professionals and/or left in places where families may see them. Printed color pages cost .56 cents per page. An estimated 500 pages are needed for the year.	\$280/ year	\$280/ year
Dissemination Costs	Dissemination will be completed primarily in person and/or online through short presentations. The majority of resources will be created through Microsoft Word and PowerPoint. For conference presentations, there is an anticipated conference fee and fee for printing posters.	\$1,000- \$2,000	\$1,000- \$2,000
Total		\$56,510.99	\$54,705.99

**Note.** Budget items, budget item description, and estimated cost for years one and two of program implementation

## Funding Sources

The implementation and dissemination of the proposed program will not be possible without monetary funding. Potential funding sources have been selected and outlined below (Table 5.3). Several foundations with grant programs whose mission statements align with the mission and goals of the proposed program have been identified. A grant would provide the monetary assistance needed to support the program throughout each year, and ideally allow for parents to participate in the program free of cost. To offload additional costs, selected small businesses and companies can choose to pay for advertisements on the program website. For specific events and/or needs, such as gift cards for parent advocates, a Go Fund Me page can assist in raising funds.

**Table 5.3**

*Description of Potential Funding Sources*

Potential Funding Source	Description/Requirements
Research Grant <i>Mend a Heart Foundation</i>	Mend a Heart foundation supports initiatives that enrich the lives of kids with congenital heart defects. Research projects must align with the mission of the foundation and recipients must serve on the grant review board the year following grant award. Past grant recipients received an average of between \$15,000-\$50,000. (Mend a Heart Foundation, n.d.)
Foundation Grant <i>Caplan Foundation for Early Childhood</i>	The Caplan Foundation’s mission is to foster innovation and research that will improve the lives of children. They offer a grant specific to parent education for projects related to child rearing differences, issues of health, prenatal care and cognitive/emotional support to parents. The grant covers a maximum of 15% of direct expenses. Previous grants have ranged from \$20,000-\$100,000. (Caplan Foundation for Early Childhood, n.d.)

Foundation Grant <i>The Tony Robbins Foundation</i>	The Tony Robbins Foundation strives to empower individuals and organizations to improve the quality of life of people often forgotten. Grant applicants must be a 501(c)(3) non-profit organization active for at least one year with a similar mission. The median allotted grant amount is \$50,000. (The Tony Robbins Foundation, n.d.)
Responsive Grant <i>Greater Rochester Health Foundation</i>	The Greater Rochester Health foundation's mission is to pursue and invest in initiatives that build healthier communities in which people can thrive. Grant applicants must be a non-profit located in nine specific counties with programs that aim to support marginalized communities and ones impacted by health inequities. Awards range from \$25,000-\$500,000 over a one to five-year period. (Greater Rochester Health Foundation, n.d.)
Foundation Grant <i>The Children's Heart Foundation</i>	The Children's Heart Foundation is dedicated to funding research related to congenital heart defects. Independent grant applicants' research can focus on fetal diagnosis/intervention, health disparities, quality improvement or neurodevelopmental/functional outcomes. The independent grant is open to non-physicians. Grant funding up to \$100,000 for up to two years is provided. (The Children's Heart Foundation, n.d.)
Intervention Research Grant <i>American Occupational Therapy Foundation (AOTF)</i>	AOTF supports occupational therapy research and increasing awareness of how everyday activities (occupations) impact health. The intervention Research Grant supports research that examines racial, social and health inequalities and injustices with the goal setting the groundwork for larger studies of proven concepts. The maximum funding for this grant is \$50,000. (AOTF, n.d.)
Foundation Grant <i>Robert Wood Johnson Foundation-Pioneering Ideas</i>	The Robert Wood Johnson Foundation's mission is to improve the health of everyone in the United States, focusing on well-being. The pioneering ideas grant calls for projects that offer unique approaches to health equity and progress towards a healthier culture. There is no limit for budget requests. (Robert Wood Johnson Foundation, n.d.)
Advertisements	Companies and/or small businesses (local or otherwise) that offer services/products which support families who have children with cCHD can pay for an ad on the Wix website. Ads typically cost \$1-\$2 dollars per click. Advertisements can offset some program costs and benefit families. For example, an ad for a company that sells baby clothes with easy buttons to allow for lines/tubes.

Go Fund Me	Go Fund Me is a trusted website for raising money. Setting up a Go Fund Me for this program would allow small and large donors to provide funds for the startup of the program and other needed items (example: gift cards for parent advocates). <a href="https://www.gofundme.com/">https://www.gofundme.com/</a>
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*Note.* Description of potential funding sources.

### **Conclusion**

The proposed program, *From Worry, to Warriors*, is founded on current literature and is created to support expectant parents of infants diagnosed with cCHD during a challenging transition period. This proposed program has many moving parts and pieces but as a whole will support and prepare parents for the experience of parenting infants with cCHD in a hospital setting. Foundational grants appear to be an ideal avenue for program funding, which will in turn support the successful implementation and dissemination of this program. Utilizing current available resources and in-kind support will only strengthen program success. The outlined funding plan provides a clear overview of in-kind support and monetary needs to ensure the success of this critical program.

