PARENT'S POST-TRAUMATIC STRESS BEFORE AND AFTER THEIR INFANT'S SECOND PALLIATIVE HEART SURGERY: THE PaTHS DESCRIPTIVE CORRELATONAL LONGITUDINAL STUDY

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PARENTS' POST-TRAUMATIC STRESS BEFORE AND AFTER THEIR INFANT'S SECOND PALLIATIVE HEART SURGERY: THE PaTHS DESCRIPTIVE CORRELATONAL LONGITUDINAL STUDY

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ABSTRACT

One percent of infants born have CHD making it the most common congenital anomaly. Of those infants born with CHD, 1% have a functionally single ventricle. This type of heart defect requires three palliative heart surgeries, the first within seven days of birth, the second at 4-6 months, and the third at 2-5 years of age. Parents endure emotional trauma from witnessing their child in life-sustaining care, experiencing reoccurring hospitalizations, and the evolving reality of having a child with a chronic illness. Parent trauma impacts typical experiences for the parent and the infant resulting in impaired coping, bonding, and confidence. The infant may have problems with feeding or neurodevelopment. Parents with unresolved trauma may be less engaged in medical care, which is a predictor of later infant outcomes. The purpose of this study is to describe the levels of parent post-traumatic stress before and after their infant's second palliative surgery for SVCHD. A descriptive correlational, longitudinal design was used. The post-traumatic stress disorder checklist revised for the DSM-5 (PCL-5) was administered via

Research Electronic Data Capture (REDCap) to 22 parents before and after the second palliative heart surgery.

Descriptive statistics were used to evaluate and describe the demographic data and the level of post-traumatic stress at the two-time points. The Wilcoxon signed-rank test was used to determine the relationship between the two PCL-5 scores. There were positive PCL-5 scores present pre-surgery and post-surgery. Most of the scores (n=13, 59%) decreased between surgery one and two, although we did not have the statistical power to make definitive conclusions from the data. An inverse association between the PCL-5 scores and income and level of education was noted. The timing of the surveys introduced many factors beyond the control of the study team. Future research should seek scores at consistent time points not bound by surgery.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the School of Nursing and Health Studies, have examined a dissertation titled "Parent's Post-traumatic Stress before and after their Infant's Second Palliative Heart Surgery: The PatHS Descriptive Correlational Longitudinal Study," presented by Melissa Deanna Elliott, candidate for the Doctor of Philosophy degree, and certify that in their opinion it is worthy of acceptance.

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CHAPTER 1

INTRODUCTION

Approximately 1% of infants born have CHD, and an estimated 1% have SVCHD (Roger et al., 2012). Infants born with SVCHD typically follow a staged palliative surgical approach, with the first surgery within 7-10 days of life, the second around 4-6 months of age, and the third between 2-5 years of age (Anderson et al., 2015). Infants depend on their parents or other primary caregivers for all care at home, and research has shown that parents with increased stress are less attuned to their child's needs (McKechnie et al., 2016). Parents of infants with SVCHD bear witness to and endure trauma from the emotional response following exposure to distressing events during their infant's hospitalization (Cantwell-Bartl & Tibballs, 2013; Muscara et al., 2015). This chapter will include an overview of the proposed study, the single ventricle surgery pathway, the theoretical framework, the significance, and innovation.

Study Purpose and Specific Aim

The purpose of this study is to measure, describe, and compare levels of parent post-traumatic stress before and after their infant's second palliative heart surgery for SVCHD. Existing research focuses on one point in time or does not provide consistent conditions with SVCHD and the use of a home monitoring program. This research aims to use a validated tool to measure posttraumatic stress symptoms at two points during the SVCHD parent journey to illuminate areas for improvement further.

Research Questions

RQ #1: What is the level of parental post-traumatic stress measured two to four weeks before their infant's second palliative heart surgery?

RQ#2: What is the level of parental post-traumatic stress two to four weeks after discharge following their infant's second palliative heart surgery?

RQ#3: What is the difference in parental post-traumatic stress level before and after their infant's second palliative heart surgery?

Hypothesis: Post-traumatic stress levels will increase after the second palliative heart surgery.

RQ#4: What demographic variables are the mediators and moderators of the findings?

Definitions of Terms

This dissertation proposal includes a mixture of multidisciplinary subjects, so this section includes definitions to clarify the meaning of several key terms.

- Single Ventricle Congenital Heart Disease (SVCHD): Anatomical difference in the heart present at birth that causes the heart to physiologically function with one ventricle (Allen et al., 2016).
- Congenital Heart Disease (CHD): A broader term referring to anyone born with an anatomical difference in the heart present at birth (Triedman & Newburger, 2016).
- Parent or caregiver: These terms was used interchangeably throughout this text to refer to the person or persons who provide care for the infant at

home. I acknowledge that the parent is not always the primary infant caregiver.

- Trauma: Emotional response to distressing experiences for families, specifically parents, throughout the diagnosis and treatment course that follows on the journey to home for an infant with congenital heart disease (Helfricht et al., 2008; Muscara et al., 2015).
- Interstage: The time between surgery one (or birth) and surgery two for infant's with SVCHD who follow a staged surgical palliation.
- Posttraumatic Stress Disorder: Diagnosis requires exposure to a traumatic event plus invasive symptoms related to the trauma such as dreams, flashbacks, or physiological reactions to trauma triggers ("Trauma and Stressor Related Disorders," 2013).
- Transition: Transition is a time of change from stability that occurs in diverse experiences (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). Transition can relate to many status variations including the change of environment, responsibility, status, development, or subject (March & Keim-Malpass, 2018; Meleis et al., 2000). Transition in this inquiry is complicated, since the caregivers may be experiencing concurrent forms of transition; however, the main transition subject was that of responsibility in caring for their child with complex medical needs.

- Community pediatric care providers: Those primary care providers who attend to typical baby medical needs (vaccines, nutrition, acute illness) including advanced practice nurses, family practice physicians, and pediatricians.
- Hand-off Process: The report or check out procedure used when transferring care to another medical provider.

The Single Ventricle Surgery Pathway

Until the invention of the Blalock-Taussig shunt in the early 1980s, there were no medical options available to infants born with a single ventricle (Sarajuuri et al., 2012). Through early research, the single ventricle surgical pathway evolved to include three staged surgeries over the first 2-5 years of life that effectively separate the arterial and venous circulatory systems (see figure 1). After that invention, early research focused on operative and immediate postoperative care resulting in these infants surviving to new milestones such as discharge home from the hospital (Brown & Smith, 2018; Sarajuuri et al., 2012; Tregay, Wray, et al., 2016). As these babies were discharged to home, a new problem emerged including death during the interstage period (Oster et al., 2015). Home monitoring programs started to increase infant interstage survival and have demonstrated a sustainable impact with a 95% interstage survival rate across 65 surgery centers in the United States (Nieves et al., 2018).

First Palliative Surgery

Shortly after birth, infants with SVCHD are started on intravenous medication, keeping the ductus arteriosus open so that they can maintain adequate cardiopulmonary circulation (Rao, 2019). They then need a surgical intervention ideally in the first 7-10 days of life to ensure adequate pulmonary blood flow (Ghanayem et al., 2012). This surgery requires the addition of a shunt to carry blood from the heart back to the lungs for oxygenation. The shunt requires the single ventricle of the heart to work twice as hard pumping to a parallel circulation that delivers blood back to the body and lungs (Ghanayem et al., 2012). A subset of these infants will also require a more invasive surgery requiring reconstruction of the aorta, also known as a Norwood surgery (Anderson et al., 2015). Other infants are born with a more balanced circulation with adequate blood flow to the lungs and the body, so they may not require an initial surgical intervention. Others will have a hybrid surgical approach with pulmonary artery banding and patent ductus arteriosus stent (Rao, 2019). Some other patients may have cardiac anatomy, such as Tetralogy of Fallot, that is amenable to biventricular repair with growth, or the second surgery (full repair versus palliative long-term approach) may be unclear until the infant is older. For this dissertation research, all these scenarios were referred to as palliative surgery.

The Interstage Period and Home Monitoring

The time after the first palliative surgery and before the second palliative surgery is known as the interstage period. During this time the infant has increased risk of morbidity and mortality. Mortality was reported as high as 20% before the initiation of comprehensive home monitoring programs (Ghanayem et al., 2012). The standard of care is that infants who are discharged home during the interstage period are followed by multidisciplinary home monitoring teams (Nieves et al., 2018; Shirali et al., 2016). Home monitoring teams utilize nurses (registered nurses and advanced practice nurses) for daily monitoring work (Bingler et al., 2018). These programs allow parents to document and share weight, oxygen saturation, heart rate, input, output, videos, and any other concerns with the team enabling the infants to go home while they grow in preparation for the second palliative surgery (Ghanayem et al., 2012; Nieves et al., 2018; Shirali et al., 2016). Initially, this monitoring data was recorded with paper and pencil and shared once per week with the team (Bingler et al., 2018). Now, this data is commonly shared instantaneously utilizing a mobile health (mHealth) application, thus allowing data review by the home monitoring team to happen more quickly (Bingler et al., 2018). The addition of the electronic transfer of home monitoring data to the team further reduced the infant interstage period mortality rate to just 4.6% with the most recently published data (Kaplinski et al., 2020).

Second Palliative Surgery

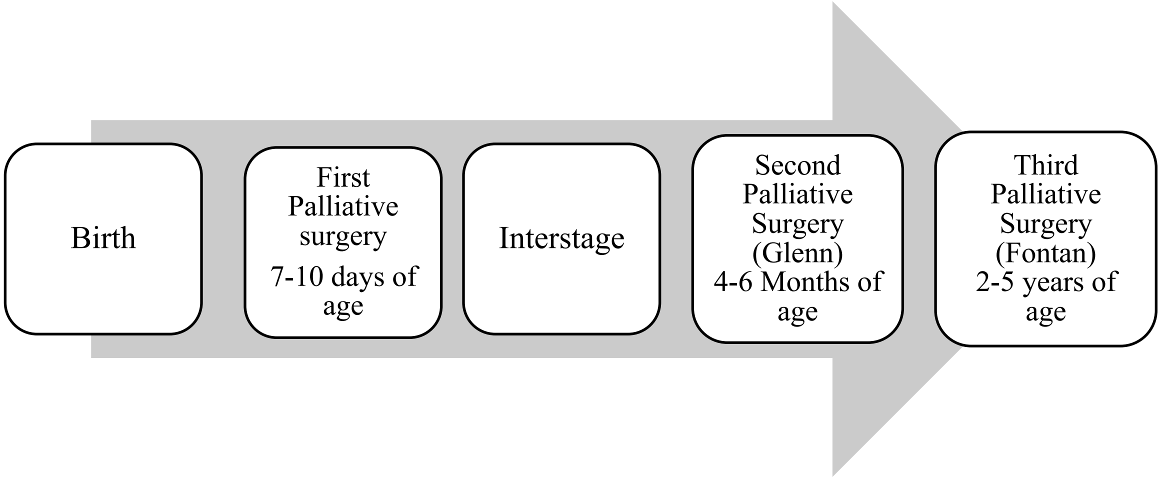
The second heart surgery usually occurs between 4 and 6 months of age. This surgery is called the bidirectional Glenn, which includes removal of the superior vena cava from the heart which is anastomosed directly to the pulmonary artery (Rao, 2019). This anastomosis provides a reliable source of pulmonary blood flow that was previously supplemented via the shunt. The surgery usually includes other elements such as ligation of the main pulmonary artery, atrial septectomy, or Damus-Kaye Stansel procedure (Rao, 2019). The usual length of hospital stay following this surgery is 7-10 days followed by home monitoring which is typically completed within one month after the surgery.