## **CHAPTER SIX – Dissemination Plan**

### **Proposed Program**

*From Worry, to Warriors* is an evidenced based parent empowerment program designed to meet the identified needs of parents of infants diagnosed with a critical congenital heart defect (cCHD). The ideas and content of this program are informed by occupational therapy concepts as well as the social cognitive theory. The proposed program aims to support parents embarking on the transition to becoming a parent of a critically ill infant. *From Worry, to Warriors* is available virtually for parents and includes access to workshops, resources, small support groups and professional guidance from an occupational therapy practitioner. The goals of the program are to improve parent well-being and engagement in parenting occupations by increasing parent awareness, knowledge and confidence. This chapter outlines the dissemination plan for *From Worry, to Warriors* following its successful implementation and positive formative evaluation results.

### **Dissemination Goals**

Dissemination of the program results is a crucial step necessary for expanding support related to areas addressed by the program, as well as support for the program itself. There are several anticipated short-term and long-term goals related to dissemination, which are listed below. The indicators of success for each of the long-term and short-term goals can be found in Table 6.3.

#### **Short-term Goals:**

- Dissemination of the program results to the primary and secondary audiences will

lead to increased knowledge related to the impact and benefits of a virtual empowerment program

- Dissemination of the program results to the primary and secondary audiences will contribute to awareness of the unique role of occupational therapy with parents of critically ill infants

**Long-term Goals:**

- Dissemination of the program results will lead to increased referrals to the program by the primary audiences
- Dissemination of the program results will contribute to increased support (financial or otherwise) of the program by target audiences

**Primary Target Audiences**

The following two audiences are considered primary audiences, as they are crucial for continued support of the program.

**Medical Staff & Administrators**

The first primary audience encompasses surgeons, physicians, nurse practitioners, physician assistants, nurses, social workers and administrators of medical facilities that support families during the early diagnosis of cCHD. These groups are key stakeholders with regards to program sustainability. Sharing program results with these groups will increase awareness of challenges faced by parents of infants with cCHD. Dissemination will also support understanding of how the proposed program positively impacts the lives of parents and families of infants with cCHD. Through dissemination of the program results to these groups, it is anticipated that referrals and support for continued

implementation of the program (monetary or otherwise) will increase.

### **Advocacy Organizations**

The second primary audience includes advocacy organizations whose focus is to spread awareness, raise money and/or support parents and families affected by congenital heart defects (CHD). This includes founders, staff, and volunteers of advocacy organizations. Established advocacy organizations likely have strong community networks. Dissemination of program results to advocacy organizations will support knowledge and awareness of program benefits for parents of infants with cCHD. It is anticipated that this will lead to increased support for the program, either monetary, marketing and/or sharing of resources.

### **Key Messages for the Primary Audiences**

- According to existing literature, parents with infants diagnosed with cCHD experience significant stress during their infants first year of life, particularly during an acute hospitalization.
- Parental role alteration and challenges faced before and after an infant's birth increase the risk of parent mental health concerns. Occupational therapy practitioners are uniquely skilled to support parental occupations, infant development, and parent transitions to the intensive care unit environment leading to increased parent empowerment.
- An evidence-based parent empowerment program incorporating peer support, education, and mindfulness can improve parent well-being and quality of life.

## **Secondary Target Audiences**

The two audiences below are considered secondary audiences, as dissemination of program results will be beneficial to each group as well as for support of the program.

### **Parents**

Parents of infants who have been diagnosed with cCHD are an important secondary audience. First and foremost, through word of mouth and online forums, parents can spread awareness of the program to others so they can receive support during their transition to parenting a critically ill infant. Dissemination of program results to parents will additionally support increased parent knowledge related to potential challenges and resources.

### **Key Messages for Parents**

- There are many barriers to parent/infant bonding while an infant is hospitalized for management of cCHD. This can impact parent/infant bonding, which has short term and long-term consequences for infants and parents.
- Taking part in a virtual empowerment program can help parents to understand ways they bond with their infant in the hospital, advocate for their infant, reduce stress, and engage in parent roles and routines that are important to them.

### **Occupational Therapy Practitioners**

Occupational therapy practitioners are also an important secondary audience for the dissemination of program outcomes. Occupational therapy practitioners play a key role in supporting engagement in parental occupational and overall parent well-being.

Through dissemination, occupational therapy practitioners can learn about the unique role

of occupational therapy within health promotion when working with parents of critically ill infants.

### **Key Messages for Occupational Therapy Practitioners**

- The lack of parent knowledge, awareness, and preparation for an acute hospital admission negatively impacts parent involvement in meaningful occupations and decreases self-confidence.
- Parents who participate in the virtual parent empowerment program have access to an occupational therapist, which can reduce stress and increase parental confidence when engaging in parenting routines in the hospital setting.

### **Sources/Messengers**

#### **Mended Hearts/Mended Little Hearts**

Mended Little Hearts is a non-profit organization whose mission is to improve the quality of life of families and patients affected by heart disease through peer support, education, and advocacy (Mended Hearts, n.d.). It is considered a national, community-based organization with branches located throughout the United States. An organization such as Mended Little Hearts has strong connections with medical facilities and community resources from all over the country, and particularly in Rochester, NY where the author is located. This organization also has an existing parent support network for parents of infants with cCHD. Having a spokesperson from a credible organization such as Mended Little Hearts would help to spread awareness of the program and its benefits.

#### **State & National Occupational Therapy Associations**

The New York State Occupational Therapy Association (NYSOTA) is a valued

organization in New York, as it is the only professional association for occupational therapy practitioners (NYSOTA, n.d.). The American Association of Occupational Therapy (AOTA) is a national organization that supports professional development, education and advocacy for the occupational therapy profession and improving health care services for all (AOTA, n.d.). Both of these organizations have established communities consisting of occupational therapy practitioners and other professionals. Each organization has unique ways of disseminating information, such as newsletters and discussion forums, including CommunOT through AOTA. These organizations would both be credible sources for disseminating information related to the proposed program to occupational therapy practitioners.

### **Dissemination Activities**

In order to disseminate program information, including program evaluation results, the author plans to facilitate several dissemination activities. For the primary target audience, flyers will be created on a free available platform such as Microsoft Word. The flyers will then be distributed electronically to the offices of local physicians, nurses, social workers, and centers who work with expectant parents of infants with cCHD. For primary and secondary audiences, blog posts and short articles will be written to include program details and outcomes. For example, a short article may be written in Parent Magazine, targeting dissemination of program benefits for parents. In person (virtually or physically) presentations will be conducted to provide opportunities for primary and secondary audience members to participate in open discussions. Offers for these in person presentations can be marketed through the flyers to medical offices and

advocacy organizations. Lastly, poster presentations will be completed in order to reach a larger audience, particularly occupational therapy practitioners. These poster presentations will occur through NYSOTA and/or AOTA.

### **Dissemination Budget**

Table 6.1 delineates the anticipated dissemination budget for each of the proposed dissemination activities. The total estimated cost for the dissemination plan is approximately \$1,000-\$2,000 per year, with the potential for extra costs.

**Table 6.1**

*Dissemination Budget*

<b>Dissemination Activity</b>	<b>Estimated Time</b>	<b>Estimated Expenses</b>	<b>Justification</b>
Written Information Flyers	Approximately 1-2 hours per flyer	\$0	Flyers can be created using Microsoft Word, which the author will have access to for no additional costs. Flyers can be distributed electronically. For five or less flyers, the author is willing to volunteer time to complete. For additional flyers, the hourly rate of \$45/hour will be required to cover time.
Written Information Articles (i.e., OT practice, Parent Magazine)	Approximately 5-10 hours per article	\$0	For two or less articles, the author is willing to volunteer time to complete. For additional articles, the hourly rate of \$45/hour will be required to cover time.
Written Information Blog Post (Conquering CHD, Mended Little Hearts,	Approximately 1-2 hours per blog post	\$0	For five or less blog posts, the author is willing to volunteer time to complete. For additional blog posts, the hourly rate of \$45/hour will be required to cover time.

Children's Heart Foundation, OT Commune Board)			
Person-to-Person Professional Presentations	Approximately 5-10 hours per presentation	\$0	Professional Presentations can be conducted through zoom which would not be associated with additional costs. For two or less presentations, the author is willing to volunteer time to complete. For additional presentations, the hourly rate of \$45/hour will be required to cover time. If an in-person presentation is requested, gas can be covered by the author. Handouts can be sent electronically to all participants and printed by the host.
Person-to-Person Posters at state & national Conferences	Approximately 15 hours per poster presentation	\$1000-\$2000 per year	Conference fee: AOTA member price ~\$450 for early full conference registration Hotel (3 nights) & Flight: Varies however, anticipate ~\$800-\$1000 Poster Printing: ~\$100 The author is willing to volunteer time to complete articles for this dissemination activity.
Total	27-37 hours (approximate)	\$1000-\$2,000 per year	

## Evaluation

For the defined dissemination activities, a list of indicators of success have been listed in Table 6.2. These indicators of success will assist in evaluating whether or not goals were met in regards to dissemination activities. A more thorough evaluation will take place for each of the short and long-term goals to determine if they were reached. These indicators are outlined in Table 6.3

**Table 6.2**

*Description of the Dissemination Activities and Indicators of Success*

<b>Dissemination Activity</b>	<b>Indicators of Success</b>
Flyers	Dissemination of at least 5 flyers (paper or virtual) within the first year following dissemination. Example: Flyers distributed via email to medical office
Articles/Blog Posts	Acceptance of at least two articles and/or blog post one year following implementation of the program
Professional Presentations	Invitation to complete at least two dissemination presentations within the first year after program implementation. Example: Presentation for medical team that serves families affected by cCHD
Posters at state & national conferences	Acceptance to at least one state or national conference for a poster presentation within the first year following dissemination. Example: NYSOTA or AOTA

**Table 6.3***Overview of Short and Long-Term Dissemination Goals*

<b>Goals</b>	<b>Indicators of Success</b>
<b>Short-term goal:</b> Dissemination of the program results will lead to increased awareness/knowledge related to the impact and benefits of a virtual empowerment program, for primary & secondary audience	A brief questionnaire will be provided to audience members. Questions will be related to knowledge and perceptions of dissemination content.
<b>Short-term goal:</b> Dissemination of the program results will contribute to awareness of the unique role of occupational therapy with parents of critically ill infants by the target audiences	A brief questionnaire will be provided to audience members. Questions will be related to knowledge of occupational therapy roles in the context of the program.
<b>Long-term goal:</b> Dissemination of the program results will lead to increased referrals to the program by the primary audiences	Evaluation of the number of participants and/or persons interested in the program each year will help to determine if this long-term goal has been met.
<b>Long-term goal:</b> Dissemination of the program results will contribute to increased support (financial or otherwise) of the program by target audiences	Evaluation of the number of external supports and/or money received towards the program each year will help to determine if this long-term goal has been met.