Third Palliative Surgery

The third surgery, the Fontan, takes place between 2 and 5 years of age. This surgery completes the long-term single ventricle circulation by connecting the inferior vena cava up to the pulmonary arteries. Following this surgery, the venous blood circulates without the assistance of a muscular pump (the heart) (Pundi et al., 2015). Thus, the blood going to the lungs is mostly non-pulsatile. This single ventricle circulation is still not normal, with the system now relying on passive pulmonary blood flow (Pundi et al., 2015). Long term, this circulation system has a known risk of complications such as plastic bronchitis, protein-losing enteropathy, heart rhythm disturbances, and liver cirrhosis (Rychik, 2010). These complications could result in the need for surgical revisions or even require orthotopic heart transplant (Pundi et al., 2015).

Figure 1

The Single Ventricle Surgical Pathway



Biventricular Repair

Some patients who need an initial palliative procedure may be candidates for a biventricular cardiac repair as a second or third surgery. Patients who are high risk as a neonate, who have borderline ventricular size, or who may need more time to grow to tell which surgical pathway is best may have an initial palliative cardiac procedure (Andersen et al., 2020; Sojak et al., 2019). High risk infants include those that are preterm, low birth weight, or have multisystem concerns (Fraser et al., 2001; Sojak et al., 2019). In that case, these infants have mixing of arterial and venous blood, thus lower oxygen saturations. This kind of staging is used with a variety of heart lesions. The staging allows time for cardiac ventricular growth and may mean the infant is then a candidate for a biventricular repair (Andersen et al., 2020). Avoiding long term single ventricle palliation with patients who are candidates is preferred since (as previously discussed here) there are known complications with long term single ventricle circulation (Andersen et al., 2020).

Theoretical Framework

Meleis's transitions nursing theory guided the proposed research by providing a research-validated roadmap of the transition experience. The specific timepoints and subject of research are guided by the transitions theory, which suggests that a time of transition is a time of increased vulnerability (Meleis et al., 2000). The timepoints during the interstage period and then after the second surgery are also directed by the theory since these points include multiple concurrent transitions. Critical points are one of the properties of transition (Meleis et al., 2000), By exploring the topic of posttraumatic stress, the proposed research is exploring the transition conditions for the infant and the patterns of response for the parent. The transition process, as proposed by Meleis, also informs the descriptive correlative method of research. The property (critical time point) and condition (parent trauma on the infant) of the transition contributes to the pattern of response (increased parent trauma). In this way, the research has a theoretical basis for measuring the trauma at different time points.

Significance

The significance of the problem of parent trauma before and after their infants second palliative heart surgery includes the cost, the incidence, the child's long-term outcomes, parent's psychosocial wellbeing, and the outcomes due to unresolved trauma. Much of the published research literature for this population focuses on the infant during the interstage period (Bingler et al., 2018; Gaskin, 2018; March & Keim-Malpass, 2018; Shirali et al., 2016).

Cost and Incidence of SVCHD

The staged palliative surgical approach is costly, with most of the hospital expenses for CHD incurred in the first year of life (Simeone et al., 2015). Further, SVCHD ranks in the top ten most expensive pediatric diagnoses (Huang et al., 2017). The Center for Disease Control and Prevention reported in a morbidity and mortality report on inpatient hospital costs that hypoplastic left heart syndrome has the highest median inpatient cost of any congenital anomaly (Arth et al., 2017). In a five year retrospective data review, Simeone et al. (2015) found that CHD cost almost $60 million a year. These costs add stress to the families and the healthcare system (Connor et al., 2010; Huang et al., 2017). Cost is an important indication for families of children with all CHD as 89% of families report feeling troubled by the medical costs (McClung et al., 2018). The costs for the families and their infants persist past the financial burden.

Long Term Outcomes

Since surgical techniques and postoperative management are significantly improved over the last 40 years, most infants born with CHD will live into adulthood (Oster et al., 2013). Consequently, the research focus has shifted to improving the quality of their life. Children with CHD are known to have neurocognitive delays, decreased functional status, decreased academic performance, and psychosocial struggles (Bucholz et al., 2020; Gerstle et al., 2016; Marino et al., 2012; Oster et al., 2017). These struggles may be in part due to the early influences of the parent on the child (Lisanti, 2018). Parents of children with CHD struggle with post-traumatic stress disorder (PTSD), anxiety, and depression, among other psychosocial concerns (Cantwell-Bartl & Tibballs, 2013; Golfenshtein et al., 2022; Woolf-King et al., 2017). Having a child with CHD can cause dysfunction within the whole family unit, with impacts on parents, siblings, and even grandparents (Jackson et al., 2015; Rempel et al., 2013; Wray et al., 2018). The literature has primarily included infants with the single ventricle hypoplastic left heart syndrome, excluding infants with other congenital heart lesions that are functionally single ventricles (Nieves et al., 2018).

Children with CHD Neurodevelopment

In 2012 the American Heart Association (AHA) and American Academy of Pediatrics (AAP) released a joint statement regarding the evaluation and management of neurodevelopment outcomes for children with CHD (Marino et al., 2012). This statement called for developmental screening, treatment, and reevaluation of symptoms for an infant or child with CHD. Comprehensive cardiac neurodevelopmental programs are now standard, but children with CHD still remain at heightened risk of neurodevelopment delays when compared with their healthy peers (Brosig et al., 2017). Supporting neurodevelopment is a critical step in improving the quality of life (QoL) for those with CHD in the long-term (Marino et al., 2012). These delays contribute to poor academic performance in childhood for this group (Oster et al., 2017). While these concerns are multifactorial, parent and family support and mental health contribute to the success of the child with CHD (Rempel et al., 2012).

Parent Psychosocial Wellbeing

Mothers of children with CHD have decreased quality of life, increased stress, and reduced family functioning when compared to the mothers of healthy controls (Alkan et al., 2017). Parenting stress often starts with a prenatal diagnosis and is still present and not significantly decreased by one year of age (Golfenshtein et al., 2017). The infants' post-surgical course, which may be long and complicated by multiple procedures, impacts the parent trauma experience.

Parents of infants with SVCHD endure trauma from their emotional response following exposure to distressing events (Muscara et al., 2015). Additional parent trauma stems from the repeated hospitalizations and the reoccurring reality of having a child with a chronic health condition (S. Simeone et al., 2018; Woolf-King et al., 2017). Research about the general population of children with life-threatening illnesses demonstrates that parents of this group endure daily reminders of their child's potentially fatal disease and, as a result, exhibit both acute and long-term post-traumatic stress symptoms (Muscara et al., 2015).

Parents of children with SVCHD are continually balancing letting their child be "normal" versus worrying about the child's health and wellness due to the CHD (Elliott et al., 2021; Wei et al., 2016). Frequent doctor's appointments, medications, laboratory testing, procedures, and even surgery are everyday experiences that can leave these parents of children with CHD feeling alone and isolated, without other options they parent through the adversity (Imperial-Perez & Heilemann, 2019; Redshaw, 2014). This parenting can involve learning how to be a medical provider for your child while still trying to balance the usual demands of life like jobs, finances, and other children (Jackson et al., 2015; Kolaitis et al., 2017). The feelings of worry, safeguarding, isolation, and hopelessness are compounded by the other emotionally traumatic events they endure through their child's hospitalizations and medical complications (Cantwell-Bartl & Tibballs, 2013; Kolaitis et al., 2017; Muscara et al., 2018). These experiences leave SVCHD parents with a significantly increased risk of psychosocial problems such as anxiety, depression, and posttraumatic stress disorder (PTSD) (Caris et al., 2016; Woolf-King et al., 2017).

Outcomes of Unresolved Parent Trauma

New trauma and previously unresolved parent trauma inversely correlate with long term quality of life for the parent and the child (Alkan et al., 2017). The importance of a parent's psychosocial wellbeing is increasingly recognized as contributing to their children's later psychosocial and even physical wellbeing (Kasparian et al., 2019). Parent trauma limits infant bonding, and this has a known negative impact on the infant's development (Lisanti, 2018). While trials of interventions to improve parent's mental health are lacking, a few have shown early success in improving parent coping, bonding, parent confidence, infant feeding, neurodevelopment, and family functioning (Golfenshtein et al., 2020; Kasparian et al., 2019).

The importance of parent engagement for infant outcomes is well documented and is even included as a critical driver behind decreased mortality in this group (Anderson et al., 2015). Parents report that, though their children are more accessible after the Glenn surgery, they often feel a sense of loss with the end of the home monitoring period (Elliott et al., 2021). Parents trust their home monitoring team over other health care providers. But after the second palliative surgery, they transition out of the program and no longer have the same access to that team (Brown & Smith, 2018). The loss of perceived support may be compounded by unresolved post-traumatic stress symptoms that can last long after the surgeries are complete (Golfenshtein et al., 2017; Muscara et al., 2015). Improving the parent's psychosocial experience can improve the infant's long term quality of life, a national initiative mandated by the Center for Disease Control and Prevention, and the American Academy of Pediatrics (Kasparian et al., 2019).

Long term unresolved trauma can have significant negative health consequences for the parent as well. The risk of death due to cardiovascular disease in individuals with PTSD is increased by greater than 50% (Burg & Soufer, 2016). The presence of PTSD can also cause disturbances in the gastrointestinal system (Ng et al., 2019). There is also increased risk for other mental health concerns such as depression and anxiety as well as effects on cognition and emotional functioning (Magruder et al., 2017). These consequences ripple out to society as a whole and recently there are calls to treat PTSD as a public health issue due to the effects on society (Magruder et al., 2017; Watson, 2019).

Home monitoring programs provide a safety net for infants and parents during the interstage period, and there are also programs to assist with long term SVCHD care after the third palliation surgery. There is a need to extend that research to explore the transition from the interstage period after the Glenn surgery leading up to the Fontan, the third palliative surgery, particularly regarding the parent experience, including trauma. Successful transition and continuance of care for infants in the community would benefit the infant, parents, and the healthcare system by possibly reducing costly long-term health consequences for the child with SVCHD (Kolaitis et al., 2017; Lisanti, 2018).

Innovation

This study is innovative since it will extend the currently available literature to include the parent experience at two time points outside of the hospital setting. Parent trauma is rarely studied outside of the intensive care unit setting (Cantwell-Bartl & Tibballs, 2013; Kasparian et al., 2019; McMahon & Chang, 2020). This research will expand the traditional sample by including those at home during the interstage and after the second surgery.