**Conclusion**

The successful implementation of the program *From Worry, to Warriors* will yield valuable information on the benefits of an empowerment program for parents with infants prenatally diagnosed with cCHD. Evaluation of long-term and short-term goals for dissemination will be imperative for continued success of the program. Sharing program outcomes with primary and secondary audiences through dissemination activities will be critical in increasing program awareness, support, and enrollment.

## **CHAPTER SEVEN – Conclusion**

Thousands of families in the United States are affected by a critical congenital heart defect (cCHD) diagnosis every year. A prenatal diagnosis of cCHD is disruptive and parents are often not prepared for the challenges and barriers that they face as new parents of a hospitalized, critically ill infant. This has been associated with increased parent stress, difficulties with parent/infant bonding and negative effects on parent mental health, well-being and quality of life. Even though parent challenges and consequences have been outlined in current literature, evidence-based solutions to support parents during this difficult transition are significantly lacking.

Parent participation in prenatal education programs provides parents with an opportunity to gain new knowledge in preparation for the birth of their infant. However, historically these programs have lacked the inclusion of other parenting topics that parents feel to be important, such the topic of bonding/attachment (Kovalala et al., 2016). Identified needs of parents with infants diagnosed with cCHD are highlighted in this dissertation, including the importance of having access to support from peers going through a similar experience (Woolf-king et al., 2018) and the need for more information related to caring for their infant in the hospital (Kosta et al., 2015; Sood et al., 2018). The best methods for supporting parent education have also been identified, supporting the use of technology-based education programs (Abbass-Dick et al., 2020; Shorey et al., 2019; Kovalala et al., 2016) with varied teaching methods, such as written, visual and audio-visual methods (Nightengale et al., 2015).

Evidence-based literature supporting the critical role that occupational therapy practitioners have with critically ill infants and their families has been established for many years. The lens of occupational therapy maintains a focus on supporting meaningful occupations, or everyday activities, advocacy, education and mental/physical health and well-being. Occupational therapy practitioners can play a key role in supporting parents with infants diagnosed with cCHD during this challenging time where meaningful parental occupations are disrupted. Although the documented presence of occupational therapy involvement with this unique population is limited, there is a true need for future interventions and evidence-based literature stemming from the domain of occupational therapy.

*From Worry, to Warriors* was created to be the first completely virtual evidence-based empowerment program designed for expectant parents with an infant diagnosed with cCHD and facilitated by an occupational therapy practitioner. After receiving a diagnosis of cCHD, parents are able to enroll in the online program and immediately have access to educational workshops, multi-modal resources, a peer support network and experienced health care professionals. During the pilot and full implementation phases, parents will be able to complete surveys before and after participation. The results of these survey will assist in obtaining information related to program evaluation and outcomes, which will aide in expanding literature supporting program development for families affected by cCHD.

Although it is impossible to fully prepare parents for the experience of becoming a parent to a hospitalized critically ill infant, a prenatal empowerment program can have a

profound impact on parents with infants diagnosed with cCHD and their families. It is anticipated that participation in this program will result in increased parent knowledge, preparedness, empowerment, self-efficacy, increased parent/infant bonding and decreased parent stress, which will in turn have a positive impact on long-term parent/infant outcomes.

## APPENDIX A – *From Worry, to Warriors* Website Draft

[Home](#) [Forum](#) [About](#) [Programs](#)

# From Worry, To Warriors



## Tell me more...

What is this program?

*From Worry, To Warriors* is the first and only virtual prenatal parent empowerment program for parents of infants diagnosed with a critical congenital heart defect (cCHD). This theory and evidence-based program aims to support and prepare parents for challenges they may face during the transition to parenting an infant diagnosed with cCHD.

Created by an occupational therapy practitioner, this program focuses on the things that are important to parents, such as parent/infant bonding and infant care. The program is entirely virtual to support parents anywhere and anytime that is convenient for them.



## PREPARING FOR YOUR HOSPITAL STAY

Listed below are some *recommended* items that you may want to bring to the hospital to help support you and your baby.

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### For my baby:

- A few books to read to your baby
- Baby hats, mittens and socks
- Swaddle blankets and/or sleep sacks
- Onesies with snaps that open at the front/side
- A Boppy pillow
- One or two small pictures of siblings and/or family
- A small stuffed animal and/or baby rattle
- Small baby noise machine



### For myself/my partner:

- A few changes of clothes & toiletries
- Electronic chargers (i.e., phone, computer, IPAD)
- Ear plugs for sleeping
- Headphones
- A writing journal & pens
- Favorite pillow/blanket
- Ready to go snacks (i.e., bars, trail mix)

**APPENDIX C – Program Manual Draft**



**From Worry, To Warrior**

**Program Manual Draft**  
**Anjelica Fortunato, OTR/L, Boston University**

# *From Worry, To Warrior* Program Manual Draft

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## Introduction & Purpose

*From Worry, To Warrior* is a completely virtual parent empowerment program created for expectant parents with infants diagnosed with a critical congenital heart defect (cCHD). The following document is intended to raise awareness among health professionals and community members regarding the health and wellness issues faced by this priority population. This document is also intended to act as a comprehensive manual for program staff, designed to support program content and guide program implementation.

## Priority Population

According to the March of Dimes (2021), every year, nearly 40,000 babies in the United States are born with a congenital heart defect (CHD). Approximately 1 in 4 infants with CHD are diagnosed with a form of cCHD (Center for Disease Control, 2020). This life-threatening condition typically results in an infants' hospitalization in a pediatric cardiac intensive care unit (PCICU) and/or surgical intervention after birth (Center for Disease Control, 2020).

<b>Determinants</b>	<b>For Priority Population</b>
<b>Behavioral</b>	Parent knowledge related to stress/parental roles; attitudes related to stress management and parental roles based on culture, religion, personal
<b>Environmental</b>	-Hospital policies (i.e., policies on holding, skin to skin, developmental care, parent visiting) -Other commitments (example: other children, jobs, family challenges) -Infant fragility/intensive care unit (ICU) environment -Lack of resources for parents on stress reduction -Lack of resources for parents on ways to participate in parenting roles in ICU

## Health & Wellness Concerns

Parents of infants with cCHD experience significant stress from the time their child is diagnosed, through infants' hospitalization and following discharge from the hospital (Lisanti, 2018). Parental stress has been found to negatively affect parent quality of life and mental health (Lisanti et al., 2019).

## Supporting Epidemiological Facts

-80% of parents whose child is hospitalized for management of cCHD demonstrate symptoms of trauma and 30% demonstrate symptoms consistent with Post-Traumatic Stress Disorder (PTSD) (Woolf-king et al., 2017)

-25-50% of parents whose child is hospitalized for management of cCHD have increased symptoms of depression/anxiety (Woolf-king et al., 2017).

## Recruitment of Participants

The primary goal of participant recruitment is to identify and support parents as early as possible. Expectant parents who receive a diagnosis during routine ultrasounds prenatally will be referred to the program by an obstetrician-gynecologist (OBGYN), social worker and/or cardiology practitioner. Not all parents will have a prenatal diagnosis, in which case hospital practitioners may refer them to the program after an infant's birth.

## Intended Program Outcomes

After parents participate in the program *From Worry, To Warrior*:

- They will have an increased sense of belonging & community
- They will be able to more confidently engage in caregiving related roles
- They will have increased knowledge and awareness
- They will have reduced stress & improved sense of well being

## Program Objectives:

One month following program completion:

- 85% of parents will report increased confidence related to caregiving their infant with cCHD

- 95% of parents will report increased utilization of coping techniques
- 90% of parents will report increased perceived feelings of being supported

## Guiding Theoretical Frameworks

### Social Cognitive Theory (SCT)

- From *Worry, To Warriors* highlights the important impact of the dynamic relationship between a person’s environment, behavior and personal factors on health behaviors changes. Many important constructs of SCT have been incorporated within this program:
  - Personal factors: Self-efficacy (i.e., confidence to engage in a behavior), knowledge and expectations
  - Environmental factors: Social support and perceived/physical environment
  - Behavioral factors: Reinforcement

### Transactional Model of Stress & Coping

- Parents’ perceptions of an external stressor (primary appraisal), their perception of their ability to cope with stressors (secondary appraisal) and resources available to parents (i.e., psychological, social and material) determine how they manage stress and coping. Important extensions of this theory are utilized to guide program content, such as information seeking and social support.

### Diffusion of Innovation

- This theory supports how technology innovations are adapted, by whom and how they facilitate participation in health promotion, which supports this virtual program. Below are some of the theory constructs that are utilized to guide the program.

Theory’s construct	How it will support program
<b>5 stages of adoption process (awareness, persuasion, decision, implementation, confirmation)</b>	Each stage is considered and integrated to support continued program participation of parents.

<b>Simplicity (factor influencing adoption)</b>	The program is created to be easily understood and accessed virtually. Different education levels and economic backgrounds are supported.
<b>Compatibility (factor influencing adoption)</b>	Thinking of what the needs and experiences of the adopters (parents), will help to support their engagement and continued participation in the program. This virtual program has the opportunity to be accessed at parents' convenience which supports compatibility.
<b>Trialability (factor influencing adoption)</b>	Parents will have the ability to access parts of the program that have been pre-recorded vs attending a workshop live to see if it is something they could see themselves utilizing. Parents will have access to exclusive resources as part of the program.
<b>Relative advantage (factor influencing adoption)</b>	There are not currently programs similar to the proposed program therefore, parents who participate will experience a benefit from participating.
<b>Cost</b>	Each component of the program is not overly time consuming and affordable and/or free to parents.