Single Ventricle Congenital Heart Disease

The existing parent trauma literature tends to focus on all types CHD (Alkan et al., 2017; Kasparian et al., 2019; McMahon & Chang, 2020). Also, though the surgical plan is the same no matter the subtype of SVCHD, many studies focus on just hypoplastic left heart syndrome (Alkan et al., 2017; Cantwell-Bartl & Tibballs, 2013; Kasparian et al., 2019; March & Keim-Malpass, 2018; S. Simeone et al., 2018). This excludes the other SVCHD subtypes limiting the generalizability of those findings to the larger group of SVCHD patients. This study will expand the sample by including all types of heart lesions that require initial palliative surgeries.

Longitudinal Data

This study will also examine two understudied timepoints for parent posttraumatic stress at home before and after the second palliative heart surgery. Preliminary qualitative research demonstrates that parents continue to need support after the second palliative heart surgery of their infant with SVCHD (Elliott et al., 2021). Parent trauma seems to extend past the critical interstage period, which is not unexpected since available longitudinal data with parent traumatic stress symptoms including other chronic illness groups (oncology, cardiology, and general pediatric ICU parents) show that many parents still have symptoms 18 months after the trauma occurs (Muscara et al., 2018). A descriptive correlational longitudinal study is the best next step to quantify the level of parent posttraumatic stress that has been demonstrated in qualitative research and more particularly to examine that stress changes before and after their infant's second palliative heart surgery for SVCHD.

CHAPTER 2

REVIEW OF LITERATURE

This chapter presents a synthesis of the current relevant literature associated with parent trauma in caring for an infant during the single ventricle interstage period and following the second palliative heart surgery. A synthesis involving the transition to home, the parent experience, and outcomes for infant and parent was explored. The chapter will conclude with the identification of gaps in the literature as a rationale for this dissertation research.

Synthesis of Research in Transitions to Home for Infants with SVCHD

Transition is a time of vulnerability. For this population, the transition is a period of vulnerability that follows a time that is fraught with trauma, which may be unresolved. Preparing the patient, family, and providers in the community for the infant's discharge is an imperfect science with relatively high readmission and late mortality risk (Bingler et al., 2018; Oster et al., 2015; Shirali et al., 2016; Tregay et al., 2015). Once in the community, there is a lack of specialized knowledge relayed to the general pediatric providers (Tregay, Brown, et al., 2016; Tregay, Wray, et al., 2016). The parents who are expected to provide skilled care to these medically complex infants also endure personal challenges throughout this process (Gaskin et al., 2016).

Balancing Roles of Parent and Parent as Provider

The transition to home is superimposed on other transitions with the parents balancing their new role as a medical care provider in addition to parenting in general. Recent evidence underscores the importance of discharging infants with SVCHD to home as soon as they are clinically ready, while also attempting to reduce the risk of readmission. Infant caregivers are primarily responsible for the success of the transition, and authors have identified that the transition to home impacts the patient and family in a multitude of ways (Gaskin, 2018; Solan et al., 2015). This process is one of many co-occurring transitions for the infant, parents, and family at the time of hospital discharge (Gaskin, 2018; Solan et al., 2015). Co-occurring transitions can include becoming a parent for the first time, becoming a skilled provider, infant developmental milestones, or becoming the primary source of financial support among others depending on the individual family circumstances (Gaskin, 2018; Lerret, 2009; Meleis et al., 2000; Solan et al., 2015).

Knowledge Deficit, Communication, and Uncertainty

Knowledge deficit, communication, and uncertainty underscore the current state of the transition to home for infants with SVCHD and their families. Review of the literature supports the importance of communication with primary providers, parent perception of providers' knowledge deficits, and distrust of those providers fueled by poor interactions (Brown & Smith, 2018; Gaskin, 2018; Wray et al., 2018). Parents have described general practitioners as lacking knowledge and have felt they were being judged as overprotective by their primary providers (Wray et al., 2018). These poor relationships can be strengthened or further deteriorate in the presence of nurse-led home monitoring programs that can provide more reliable care (Brown & Smith, 2018; Golfenshtein et al., 2020; Tregay, Wray, et al., 2016; Wray et al., 2018). Since nurses often handle the patient discharge process and also the home monitoring programs, they are in an ideal position to work together with community pediatric care providers to improve the handoff process (Brown & Smith, 2018). Another issue is that the handoff procedure is highly variable between institutions. Tregay and Wray et al. (2016) published a qualitative study that demonstrates this observation. Semi structured interviews were conducted with 20 parents of children with CHD who were emergently readmitted to the hospital or died at home following a hospital discharge. The sample also included 25 cardiologists and nurses from specialty surgery centers and 11 community providers (pediatricians or cardiologists) across the United Kingdom to assess discharge processes and community care following discharge. The authors found that discharge and home monitoring practices varied widely between systems. Handoff communication was lacking, contact information for the specialty centers was not readily available to the community providers, and parents and outside providers felt ill-equipped to identify and respond to infant deterioration in the community (Tregay, Wray, et al., 2016). These findings were limited to specialty centers in the United Kingdom but provided opportunities for practice improvement that resonate in similar infant populations.

A secondary effect of poor communication is a general lack of understanding about post-hospital care. Documentation of knowledge deficit exists for both the community provider and the parents. Parents report a lack of trust in their child’s community providers and report feeling unprepared to identify if their infant is decompensating at home (Tregay, Brown, et al., 2016). Wray et al. (2018) used a closed online forum allowing parents to respond to questions about their experiences at home.

They found that parents felt lacking in knowledge and burdened by the responsibility of being the "keeper" of information about their child, and as such expected to report data on demand to community pediatric providers and others. These feelings also were found in a longitudinal mixed methods study where parents ranked their general practitioner's knowledge of their child's heart lesion at just over 20% and the cardiac home monitoring nurse's knowledge at 100% (Gaskin, 2018). This same study analyzed retrospective data from 22 parent surveys and found that parents who do not feel prepared to discharge to home and were not ready to identify clinical changes in the infant once at home (Gaskin, 2018). The researchers used the findings from this study to create an early warning tool using the baby's skin color, activity, breathing, circulation, and feeding to aid in parent recognition of their child's clinical deterioration (Gaskin, 2018). The tool is organized into a traffic light system (green, yellow, red), which prompts the parent to act according to the appropriate response for each category. This tool could aid in the identification of clinical changes by parents at home. It may bridge the knowledge gap when they are discussing the infant changes with the community providers. The knowledge deficit was further replicated in Tregay and Brown et al.'s (2016) study using semistructured interviews to explore 21 parent experiences in recognition and response of clinical deterioration in infants who were readmitted or had late mortality after discharge from the hospital following surgery for CHD. The researchers found that parents were not adequately prepared to identify early warning signs, with some parents unable to recall any symptoms at all (Tregay, Brown, et al., 2016). The findings also showed that even when the parents recognized and reported warning signs, they either were not taken seriously by community providers or did not know how to escalate their concerns (Tregay, Brown, et al., 2016). Parents and community providers are not always adequately prepared to identify or respond to critical infant clinical changes at home (Tregay, Brown, et al., 2016).

Further highlighting the risks that knowledge deficits and poor communication pose was a recent study by Gaskin (2018). This prospective longitudinal mixed method study used surveys and semistructured interviews to gather information about the transition to home experience for 12 parents of infants with shunt-dependent CHD (Single ventricle n= 11; tetralogy of fallot n=1). Interviews conducted at two weeks before discharge, day of discharge, and two times after discharge, reported that the experience is unique to each family with both expected and unexpected transitions often co-occurring throughout the process. An essential finding of this study was that the parents' uncertainty was most related to not knowing what to do with infant deterioration at home, which provides a significant opportunity for future research (Gaskin, 2018). This research finding underscores the need for personalization of the transition process to meet individual family needs and the critical role that nursing has in making these transitions to home more successful. Difficulties with knowledge, communication, and feelings of uncertainty are vital pieces of the transition literature review for this population of patients. The parent burden continues with personal effects from having a child with SVCHD.

Synthesis of Literature Regarding the Parent Experience

Transitions are shaped by the uniquely intense nature of the stress that parents experience and its effects on their ability to care for their child. The parent experience of having an infant with CHD sometimes requires extraordinary actions in everyday tasks such as feeding, bathing, or activities. There are many factors that contribute to the parent experience during a healthcare transition, topical research is presented below.

Implications of Complex Trauma

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) outlines that witnessing life-threatening events in person is a criterion for the development of Post-traumatic stress disorder ("Trauma and Stressor Related Disorders," 2013). Parents of infants with SVCHD experience their child receiving life-sustaining interventions sometimes started during fetal life and continuing throughout all stages and palliative interventions following their child's diagnosis (Cantwell-Bartl & Tibballs, 2013). Witnessed events, include but are not limited to, mechanical ventilation, continuous intravenous medication, cardiopulmonary resuscitation, extracorporeal membrane oxygenation, or various medical catastrophes for the infant (e.g., a life-threatening hemorrhage) (Cantwell-Bartl & Tibballs, 2013). The literature on this topic with this population exists but is sometimes vague, with some studies not even using the word trauma (McMahon & Chang, 2020). Research about the general population of children with life-threatening illnesses demonstrates that parents of this group endure daily reminders of their child's potentially fatal disease and, as a result, exhibit both acute and long-term post-traumatic stress symptoms (Muscara et al., 2015). Verification of the notion that acute post-traumatic stress is present can be found in one study involving parents of infants with hypoplastic left heart syndrome. Cantwell-Bartl and Tibballs (2013) used Structured Clinical Interview for Diagnosis-Clinical Version (post-traumatic stress disorder module) to explore the psychosocial experience of parents while in the pediatric intensive care unit finding that 83% of parents exhibit symptoms of post-traumatic stress disorder during that time. The parents who received a prenatal diagnosis had a slightly higher rate, with 88% of mothers and 66% of fathers testing for clinically significant post-traumatic stress disorder.

Parents of children with congenital heart disease are forced to function in an unfamiliar and often unwelcoming environment for weeks or months after their baby is born. After surgery, parents witness their child receiving mechanical support to help them breathe and to help with oxygenation and circulation via extracorporeal membrane oxygenation (ECMO) in some cases (Cantwell-Bartl & Tibballs, 2013). The foreign environment and sometimes the jarring appearance of their child add to the trauma experiences for the parent. Parents report that they are often unprepared for the intensive care environment and often ill-equipped to cope with the traumatic experience (Cantwell-Bartl & Tibballs, 2013).

Muscara et al. (2015) used a prospective longitudinal study to examine post-traumatic stress symptoms in 159 parents of children with cardiology, oncology, and intensive care needs over four time periods- at diagnosis, 3 months, 6 months, and 18 months later. Parents reported that seeing their child receive painful interventions triggers traumatic stress reactions (Muscara et al., 2015). These acute stress reactions have implications that persist beyond the initial hospitalization and may weaken the parent's ability to provide care for their medically complex child long-term (Muscara et al., 2015). Many of the parents in the Muscara et al. study still reported post-traumatic stress symptoms 18 months after their initial diagnosis. The shocking reality of seeing their child in an uncomfortable situation is one of many stressors for the parent of an infant with congenital heart disease.