### Role of Personnel

<b>Personnel</b>	<b>Role</b>	<b>Responsibilities</b>
<b>Primary Occupational Therapist</b>	Program Facilitator	-Facilitate/organize virtual workshops -Provide verbal and written education within scope of OT to support parent's self-efficacy, knowledge and well-being -Creation of evaluation surveys -Assist with facilitation of support group
<b>Secondary Occupational Therapist</b>	Co-facilitator	-Assist with facilitating virtual programs when needed -Management of website -Evaluation data collection
<b>Experienced Professionals (i.e. mental health counselors, social workers, child life specialist)</b>	Co-facilitators/Support	-Provide relevant support and education to parents during additional workshops and/or written resources -Availability for questions from parents

<b>Peer Advocates</b>	Co-facilitator/Support	-Communicate with parents to provide social support during workshops and support groups -Availability to answer questions from parents relevant to program
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### Important Program Features & Evidence

<b>Program Content</b>	<b>Theoretical Grounding</b>	<b>Supporting Evidence</b>
<b>Use of Virtual Platform</b>	Diffusion of Innovation	-153 of 181 parents surveyed indicated they would prefer a face-to-face and online approach to education (Kovala et al., 2016) -Internet-based education resources are valuable as they support independent learning and allow learner to set the pace and complete when it's convenient for them (Kovala et al., 2016)
<b>Peer interaction/ support</b>	Social Cognitive Theory; Transactional Model of Stress & Coping	-Valuable to be able to interact/learn from peers (Entsieh & Hallstrom, 2016) -CHD Parents interviewed wanted to connect with each other, establish a peer mentor and/or have a web-based support group for parents (Woolf-King et al., 2018)
<b>Education on Coping Techniques/ Mindfulness</b>	Social Cognitive Theory; Transactional Model of Stress & Coping	-No current evidence demonstrating programs that support education for parents to assist with mental/physical demands of parenting (Abbass-Dick et al., 2019) -85% of parents surveyed wanted to learn more about mindfulness practices, supporting need for more prenatal education on this topic (Abbass-Dick et al., 2019)
<b>Education on Enhancement of Parental Role</b>	Social Cognitive Theory; Transactional Model of Stress & Coping	-Second highest stressor is parent role alteration (Lisanti, 2017) -Health care professionals can facilitate/education parents on ways they can enhance parental roles (Lisanti, 2017)

		-Parents feel there is often little to no information provided during prenatal classes related to parenting skills or responsibilities that they will face (Entsieh & Hallstrom, 2016)
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## Program Content Outline

### Prior to the start of the program:

Parents will complete pre-participation surveys

### Month #1:

- Parents will engage in introductory virtual workshop with other parents; 30 minutes of education, time for questions and opportunities for social engagement with peers
- Parents have option to participate in monthly ‘drop in’ support groups virtually
- Parents will have access to website with multi-model resources, including additional workshops they can attend virtually (either recorded or live)
- Parents will receive text message check in with facilitator

### Month #2 & 3:

- Parents have option to participate in monthly ‘drop in’ support groups virtually
- Parents will have access to website with multi-model resources, including additional workshops they can attend virtually (either recorded or live)
- Parents will receive text message check in with facilitator

## Administrative Assessment

Critical Resources to support *From Worry, To Warriors*:

- Personnel:
  - Goal: Recruit and retain personnel (i.e., parent advocates, occupational therapists and other experienced practitioners)
  - Outcomes: Personal & professional development, support potential research opportunities by promoting awareness, community involvement/connection and personal fulfilment
  - Assessment: Utilization of feedback survey

- Equipment Resources:
  - Goal: Ensure access to technology equipment necessary for parents to participate in program
  - Outcomes: Secure funding for equipment needed in hospital; locate organizations willing to loan equipment to parents
  - Assessment: Survey
  
- Educational Resources:
  - Goal: Website with available handouts, websites & videos
  - Outcomes: Ensure education is available in different formats (i.e. visual, auditory) and literacy levels are appropriate for participants
  - Assessment: Pre-participation survey

### Evaluation Plan

Qualitative and quantitative data will be collected before the program, at one month and three months following completion of the program. Program evaluation will be provided to parents online and will contain both open-ended questions and Likert style questions related to intended outcomes.

### Critical Program Review

#### Evidence Base

##### Strengths:

- Evidence exists that supports the importance of early, prenatal education and what parents hope to learn about during this education
- Evidence exists that demonstrates the need for programs that support parents of infants with cCHD

##### Limitations:

- Limited evidence demonstrating examples of successful programs specific to parents with infants of CHD; no found prenatal programs

- Limited evidence supporting a virtual program with this unique population who are often not participating in the program from home and are facing many challenges

### Strengths & Limitations of Theoretical Base

- Social Cognitive Theory:
  - Strengths: Evidence to support use with health promotion programs with parents
  - Limitations: The theory does not take into account how emotion may play a role in affecting health behaviors
- Diffusion of Innovation:
  - Strengths: Theory takes into account characteristics of the priority population
  - Limitations: Limited evidence supporting use of diffusion of innovation with health promotion programs and effect on health behaviors

### Potential Barriers & Challenges

- Challenges with parent participation: Although this program has many benefits for parents, it requires physical time, motivation and readiness to participate in this type of a program. Parents are likely to be overwhelmed and have limited time, making participation in this program challenging.
- Hospital resources, environment & policies: Not every hospital is equipped to support parent mental health and parents as primary caregivers while their infants are hospitalized. PCICU's lack consistency with care and/or are lacking policies that support parent engagement.

### Conclusion

Current evidence exists that outlines the challenges and impacts of having an infant diagnosed and hospitalized for cCHD. However, evidence supporting successful programs to aid these parents and families are almost non-existent. *From Worry, To Warriors*, is theoretically grounded program and supported by strong evidence. Raising

awareness of the health concerns related to this priority population through the creation of this program and manual is only the beginning.

## **APPENDIX D – Executive Summary**

### **Introduction**

In the United States every year, approximately 7,200 infants are born with a critical congenital heart defect (cCHD), a life-threatening condition that often requires infant hospitalization and multiple surgeries after an infant's birth (CDC, 2020). Roughly 20% of infants diagnosed with cCHD who require a hospital stay are admitted for 2 months or more, with some hospitalizations lasting as long as a year (Lisanti et al., 2019). A diagnosis of cCHD before birth, or prenatally, is almost always unexpected and overwhelming for parents. After an infant's birth, parents find that their parental occupations, or the everyday activities associated with being a parent, they once imagined are significantly different from the reality they face (Gibbs et al., 2016).

For decades, occupational therapy practitioners have supported critically ill infants and their parents through family education, health promotion and advocacy, focusing on developmental, physical, and mental health. In times of occupational disruption, or when parents are unable to fulfill their parenting roles as expected, an occupational therapy practitioner is distinctly qualified to assist parents to adapt (Whitney & Walsh, 2020).

### **Key Findings**

Findings from an extensive literature review revealed that parents are not equipped to navigate the challenges and barriers associated with parenting a hospitalized, critically ill infant. The current evidence-based literature outlines several contributing factors. These factors include the medical fragility of the infant, the hospital environment,

parent/infant separation, lack of preparation/knowledge, and limited early focus on parent well-being/mental health. Additionally, parental stress has been reported to begin at the time of an infant's diagnosis and extend through the infant's hospitalization and beyond (Golfenshtein et al., 2017). This has been found to negatively affect parent quality of life, mental health, family function, child development, and child behavioral outcomes (Lisanti et al., 2019). When surveyed, parents with infants hospitalized within a pediatric cardiac intensive care unit (PCICU) identified parental role alteration as one of the greatest sources of stress (Lisanti et al., 2017). Parental role alteration is experienced when parents are physically unable, or feel that they are unable, to care for their infant (Lisanti et al., 2021).

While parents reported wanting to be involved in caring for their infant in the PCICU, they often felt unsure about how to touch, hold, or interact with them safely (Ames et al., 2011). Delays in parents' ability to care for and/or have unlimited access to their infant have been associated with increased feelings of guilt, parental role alteration, and issues with parent/infant bonding (Cockcroft, 2011). Up to 80% of parents with an infant diagnosed with cCHD experience short-term and long-term psychological distress, including symptoms of depression, anxiety, and trauma (Woolf-king et al., 2017).

Prenatal parent education programs have been associated with positive effects on parent self-efficacy (Jamalivand et al., 2017; Shorey et al., 2019; Tsai et al., 2018) and stress levels (Tsai et al., 2018). Prenatal parent education programs often focus on the childbirth process rather than empowering parents and preparing them for the early stages of parenthood (Entsieh & Hallström, 2016). Current evidence supports that parents prefer

technology based education programs (Abbass-Dick et al., 2020; Shorey et al., 2019; Kovala et al., 2016) with varied teaching methods, such as written, visual and audio-visual methods (Nightengale et al., 2015). Further, parents highly value opportunities for psychosocial support and when surveyed, suggested the need for more opportunities to connect with other families with infants diagnosed with cCHD (Woolf-king et al., 2018). Positive coping techniques, such as connecting and interacting with parents who are or have gone through similar experiences, have the potential to reduce feelings of parent isolation and improve quality of life (Sira et al., 2014). Although a multitude of challenges have been documented in current literature and several solutions have been proposed, there are currently no prenatal education programs for parents of infants diagnosed with cCHD.

### **Program Overview**

*From Worry, to Warriors* was designed to be the first virtual empowerment program for parents of infants prenatally diagnosed with cCHD. Parents whose infant receives an unexpected post-birth diagnosis of cCHD within the first month of life will also have access to the program. This program utilizes constructs within the occupational therapy scope of practice to support parental roles and well-being during the transition to becoming a parent of a critically ill infant. The empowerment program will be conducted entirely online and will incorporate evidence-based components, such as multimodal education and parent support. Parent workshops lasting no more than 60 minutes will be available for parents to complete either live through Zoom or pre-recorded and available online for their convenience. Topic examples for parent workshops include:

- Strategies for how to bond with your baby in the hospital (Kovala et al., 2016)
- Mindful parenting strategies
- Supporting an environment for healing in the hospital
- Self-care in the hospital

Opportunities for parents to engage with peers going through similar experiences will be facilitated through workshop activities and support groups. Through the program website, parents will have access to other educational and local resources, as well as experienced professionals who will be available to answer questions and provide support as needed.

The program will be facilitated by a primary and secondary occupational therapy practitioner. Additionally, other trained healthcare professionals and parent advocates with similar past experiences will be actively involved in program implementation. Short-term outcomes of the program include increased parent knowledge, feelings of being supported, empowerment, and decreased stress as it relates to their infant's hospitalization. Long term outcomes include increased parent-infant bonding and perceived self-efficacy. These are anticipated to be achieved within 3-8 months through continued engagement in the program, including participation in additional workshops and use of provided resources will allow for long term outcomes.