Post-traumatic stress is just one of the concerns for parents of children with congenital heart disease. Alkan et al. (2017) examined the quality of life, anxiety, depression, parental attitudes, and family functioning in 120 child and mother pairs, 80 study participants with congenital heart disease (40 cyanotic and 40 non-cyanotic), and 40 healthy control subjects in their matched control study. Mothers of children with congenital heart disease had a statistically significantly decreased quality of life when compared to the mothers of healthy controls. Quality of life score was lowest for mothers of children with cyanotic heart disease with role difficulty due to physical ($p = 0.010$) and emotional ($p=0.006$) problems (Alkan et al., 2017). Parenting stress, attitudes, and family functioning was also considerably different for the congenital heart disease group compared to the healthy control group (Alkan et al., 2017). These findings support that parent's psychosocial wellbeing is compromised and should be considered an essential part of holistic infant patient care.

Another study supports that parents of children with CHD experience more stress than parents of children without CHD. Golfenshtein et al. (2017) examined the stress levels of mothers of infants with critical CHD (those who required heart surgery within the first six weeks of life) compared with mothers of healthy neonates in their prospective cohort study. The Parenting Stress Index- Long Form was completed by 129 parents (CHD N=66 and Healthy N =63) at 3, 6, 9, and 12 months of age. Parents of neonates with CHD had higher levels of stress on various subscales at all four-time points (Golfenshtein et al., 2017). These results support the presence of significant CHD parent stress that continues through the first year of their infant's life.

Alkan et al. (2017) and Golfenshtein et al. (2017) included only mothers in their parent sample. Sarajuuri et al. (2012) included 14 fathers out of a total of 69 parent participants, and the findings of their prospective neurodevelopmental follow-up study demonstrated that mothers and fathers differ in their stress response patterns. Cantwell-Bartl and Tibballs (2013) had a more balanced sample of mothers and fathers with 13 fathers out of 29 parent participants in their sample. Golfenshtein et al. (2017) identified a study limitation of not examining both parents in the research.

Additional Sources of Stress

Sources of stress for parents of children with CHD are plentiful and include economic burden, responsibility for the medically complex child, lack of support, knowledge deficit, and fear, among others (Alkan et al., 2017; Caris et al., 2016). March and Keim-Malpass (2018) explored six public blogs written by parents of infants with hypoplastic left heart syndrome and found that parents felt stress about their competence to provide care at home, to protect their child from infection, and about readmission, which reminded them of their child's fragility. Once home, parents feel stress about their child's reaching developmental goals, such as appropriate weight gain, and parents worry about the competence of their community providers (Gaskin et al., 2016). The stress accumulates as the parents struggle with a lack of control over the trajectory of their child's life-threatening illness.

Another source of stress stems from the almost constant feeling of helplessness. Parents are supposed to bond with, protect, and provide care for their children. Yet, when the child is born with CHD, these experiences are limited by medical necessity. The limitations placed on parents in the hospital environment alienates them according to one study's results, in which 50% of mothers and 38% of fathers reported a lack of bonding with their infant while in the intensive care unit (Cantwell-Bartl & Tibballs, 2013). The importance of including the parents in hospital care is increasingly recognized, but the feeling of a lack of control persists and continues even after the discharge to home (S. Simeone et al., 2018). This lack of control extends to the longer term after the second palliative surgery; parents report a lingering fear of the future related to their child's mortality (Elliott et al., 2021). Parents must gain skills to become expert providers of medical care and must have the psychosocial resources to deal with the stress of that new role (Stoffel et al., 2017). Once home, role transition translates into confusion for the parent who is now acting as a nurse to the child (Wray et al., 2018). The experience of not being able to parent and not initially bonding with an infant who now requires specialized care adds to the departure from normalcy experienced by the caregivers (March & Keim-Malpass, 2018).

Parental Isolation

Experiences of physical separation from regular life add to feelings of isolation described in the literature. Isolation can be physical, as parents struggle to balance hospital life and home life, or it can stem from the knowledge and social disparities. In their mixed methods longitudinal study, Kosta et al. (2015) conducted interviews with 154 parents of infants with all types of CHD who had heart surgery before three months of age after discharge, eliciting what they found to be difficult during their infant's hospitalization. The results showed that parents struggled with being in the hospital where they "essentially establish a second campus for their lives" (p. 1062). Another significant source of stress for parents was the demand for keeping friends and family up to date with the baby's progress (Kosta et al., 2015).

Many of the same topics were confirmed in Wray et al.'s (2018) qualitative study drawing on entries in an online forum run by the Children's Heart Foundation for parents of children with CHD. The foundation posted questions on the forum for parents to answer and discuss. The foundation followed up with probing questions if needed, then provided deidentified transcripts to the research team. Member responses revealed a shared experience of isolation among the 91 parents who completed the study. Responses to the study demonstrated that most of the social interactions in the hospital are with the staff, leaving the parents with a constant reminder of their knowledge deficit, which adds to both isolation and lack of control (Wray et al., 2018). Parents are surrounded by people whose lives continue while theirs may appear to them stuck in a constant state of uncertainty about their infant's status—healthy or ill (Wray et al., 2018). The Wray et al.

(2018) study further reported that isolation extends into the home environment where parents are reluctant to venture out for fear of exposing their fragile baby to germs. This feeling is compounded by home therapies such as physical therapy, occupational therapy, or home nursing that further limits the parents from leaving home (Wray et al., 2018). Numerous factors combine to cause distress that the parents may not be prepared to endure.

Long Term Single Ventricle Outcomes

SVCHD is a lifelong diagnosis with a myriad of medical, social, and emotional concerns. The diagnosis has a lasting impact on the whole family. The following is a summary of topical information about the long-term outcomes as they pertain to this research.

Children with Congenital Heart Disease Quality of Life

In 2012 the American Heart Association (AHA) and American Academy of Pediatrics (AAP) released a joint statement regarding the evaluation and management of neurodevelopment outcomes for children with CHD (Marino et al., 2012). This statement called for developmental screening, treatment, and reevaluation of symptoms for an infant or child with CHD. Comprehensive cardiac neurodevelopmental programs are now standard, but children with CHD remain at heightened risk of neurodevelopment delays when compared with their healthy peers (Brosig et al., 2017; Tan et al., 2022). Supporting neurodevelopment is a critical step in improving the quality of life (QoL) for those with CHD in the long-term (Marino et al., 2012). These delays contribute to poor academic performance in childhood for this group (Oster et al., 2017). While these concerns are multifactorial, parent and family support and mental health contribute to the success of the child with CHD (Rempel et al., 2012).

Children with SVCHD experience these same neurodevelopmental concerns with the addition of long term cardiac concerns of rhythm disturbances, additional catheter-based, and surgical interventions, or orthotopic heart transplant (Pundi et al., 2015). One retrospective 40-year review of Fontan (third palliative surgery) outcomes found that the ten-year transplant-free survival rate at one center is 73%, 20 years 59%, and 30 years 40% (Pundi et al., 2015). The overall risk of the complication of protein-losing enteropathy, which is related to late mortality is 9% (Pundi et al., 2015). The risks of a Fontan circulation increase with time with the steepest slope in death at 15 years post-surgery (Rychik, 2010). Some cardiac centers counsel families that the eventual fourth palliative surgery is the orthotopic heart transplant (Kenny et al., 2018). This option is not fail-proof with high postoperative mortality, long waiting lists, and reduced organ availability for younger patients, this is still not considered the first option in most cases (Kenny et al., 2018)

Elliott et al. (2021) conducted interviews with eight families of infants with SVCHD after their second palliative heart surgery finding that parents continue to struggle with trauma during that time. Several parents reported that varied experiences caused them to relive the traumatic moments from their child’s hospitalization. The parents also reported striving to be normal in the midst of the unusual experience parenting a toddler with SVCHD (Elliott et al., 2021). This study highlighted the gap in parent and patient support following the second palliative heart surgery.

Gaps in the Literature

While much is known about the parent trauma experience while their child is in the hospital, there are gaps in our knowledge about what happens to that trauma in the longer term through the interstage period and after the second heart surgery. The phenomenon of parent post-traumatic stress is rarely studied outside of the intensive care setting. This study will examine two understudied timepoints for parent post-traumatic stress at home before and after the second palliative heart surgery. Preliminary qualitative research demonstrates that parents continue to need support after the second palliative heart surgery of their infant with SVCHD (Elliott et al., 2021). A descriptive correlative longitudinal study is the best next step to quantify the level of parent post-traumatic stress that is demonstrated in the qualitative work. Additionally, this study will examine how parent post-traumatic stress changes before and after the second palliative heart surgery for their infant with SVCHD. This study will fill those research gaps.

Summary

Chapter 2 provided a review of the literature pertaining to current relevant literature on parent trauma in caring for an infant with SVCHD. Chapter 3 provides a complete manuscript of a qualitative study completed as preliminary work for this dissertation. This qualitative work provides the impetus for the longitudinal timing and parent post-traumatic stress focus.

CHAPTER 3

METHODOLOGY

This chapter describes the proposed study design, including the setting, sample, measures, procedure, and data analysis plan. The purpose of this study was to describe and compare the levels of parent post-traumatic stress before and after their infant's second palliative surgery for SVCHD.

Research Design

This study used a descriptive correlative longitudinal design. Parental post-traumatic stress was evaluated 2-4 weeks before and 2-4 weeks after the second palliative surgery using the Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5). The level of post-traumatic stress was described at the two-time points, and comparisons between the two scores and demographic variables was described.

Setting

Parents of infants with SVCHD were recruited from a single tertiary children's hospital located in an urban setting. The Children's Mercy Hospital in Kansas City, Missouri, is a freestanding 354-bed comprehensive pediatric medical center that provides non-profit medical care to children from birth to 21 years of age, primarily from the Midwest. Patients from all 50 states and multiple countries received medical care at Children's Mercy in the last year (*About Us Children's Mercy Kansas City*, 2020). It is the only medical center serving pediatric patients between St. Louis, Missouri, and Denver, Colorado. The hospital is a level one (highest ranking) children's surgery center, is MAGNET recognized by the American Nurses Credentialing Center, and is nationally ranked by U.S. News and World Report in 10 subspecialty services including the cardiology and heart surgery programs (*Best Children's Hospitals*, 2020). During the fiscal year 2019, the hospital staff provided care to children who were white (58.56%), black (17.40%), Hispanic (12.56%), multi-racial (5.89%), and Asian (2.24%) (*Equity and Diversity Children's Mercy Kansas City*, 2019). This mixture is comparable to the reported ethnic make-up of single ventricle patients undergoing the second palliative heart surgery in the literature white (81.3%), black (14.9%), and other (4%) (Schwartz et al., 2014).

The Cardiac High Acuity Monitoring Program (CHAMP®) is the interstage home monitoring program utilized at the hospital. Participation includes the use of a cloud-based web application that provides instant transfer of parent-entered home monitoring information to the interstage nursing team. Parents enter the intake, output, weight, heart rate, oxygen saturation, and any concerns into a tablet throughout the day (Shirali et al., 2016). The program also includes weekly communication with the interstage nursing team and clinic visits every 2-4 weeks. For optimal functioning, the program requires parent participation and interaction with the team frequently from home. This intensive outpatient monitoring and care by the multidisciplinary team is associated with decreased morbidity, mortality, and resource utilization during the interstage period (Bingler et al., 2018).

Sample

The initial sample plan was to recruit 52 participants for a high-powered study. However, preliminary data power analysis was run, and the results suggested 20—25 participants could yield a high-powered study. Therefore, once 20 participants completed the study, another analysis was completed indicating results trending in the opposite direction from the hypothesis. The resultant power of these data was 0.59. The study team decided there was enough data to stop the study once the participants currently active completed both surveys.

Ultimately, a convenience sample of 30 parents of infants with CHD were recruited from the setting. Of the 30 parents approached, 27 consented. Twenty-two participants completed both surveys and were included in the data analysis. Two parents completed only survey 2 and 3 parents did not complete either survey. Inclusion criteria were (1) parent of an infant with SVCHD (2) 18 years or older; and (3) following with CHAMP through Children's Mercy Hospital. Any person personally identifying as a parent of the child, who lives in the same household as the infant, and who provides primary care after discharge from the hospital is eligible to participate. The exclusion criteria was if the infant is undergoing end of life care, determined by the primary care team or the parent was non English or Spanish speaking.

Recruitment and Retention

The PI identified possible participants by new patient consults to the CHAMP team. Registered nurse research coordinators assigned to IRB approved studies from the heart center introduced the study to the family once the medical team determined appropriate timing. Following study introduction and consent review by the family, they were given the opportunity to sign consent to participate in the study.

Measures

Demographic Variables

The collection of demographic data for the parent and infant was assessed and recorded after consent through a retrospective chart review. Included parent and child demographics were gender, age, zip code, income, education level, family structure, age of child, and gender of child. Hospitalization demographics include number of initial intensive care unit (ICU) days, incidence of cardiac arrest or extracorporeal membrane oxygenation (ECMO) cannulation with either first or second palliative heart surgery, prenatal or postnatal diagnosis, cardiac bypass time for both surgeries, route of feeding at time of discharge for both surgeries, oxygen use at home after either surgery, and number of medications at the time of second palliative heart surgery hospital discharge. These choices are informed by previously identified factors contributing to parent trauma and medical acuity in the literature (Alkan et al., 2017; Bucholz et al., 2020; Cantwell-Bartl & Tibballs, 2013; Lerret et al., 2020; Muscara et al., 2015). Notes were kept by the research team tracking reasons for surgery delays or any other unexpected circumstances.

Posttraumatic Stress Disorder Checklist for DSM-5

Parent post-traumatic stress disorder symptoms was measured using the Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5). This tool is a revision of the widely accepted Posttraumatic Stress Disorder Checklist (PCL), which reflects the Posttraumatic Stress Disorder (PTSD) clinical criteria changes in the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) (Blevins et al., 2015). The original PCL comes in three versions (civilian, military, and special) and has been validated extensively. The instrument has strong psychometric properties including test-retest reliability (.66 to .96), internal consistency (α ranging from .83 to .98), convergent validity (correlations with other PTSD measures ranging from .62 to .93), and discriminant validity (< .87) (Blevins et al., 2015). To further support this versions validity, it was created to be consistent with the original PCL by maintaining the same verbal anchors, using the same timeframe of the past one month for symptoms, making few changes to instrument instructions, and including nine completely unchanged items (Blevins et al., 2015).

The PCL-5 has robust internal consistency with Cronbach's alpha .94 to .95, test-retest reliability is reported as .89 at an average of 20.95 days and .82 at an average of seven days between testing (Ashbaugh et al., 2016; Blevins et al., 2015). The correlation between the PCL-5 and Impact of Event Scale-Revised (IES-R) resulted at $r = .80$, $p < .001$, thus supporting convergent validity (Ashbaugh et al., 2016). The correlation between the PCL-5 and the Center for Epidemiological Studies–Depression Scale (CES-D) is $r=0.64$ ($p < .001$), which is lower than between the PCL-5 and the IES-R ($r = 0.80$) (Ashbaugh et al., 2016). This finding supports the divergent validity of the PCL-5 from measures of depression. Construct validity scores are high as well, indicating that the instrument accurately measures the symptoms of PTSD with r alerting-CV = .90, and r contrast-CV = .92 (Blevins et al., 2015).

The instrument is designed for self-report but can also be read to participants either in person or over the phone (National Center for PTSD, 2018). The PCL-5 includes 20 items that correspond to the 20 criteria for PTSD, as outlined in the DSM-5 (Blevins et al., 2015). Each question is answered using a Likert scale of 0-4 corresponding to the choices, “Not at all,” “A little bit,” Moderately,” “Quite a bit,” and “Extremely.” The PCL-5 takes approximately 5-10 minutes to complete (National Center for PTSD, 2018). The questions are divided to correspond to the criterion B five subscales of symptoms for PTSD in the DSM-5 (“Trauma and Stressor Related Disorders,” 2013). A positive test requires a clinically relevant score of two or more on one re-experiencing symptom, one avoidance symptom, two symptoms of negative alterations in cognition and mood, and two arousal symptoms (Ashbaugh et al., 2016). A total severity score can be assessed by summing the rating for each item on the instrument (total score range: 0-80) (National Center for PTSD, 2018). A score of 31 or greater (“positive score”) indicates probable PTSD per the DSM-5 guidelines (Ashbaugh et al., 2016). Please see the attached Appendix A for a full copy of the instrument.

Procedures

This study was approved by the Institutional Review Boards (IRB) at Children’s Mercy Hospital and the University of Missouri – Kansas City. The PI identified eligible infants and parents through new CHAMP team referrals and tracked their progress towards discharge during daily surgical conferences or chart review. Since the PI is a primary provider for this patient population, a nurse research coordinator made initial contact with the family once the medical team identified an appropriate time considering the infant’s medical status. Due to the unique infant and parent presentation, the time of study introduction varied. Especially with a postnatal diagnosis, timing of introduction to research is driven by the primary inpatient team’s assessment of readiness. The research coordinator was notified by the CHAMP team when the family was ready to discuss the research study. The coordinator reviewed the informed consent and study information with interested parties. The Heart Center research coordinators complete research ethics and compliance training through the Collaborative Institutional Training Initiative (CITI) before being cleared to consent participants. CITI training is reviewed every two years to maintain the ability to participate in research studies at Children's Mercy. The coordinators were oriented to the study aims, design, and procedures before consenting participants for this study. Following orientation, the PI supervised the first consent completed by the assigned coordinator to check competency.

Once consented during the interstage period, the participant was provided an email link to access the survey in Research Electronic Data Capture (REDCap) (*About – REDCap*, n.d.) two to four weeks prior to the second palliative heart surgery. The PI emailed the instrument link for REDCap again two to four weeks after the second palliative surgery hospital discharge. If either survey was not completed within seven days, there was an automatic reminder e-mail generated by REDCap and sent to the participant. Additionally, the participant received a reminder during regularly scheduled weekly communication or clinic visits for routine medical care. The PI manually gathered demographic data from medical records. The demographic data was stored and maintained on REDCap via a password-protected computer to protect participants' confidentiality. As a thank you participants received a $25 visa gift card from the PI in person or by mail after completion of the second survey.

Contact information for the Thrive team was provided to participants, and any family approached for the study since the subject matter may cause distress to the parents. The Thrive team is a multidisciplinary support team for patients and families of CHD that includes members from social work, psychology, child life, music therapy, financial counseling, chaplaincy, and palliative care. There was a separate e-mail referral from the PI to the heart center psychologist for any positive test (PCL-5 scores >/= 31) results. Once the referral was placed, the psychologist checked in with the family by phone or in person at the next clinic appointment. The consent identified the benefits and potential risks to the participants, including emotional distress from the subject matter.

Data Analysis

The survey materials were administered and data was maintained by the PI through REDCap (Harris et al., 2009). The data was extracted from REDCap and exported into Statistical Package for the Social Sciences (SPSS) (version 28) for data analysis by the PI. The data was cleaned by the PI as well as two members of the supervisory dissertation committee. Missing data was limited since the REDCap survey required completion of all 20 PCL-5 questions. Only participants who completed the instrument at both timepoints were included in the data analysis. Statistical analyses were completed using SPSS statistical software (Version 28, IBM Corporation, 2019). Descriptive statistics included measures of central tendency and variation. Distributions of scores pre-surgery and post-surgery two were tested for normality and homogeneity (Plichta & Kelvin, 2013). The data were not normally distributed, so the non-parametric Wilcoxon signed rank test was conducted (Plichta & Kelvin, 2013).

RQ 1: What is the level of parental post-traumatic stress measured two to four weeks before their infant's second palliative heart surgery? This question yields ordinal level data from the Likert scale questions on the PCL-5.

RQ 2: What is the level of parental posttraumatic stress after their infant's second palliative heart surgery? This question yields ordinal level data from the Likert scale questions on the PCL-5.

RQ 3: What is the relationship of parental posttraumatic stress level before and after their infant's second palliative heart surgery?

RQ 4: What demographic variables are the mediators and moderators of the findings?

Data for RQ 1 and RQ 2 was analyzed using descriptive statistics, including mean, standard deviation, median, and range of the PCL-5 cumulative scores. For RQ 3, which included scaled level data with dependent groups (testing before and after the second palliative surgery), the Wilcoxon signed rank test was used to determine the relationship between the PCL-5 scores (Plichta & Kelvin, 2013). A significance level of $p = 0.05$ and a confidence interval of 95% was used for the data analyses. For RQ 4, the parent education and income as well as the child's feeding route were used to examine group differences by positive or negative PCL-5 scores at both timepoints.

CHAPTER 4

RESULTS

Chapter 5 includes results of the PaTHS study a longitudinal, descriptive, correlative study describing the levels of parent post-traumatic stress before and after their infant's second palliative surgery for SVCHD. The chapter is organized by participation rates, sample demographics, reliability of the instrument, preliminary analyses, key findings, and findings for each research question and hypothesis.

Participation Rates

Participants were recruited from March 1, 2021 to June 20, 2022. Thirty parents met eligibility criteria and were approached for participation in the study. The initial sample plan was to recruit 52 participants for a high-powered study. However, preliminary data analysis revealed results that were trending opposite from the hypothesis. A decision was made to stop the study once currently active participants completed both surveys. This resulted in a total of 27 participants who consented and 22 who completed both surveys. Three parents did not complete either survey and, due to urgent surgical timing, two participants completed only survey 2. Those two participants had clinical changes that necessitated urgent surgical intervention, so the PCL-5 data was not able to be captured prior to the surgery. This represents a 90% participation rate and 81% response rate. See full participant flow chart in Figure 2 below.