### **Guiding Theory**

Social Cognitive Theory and the Transactional Model of Stress and Coping were utilized to guide the development of the *From Worry, to Warriors*. Social Cognitive Theory, created by Albert Bandura, was utilized to analyze the problem and contributing factors identified during the literature review. According to Social Cognitive Theory,

human behaviors can be explained by the causal interaction between personal cognitive factors, behavioral factors, and socio-environmental factors (Kedler et al., 2015). Parents who receive a prenatal diagnosis of cCHD are at a disadvantage as they lack important personal cognitive, behavioral and socio-environmental factors that would facilitate a more successful transition to parenting a critically ill infant. The Transactional Model of Stress and Coping was utilized to guide aspects of the proposed program. The Transactional Model of Stress and Coping highlights the importance of the person-environment transactions that occurs during a stressful event and how stress is mediated by a person's judgement of the stressor, as well as psychological, social, and material resources available to them (Wethington et al., 2015).

### **Program Funding**

To ensure successful implementation of the program, in-kind and monetary support will be utilized. The program's budget includes paid employee time, equipment, online platforms, marketing and dissemination costs. Funding for the program will primarily be received from grants but additional funding may come from paid advertisements on the program website and donations.

### **Program Evaluation and Dissemination**

The program will be evaluated with a one-group pre- and posttest design. The first two years of program implementation will be considered a pilot phase, with a full launch to follow. Surveys will include both quantitative and qualitative questions in order to gain valuable information related to program implementation and anticipated outcomes. Quantitative questions will be in the form of a Likert scale and qualitative questions will

be collected through open-ended questions with a word limit. All evaluation surveys will be collected and analyzed utilizing an online platform.

After the successful implementation, it will be critical to share the preliminary results of the program with stakeholders and community members for continued program growth and awareness of impact. In order to expand to a large and varied audience, several methods will be utilized to disseminate this information. This will include virtual flyers, articles, blog posts, presentations, and posters at state and national conferences. Primary and secondary audiences will be targeted, including health care professionals, advocacy groups, parents and occupational therapy practitioners.

### **Conclusion**

The evidence is clear, expectant parents are not equipped to navigate the challenges and barriers of transitioning to parenting a critically ill infant diagnosed with cCHD. Every year, thousands of parents are negatively impacted by trauma, isolation and feelings of loss associated with their inability to participate in desired parental roles as a result of a required infant hospitalization. *From Worry, to Warriors* will be the first fully online prenatal empowerment program for families affected by cCHD, allowing parents to participate when and where it is convenient for them. It will provide expectant parents with opportunities to seek education related to topics that will increase their feelings of empowerment and self-efficacy, their sense of control, and their engagement in meaningful parenting occupations. Lastly, this program will provide parents with the opportunities to connect with peers and professionals, fostering a sense of community and support. With preparation, knowledge and support, *From Worry, to Warriors* will

help parents to take steps away from worry and take a leap closer to unlocking the warrior parent they were meant to become.

## APPENDIX E – Fact Sheet



*From Worry, to Warriors:*  
**A parent empowerment program for  
parents of infants diagnosed with a Critical  
Congenital Heart Defect (cCHD)**  
Anjelica Fortunato, MSOT, OTR/L  
OTD Candidate

*From Worry, to Warriors* is the first evidence-based virtual empowerment program designed for expectant parents with infants prenatally diagnosed with a critical congenital heart defect (cCHD). This program was created to support parents utilizing key constructs from the profession of occupational therapy.

### Introduction to the Problem



- In the United States every year, ~7,200 infants are born with a critical congenital heart defect (cCHD) (CDC, 2020)
- Lack of parent preparation for the transition to parenting a critically ill infant negatively impacts parent mental health, parent/infant bonding and parent quality of life
- Up to 80% of parents with an infant diagnosed with cCHD suffer with short-term and long-term psychological distress, including symptoms of depression, anxiety, and trauma (Woolf-king et al., 2017)

### Evidenced-Based Solution-From Worry, to Warriors

- Current evidence supports that parents prefer technology-based education programs (Abbass-Dick et al., 2020; Shorey et al., 2019; Kovala et al., 2016)
- Parents highly value opportunities for psychosocial support, which is often lacking for parents of infants diagnosed with cCHD (Woolf-king et al., 2018)

### Program Components

- Completely virtual program to support parents when and where it is convenient for them
- Access to virtual educational workshops with content based on parent needs and wants
- Virtual support network to connect with other parents going through similar experiences
- Access to varied experienced healthcare professionals, including the primary facilitating occupational therapy practitioner





### Sample Workshop Topics

\*Parents will have the option to attend workshops virtually, in real time or by watching a recorded version\*

- Strategies for parent/infant bonding in the hospital
- Mindful parenting strategies
- Supporting an environment for healing in the hospital
- Parent self-care in the hospital

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### Program Outcomes

- Increased parent knowledge
- Increased parent preparedness
- Parent empowerment
- Increased parent/infant bonding
- Decreased parent stress



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### Impact on Future Occupational Therapy Practice

- For decades, occupational therapy practitioners have supported critically ill infants and their parents through family education, health promotion and advocacy, focusing on developmental, physical, and mental health.
- In times of occupational disruption, or when parents are unable to fulfill their parenting roles as expected, an occupational therapy practitioner is distinctly qualified to help parents to adapt (Whitney & Walsh, 2020).
- This program supports the American Association of Occupational Therapy (AOTA) 2025 vision to “maximize health, well-being and quality of life” for parents of infants diagnosed with cCHD through advocacy, education and collaboration (AOTA, 2021).

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