Sample Demographics

For the 22 participants who consented to the study and completed both surveys, 90.9% (20/22) participants were primarily mothers between the ages of 20-42 years of age, with a mean age of 30. All participants had at least a high school degree, with 50% (11/22) having a bachelor's degree. Most families had at least two parents in the home (90%), of that, one family also had extended family at home. See full demographic data in Table 5.1.

Figure 2

Participant Flow Diagram

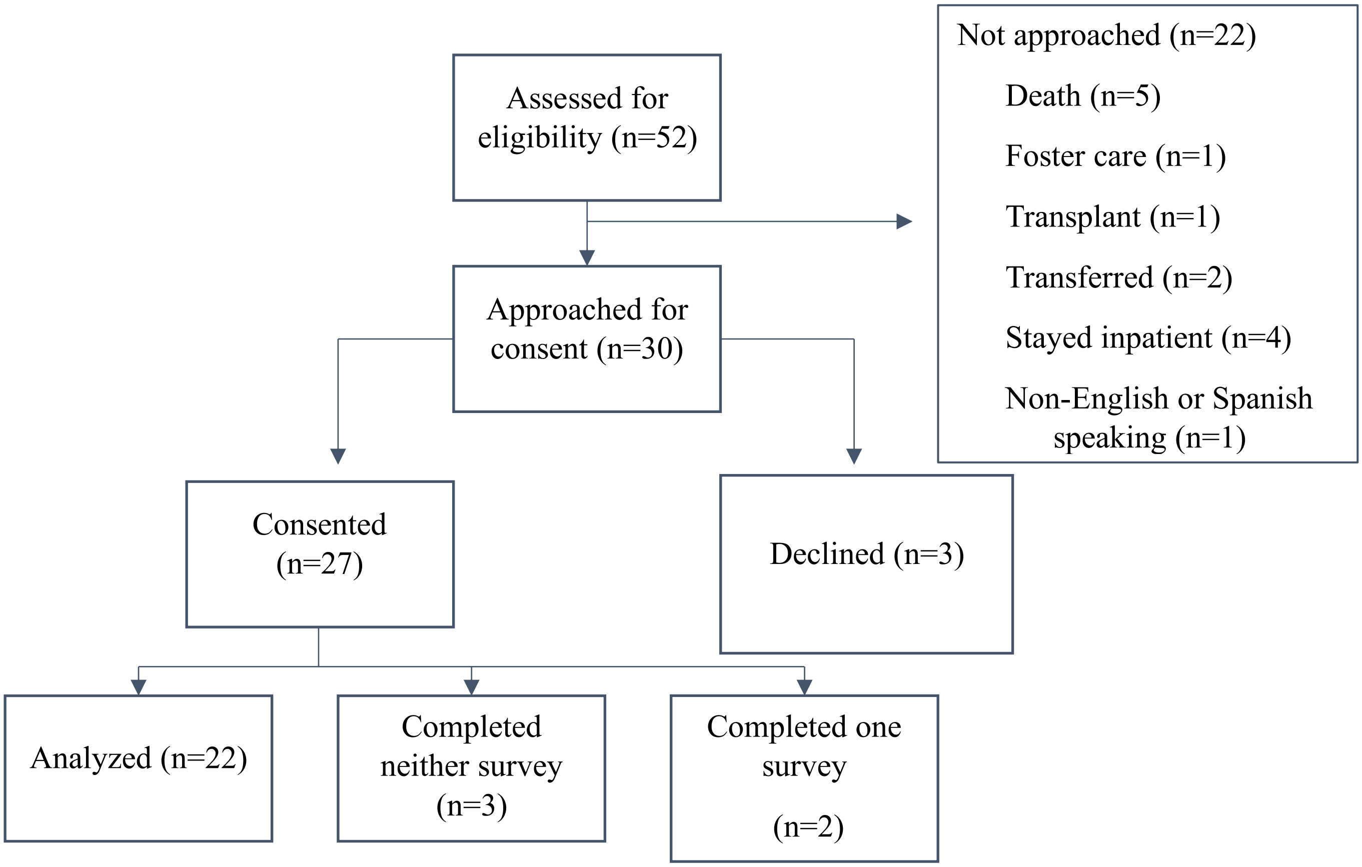


Table 5.1

Demographics

	Frequency (%)
Gender parent (n=22)	
Male	2 (9)
Female	20 (91)
Other	
Income	
< $20,000	2 (9)
$20,000- $40,000	5 (23)
$40,000- $60,000	4 (18)
$60,0000- $80,000	5 (23)
>$80,000	6 (27)
Education Level (years of education)	
1-12 years	8 (36)
13 years	1 (5)
14 years	2 (9)
16 + years	11 (50)
Family Structure	
Single parent	2 (9)
Two parents	19 (86)
Single parent plus extended family	1 (4)
Two parents plus extended family	1 (4)

Table 5.2

Descriptive Statistics

	Min	Max	Mean	Median	Interquartile Range	
					25th	75th
Age of parent in years	20	42	30	29.50	25.5	32.50
Days in the intensive care unit before first discharge	7	75	29.64	27.50	18.50	37.50
Cardiac Bypass time (in minutes)						
Surgery 1	0	196	98.14	119.50	39.00	144.50
Surgery 2	55	219	118	106.00	71.50	164.50
Number of Medications						
Surgery 1	1	14	6.36	6.00	5.00	8.00
Surgery 2	5	14	8.50	9.00	7.00	9.50

Table 5.3

Infant Demographic Characteristics (n=22)

	Yes	No
Experienced cardiac resuscitation	2	20
Experienced ECMO	0	22
	Frequency (%)	
Diagnosed		
Prenatal	17 (77)	
Postnatal	5 (23)	
Route of Feeding Surgery 1		
PO	16 (73)	
GT	2 (9)	
PO + GT	4 (18)	
Route of Feeding Surgery 2		
PO	16 (73)	
GT	1 (5)	
PO + GT	5 (22)	

Reliability of the Instrument

Internal consistency of the PCL-5 was tested using Cronbach's alpha and the results were similar to previous tests of the instrument (Ashbaugh et al., 2016; Blevins et al., 2015). Reliability coefficients for the instrument at timepoint one was α .955 and timepoint 2 α .944, indicating a robust internal consistency of the 20 items on each test at the two timepoints.

Findings

Table 5.3 displays the infant demographic characteristics. The sample included 17 patients who were prenatally diagnosed, none experienced ECMO, and two experienced cardiopulmonary resuscitation. Cardiac surgery bypass times ranged from 0 to 198 minutes (mean 98.14 minutes) for surgery 1 and 55 to 219 minutes (mean 118 minutes) for surgery 2. Most of the participants were fed orally at both time points (72.7%). The number of medications at discharge for surgery 1 ranged 1 to 14 (mean 6.36), and for surgery 2 range from 5 to 14 (mean 8.50).

Figure 3 illustrates the timing of the surveys within the single ventricle surgery pathway that was introduced in chapter 1. Due to collection of data during the viral season and some surgeries being completed outside of the plan for medical reasons, survey one had significant variability in delivery. See Table 5.4 below for a summary of the dates. For the pre-surgery PCL-5, the range was 3-118 days and for the post-surgery PCL-5 the range was 14-32 days (Table 5.4). Nine participants had positive scores on the PCL-5 before surgery two, and 6 had positive scores after surgery two. Seven participants had a higher score on the second PCL-5 after surgery two, following the hypothesized results. Contrasting with the hypothesis, most participants demonstrated a decreasing mean PCL-5 score over time, and this finding was statistically significant (p = .027). The minimum, maximum, mean, median, and interquartile range of the scores are presented in Table 5.5.

Figure 3

Timing of PCL-5 Survey

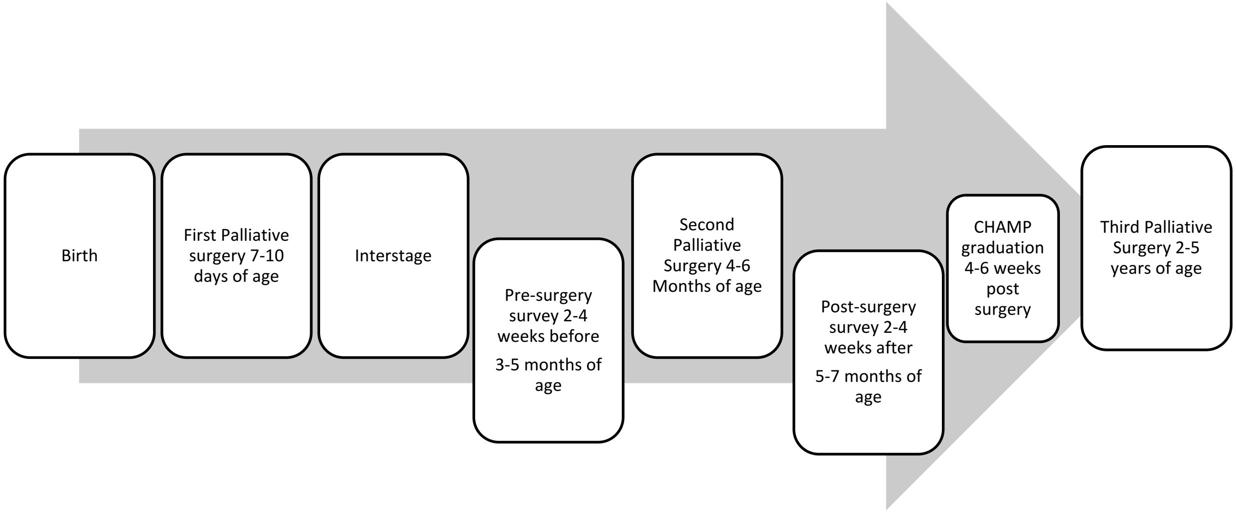


Table 5.4

Survey Timing in Days

Participant	PCL-5 #1 Days prior to surgery	PCL-5 # 2 Days post-surgery
1	28	17
2	21	14
3	7	22
4	3	15
5	8	31
6	7	18
7	26	26
8	21	18
9	21	14
10	12	28
11	101	16
12	28	14
13	53	14
14	1	14
15	53	17
16	118	22
17	23	32
18	28	17

19	55	18
20	34	17
21	24	14
22	18	29

Research Question 1 Findings

RQ 1: What is the level of parental post-traumatic stress measured two to four weeks before their infant's second palliative heart surgery?

The level of parent post-traumatic stress prior to their infants second palliative heart surgery was measured with 22 participants. These scores showed a wide range of results with a minimum of 0 and a maximum of 61 (positive results indicating high level of post-traumatic stress are a score of >/= 31), and the mean was 26.45. There were 9 positive scores (41%) at this timepoint. See Table 5.5 below for more descriptive findings of the PCL- 5 scores.

Research Question 2 Findings

RQ 2: What is the level of parental post-traumatic stress two to four weeks after discharge following their infant's second palliative heart surgery?

The level of parent post-traumatic stress 2 - 4 weeks after their infants second palliative heart surgery was measured with 24 participants, 2 participants did not complete survey one and were excluded from all data analyses. The scores ranged from 0 – 52 with a median of 23. There were 6 positive scores (27%) at this timepoint. See Table 5.5 below for more descriptive findings of the PCL- 5 scores.

Table 5.5

Descriptive Statistics

	n	Min	Max	Mean	Median	Interquartile Range	
						25th	75th
PCL- 5 pre surgery	22	0	61	26.45	23.00	11	44.25
PCL- 5 post-surgery	22	0	52	18.68	16.00	4.75	32.75
Difference	22	-38	16	-6.77	-2.00	-15	1.25

Research Question 3 Findings

RQ 3: What is the difference in parental post-traumatic stress level before and after their infant's second palliative heart surgery?

Hypothesis: Post-traumatic stress levels will increase after the second palliative heart surgery.

Most of the scores (13/22; 59%) decreased between the two timepoints. There was a range of negative 38 to positive 16 points, with an average score of negative 6.77 between presurgical and postsurgical testing.

Initially a paired t-test was planned to compare the scores Using the Kolmogorov-Smirnov test for normality, the p-value for the difference was found to be 0.030, indicating the data were not normally distributed. As such, the non-parametric Wilcoxon signed rank test to explore the means of the matched pairs was utilized. The relationship between the two scores indicated a statistically significant trend of decreased average score between the pre-surgery and post-surgery PCL-5 scores (Z= -2.206; p= .027). Therefore, the null hypothesis was rejected that post-traumatic stress did not change between the two surgeries.

Research Question 4 Findings

RQ 4: What demographic variables are the mediators and moderators of the findings? There were not enough participants to support a fully-powered exploration of this question. Therefore, to avoid erroneously suggesting any correlations with demographic variables, a robust analysis of the mediators and moderators was not completed. However, demographics were used to explore the percentage of positive and negative scores at each timepoint (see Table 5.6), based on their potential associations with stress as reported in the literature. There was an inverse relationship with the trauma score and level of education and income. Future research could explore these trends with a larger sample size.

Table 5.6

Demographics and PCL-5 scores at each timepoint

	PCL-5 # 1 Negative	PCL-5 # Positive	PCL-5 # 2 Negative	PCL-5 # 2 Positive
Parent demographic	Frequency (%)	Frequency (%)	Frequency (%)	Frequency (%)
Education				
High School Degree	3 (37.5%)	5 (62.5%)	4 (50%)	4 (50%)
Some college	1 (100%)	0 (0%)	1 (100%)	0 (0%)
Associates Degree	1 (50%)	1(50%)	1 (50%)	1 (50%)
Bachelor's Degree	8 (72.7%)	3 (27.3%)	10 (90.9%)	1 (9.1%)
Income				
< $20,000	0 (0%)	2 (100%)	1 (50%)	1 (50%)
$20,000-$40,000	1 (20%)	4 (80%)	2 (40%)	3 (60%)
$40,000-$60,000	3 (75%)	1 (25%)	4 (100%)	0 (0%)
$60,000-$80,000	4 (80%)	1 (20%)	4 (80%)	1 (20%)
> $80,000	5 (83.3%)	1 (16.7%)	5 (83.3%)	1 (16.7%)
Child demographics				
Feeding Route				
By mouth (PO)	11 (68.8%)	5 (31.3%)	13 (81.3%)	3 (18.8%)
By gastrostomy tube (GT)	0 (0%)	2 (100%)	1 (50%)	1 (50%)
Combination PO +GT	2 (50%)	2 (50%)	2 (50%)	2 (50%)

Notes. PCL-5 #1 is pre surgery, PCL-5 #2 is post-surgery. PCL-5 Score ≥ 31 (positive) indicates a probable diagnosis of PTSD

Summary

This chapter included a description of the participant response rates, demographics of the sample, reliability of the instruments, and preliminary analysis of the data. Discussion of the relationship between the pre-surgery and post-surgery scores, selected demographic variables, strengths, and limitations of this study, and implications of the findings are included in the next chapter.

CHAPTER 5

DISCUSSION

The purpose of this study was to describe and correlate the levels of parent post-traumatic stress before and after their infant's second palliative surgery for single ventricle congenital heart disease. The chapter includes a dialogue about the results organized by individual research questions. This is followed by a discussion on the strengths and limitations of the study, implications of the findings for research, theory, practice and policy, and conclusions.

Interpretation of Findings

Prevalence of Post-traumatic Stress

Pre-surgery

RQ1 focused on the rate of clinically measurable post-traumatic stress measured by the PCL-5 2-4 weeks prior to surgery 2. Results indicated that 40% of the scores were positive for post-traumatic stress symptoms. The high scores prior to the second surgery could be related to many factors. The first eight questions reference symptoms related to the "stressful experience," which in this case was parenting an infant with critical congenital heart disease. Thus, the idea of being back in the hospital may have increased perceptions of experiencing some of these symptoms. Parents may have intrinsic trauma that was not controlled for in this study. The viral season was more robust than usual causing significant surgical delays due to illness symptoms. These delays could increase parenting stress as they were anxious to get the surgery completed. We also cannot know what effect the global pandemic from COVID-19 had on the parents PTSD symptoms-this is discussed at length later. Parents were also juggling complex medication and feeding regimens during this time (Tregay, 2015).

Post-surgery

Research question 2 (RQ 2) focused on the rate of clinically measurable post-traumatic stress measured by the PCL-5 2-4 weeks after surgery 2. At this timepoint 27% of participants were positive for post-traumatic stress symptoms. This decrease in symptoms from prior to surgery 2 was found to be statistically significant. The score was obtained 2-4 weeks after surgery, so the child would likely be nearly recovered from the surgery and nearing CHAMP graduation. This may represent a decrease in parent stress related to the completion of the second heart surgery, which many parents see as a significant endpoint that may signify a return to "normal" life (Elliott et al., 2021; March & Keim-Malpass, 2018).

Relationship of Pre-surgery and Post-surgery Scores

Research question 3 (RQ 3) examined the relationship between the two scores. Based on prior research, the initial hypothesis expected increasing PCL-5 scores after surgery 2 due to the pending CHAMP graduation. Preliminary data analysis indicated that the results differed from this hypothesis in a statistically significant way. Over time, a decreasing mean was found instead of an increasing one with a wide range of scores at both time points. Due to this finding, the prediction that obtaining a highly-powered sample would require significantly more participants with a historically small sample pool (approximately 50 patients/year), the lack of previous studies to support any sample size, and the significant limitations to the study design, participation was capped at 22 participants, which is supported in the literature (Schmidt et al., 2018). The increased prevalence of positive scores pre-surgery compared to the post-surgery may be due to factors that could not be controlled. One possibility is that the score was elevated to anticipatory stress related to the upcoming hospitalization.

Demographic Variables and Pre-surgery and Post-surgery Scores

Research question 4 (RQ 4) sought to examine the demographic variables and their association with the PCL-5 scores at each timepoint. Due to the small sample size, we are unable to draw any definitive conclusions, but there were some interesting patterns in the data that can inform future work. Regarding education levels of the participants, most of the results were evenly split, except for participants with bachelor's degrees or higher reporting more frequent negative scores. It is also interesting that our sample demographics included a higher level of education than the general CHAMP population, so these findings may not represent the larger group of CHAMP parents (Cardiac High Acuity Monitoring Program, 2022). A higher income also seems to be inversely correlated with the PCL-5 scores in our sample. The feeding route, specifically the use of a feeding tube which is commonly cited as a source of increased stress for parents, did not seem to have any effect on our findings (Tregay et al., 2015). There were no readily discernable trends in the other demographic data, although it is unclear if a larger sample size would produce significant group differences.

Strengths and Limitations

One strength of this study was that it builds on prior qualitative research with this population. Using findings from that work provided an evidence-based starting point

(Elliott et al., 2021). To our knowledge, this is the first study to explore PCL-5 findings of this population during outpatient care. Medical and surgical options for the infant with SVCHD have advanced tremendously and current research is turning to improve the quality of life for these children across the life span. Therefore, exploring this population is important given that parent trauma is linked to long term problems for the children. Previous work with parent trauma focused on the inpatient and interstage time, which is comparatively a much shorter period, so extending that research to the outpatient and post SVCHD interstage population is critical. This work adds to the available work and provides impetus for future research.

An additional strength of this study is in the timing. This study was completed during that time which we know is very stressful for parents. The research team usually aims to avoid this time to not add undue stress on the family. We were able to complete research during this time with no reported post study concerns on psychosocial follow up, so we may have captured more high-quality data by using a prospective approach.

A limitation of this study is not controlling for any baseline PTSD with the parent participants, we are unable to say that the trauma we measured is from parenting an infant with SVCHD. The lack of randomization of the sample may result in selection bias so that factors other than the independent variable (time) may influence the findings (Polit & Beck, 2017). Randomization was not feasible with this study and given the limited population size it would take many years to recruit enough participants for a fully powered study. Therefore, it is possible external factors, such as surgical timing and COVID-19 pandemic visitor restrictions could explain differences between timepoint 1 and 2. The significantly different post-traumatic stress scores at the two time points provide an initiative to guide future research.

The timeframe of administration times between the first PCL-5 survey and the second with some participants is an important limitation. Due to the change in anesthesia guidelines and a more prolific than usual viral illness season, there was wide range in days of data collection between survey 1 and survey 2 (3-118 days). This was an unanticipated concern that may have affected the study results.

The sample size and homogenous sample limit the generalizability and the statistical power. The convenience sampling with a single site may also influence findings as the resources, such as a comprehensive interstage monitoring team, available at this institution may differ significantly from other institutions.

Another important limitation of this study is the PCL-5 is a validated tool that measures any kind of PTSD, and perhaps the stress experienced by these parents dissipates over time indicating a more specific tool may be needed to measure posttraumatic stress in this population. The tool has been used for a larger group of parents of children with various life-threatening illnesses, including parents of children with cancer, neurological, and cardiac concerns (Muscara et al., 2018). Our generalizability may be limited as our sample differed from the larger CHAMP population at our site. The sample of this study had a mean age of 30 years and 50% of participants had at least a bachelor’s degree. This data differs from the larger group of CHAMP participants who have an average age of 28 years and 28% have a bachelor’s degree (Cardiac High Acuity Monitoring Program, 2022).

Impact of Coronavirus Disease Pandemic

This dissertation study was completed during the second year of the COVID-19 pandemic which affected multiple areas of the study. First, 2021 had higher than usual volumes of respiratory illness across the nation (Olsen et al., 2021). This potentially affected recruitment at the study site by increasing illnesses among both patients and their immediate family members. There were new guidelines for infants who had SVCHD and needed anesthesia that were published by the Congenital Heart Surgeons Society that suggested a longer wait time follow possible COVID19 infection (Levy et al., n.d.). Given the concerns for COVID-19 transmission and treatment, infant procedures and appointments were delayed with immediate family member illness even if the infant was without illness symptoms. Increased viral activity and policies limiting access due to both parent and infant illness affected safety protocols and routine study procedures. Parents were oftentimes not as accessible as usual for recruitment since the hospital visitor restrictions limited siblings and other family members from visiting. This meant parents had to choose between their children and family and they might have chosen to spend more time at home instead of at the bedside. The study procedures were also limited by the restrictions since finding time to meet parents to consent after initial recruitment could also be complicated. The IRB required full consent for this study, necessitating making time to review the consent with parents in person prior to signing.

For elective procedures (not deemed urgent or emergent in timing) involving anesthesia, infants had to be in good health and free of respiratory illness. Routine delays for these procedures are 4-10 weeks depending on the symptoms and/or identified respiratory pathogen. The COVID-19 pandemic created an operational issue since the data collection surveys were timed at 2-4 weeks prior to and 2-4 weeks following the scheduled heart surgery. Oftentimes the first survey was already completed prior to the respiratory illness symptoms. This change in timing was true for all cardiac procedures at the study site and resulted in surgery dates being open with very little notice due to cancelled procedures. Thus, some infants had very rapid turnaround time with surgery dates, and the first survey was missed. These concerns meant some surveys were completed outside of the planned timeline, as discussed in the findings section.

In general, the COVID-19 pandemic affected everyday life and could have adversely affected the experience of parenting an infant with SVCHD. In particular, the hospital procedures limiting visitors other than parents could have provided more stress to parents during infant hospitalizations. They were unable to have additional family support and were often forced to choose between the infant in the hospital and other children or family members at home who were unable to visit the hospital. Also, parenting stress may have increased knowing that COVID19 may be more dangerous to infants with SVCHD (Alsaied et al., 2020).

Further, the appointment and surgical delays due to illness may have impacted the parents' PCL-5 scores as COVID-19 affected work, home, and school life for families, which we were unable to account for in the design of this study. We did not gather information on or control for parent mental health, psychosocial concerns, or any previous concerns for PTSD at baseline in this study. This means that our PCL-5 scores may reflect different trauma or stress than that of caring for an infant with SVCHD.

Hospital operational changes also impacted recruitment procedures as research staff started working from home early in the pandemic. While still on campus as needed for study procedures, there were sometimes problems having study staff and parents present simultaneously, given the strict visitation policies.

Conclusion

Previous qualitative research demonstrated that CHAMP parents had a significant response to the end of their child's time following with the CHAMP program (Elliott et al., 2021). This study aimed to further explore that phenomenon quantitatively and found somewhat contradicting results. Since the end of the CHAMP program is variable for patients depending on their specific heart lesion, surgical plan, and postoperative course, we sought to standardize the timing around the second heart surgery, which is when the process is started to transition the patient out of the CHAMP program to a primary cardiologist's care. This time provided standardization but also introduced factors that could not be controlled such as anticipatory stress and postoperative stress related to surgical outcomes or additional procedures that may have been necessary.

Initial qualitative work included parents of patients who completed the CHAMP program within the previous 2 years, which meant the sample was much farther out from their second heart surgery and had not followed up with the CHAMP team recently. As a result, the parents may have had more time to reflect on that journey. The reflection time and perhaps other interactions with the health care system could contribute to the findings of increased stress around the CHAMP graduation (typically around 4-6 weeks after the second surgery) found in the qualitative study. Additionally, parents may have protective feelings around the stress of surgery, so the retrospective nature of the qualitative study may not reflect in a prospective design.

Though the results of this did not follow our hypothesized findings, this study adds to the existing body of literature in this area. This is the first study to explore PCL-5 findings of this population during outpatient care. Parents in our study had significant post-traumatic stress symptoms at both time points. This finding provides some direction for future research of this population which should include a larger sample size.

With all positive scores, there was a referral to the heart center psychologist for follow up. This provided an opportunity to counsel families and provide resources. The hospital's psychosocial team does not routinely follow up with families after hospital discharge following heart surgery. This study provided a screening tool that allowed the team to deliver anticipatory guidance to the most vulnerable families instead of a reactive support model. These unexpected changes due to the study design highlight the continued need for comprehensive psychosocial care for these vulnerable patients and families (Golfenshtein et al., 2020; Muscara et al., 2018; Utens et al., 2018). The PCL-5 or a similar tool used routinely may continue to support these prophylactic conversations.

Seven participants (32%) did follow our hypothesized findings with PCL-5 scores increasing at the second survey after surgery. The overall increase in scores was relatively small (mean = + 4.4) compared to the drop in scores that other participants had (mean = -13.8). There is a clear need to examine factors associated with increasing versus decreasing PCL-5 scores in this parent population, given previous work indicating that stress increased (Elliott et al., 2021).

Implications

The results of this study highlight implications for research, practice, theory, and policy. Each area is discussed individually below.

Research

There were positive PCL-5 scores recorded at both timepoints. This provides impetus for future research with this phenomenon and population. This study demonstrated that families are willing and able to discuss these sensitive subjects with their nursing care providers. None of the families who declined to participate did so due to the nature of the study. Every parent who declined this study also declined the other research studies that were presented to them. Though there is a need for multidisciplinary support, our study was developed and led by nurses. This supports the idea that conversations around mental health are welcome by the families and every member of the care team should be assessing the emotional wellbeing of the family members

Practice

Parents had measurable levels of trauma symptoms at both timepoints. There is a need for comprehensive psychosocial screening, care, and follow-up in the outpatient setting. Parents of infants with SVCHD have significant symptoms of post-traumatic stress even after the stressful intensive care unit stays. Attention should be given to routine screening and follow-up for these symptoms to support proactive psychosocial interventions. Additionally, given that the PCL-5 scores may correlate with clinical PTSD levels, pediatric cardiology healthcare teams should have strong psychosocial teams available to follow up with these families during vulnerable transitions.

Theory

This study used Meleis' transition study to provide a validated roadmap of the transition experience. Specifically, the nature of transition including critical time points and events were guided by the transitions theory. In this case, the critical time points are surgery two and the impending CHAMP graduation. This research also explored the infant's transition conditions and the parent's response patterns. The findings of this study support Meleis' posit that times of transition are times of increased vulnerability and that traumatic experiences are experienced differently by individuals (Meleis, 2015).

Policy

Healthcare policy should support regular payment for mental health care for this population. There were measurable levels of traumatic stress symptoms at both time points, and research has shown that parents must be in good shape to provide optimal care for their children. For some parents, this may include care from a mental health professional, which is not always covered by health insurance.

Future Research

The findings of this research study provide many ideas to validate and improve upon this research in future work. A principal goal of future research should be to identify the timeline and timing of parent trauma in this population. Doing so would guide future work, including interventions aimed at mitigating the trauma in this population. Although I did not find what I initially hypothesized, there were positive PCL-5 scores at both time points, indicating there is likely some level of parent trauma at both time points. The design of future work should include randomization to ensure the participants are equivalent and comparable to the general single ventricle population. Consideration should also be given to improved generalizability of the findings by expanding the sample size and recruiting from multiple pediatric cardiac participating sites.

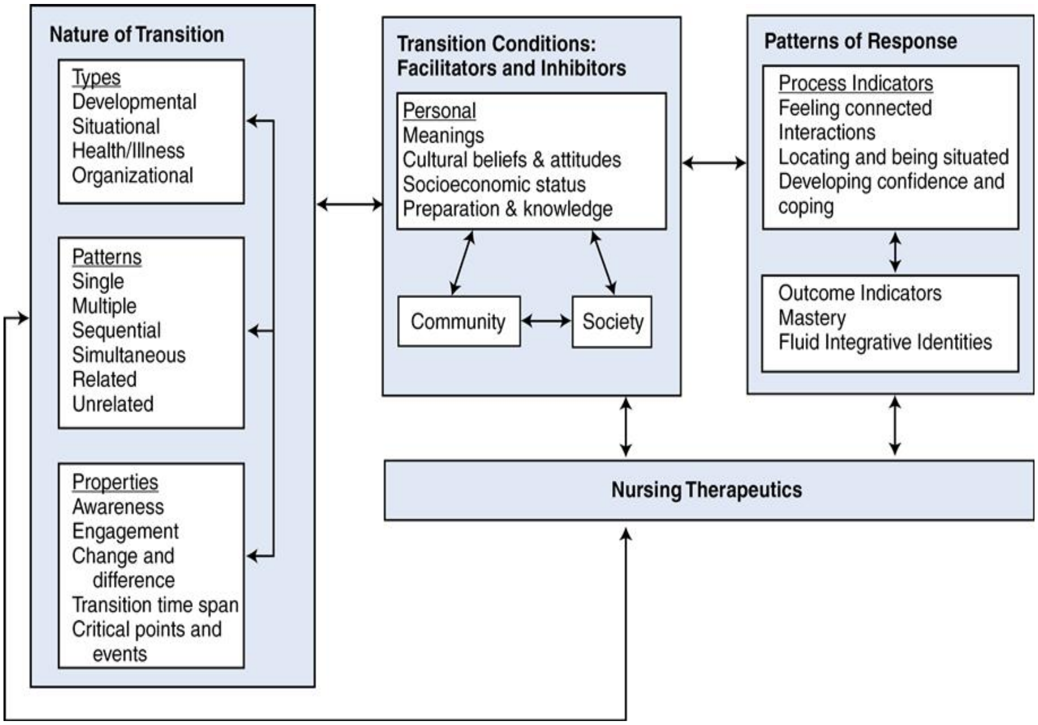
Future research should gather more data on any baseline parent trauma history. Our study did not assess this factor, so it is unclear if any historical trauma impacted the participants with positive scores besides parenting an infant with single ventricle congenital heart disease.

Assessing post-traumatic stress symptoms at a time point not bound by a surgical date is another important implication for future research. This design decision proved to be a challenging to control factor in the post-COVID world. Since the scheduling decisions were impacted by a worse-than-usual respiratory viral season, causing numerous surgery date changes, there was little control over how much surgical scheduling and planning factors contributed to the parenting stress during the time of the study.

Future work can build off these study results by increasing the sample size and designing the study with more strict and attainable guidelines around data collection. It should avoid basing timing off a surgical date especially during the viral season. Clinical courses during the interstage can be highly variable, but using something like hospital discharge and the first clinic follow-up could provide a more predictable timeline for longitudinal data collection.

Appendix A

Transitions: a middle range theory (Meleis et al., 2000)



Appendix B

PTSD Checklist for DSM-5 (PCL-5) (National Center for PTSD, 2019)

PCL-5

Instructions: Below is a list of problems that people sometimes have in response to a very stressful experience. Please read each problem carefully and then circle one of the numbers to the right to indicate how much you have been bothered by that problem <u>in the past month</u>.

In the past month, how much were you bothered by:	**Not at all**	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1. Repeated, disturbing, and unwanted memories of the stressful experience?	0	1	2	3	4
2. Repeated, disturbing dreams of the stressful experience?	0	1	2	3	4
3. Suddenly feeling or acting as if the stressful experience were actually happening again (as if you were actually back there reliving it)?	0	1	2	3	4
4. Feeling very upset when something reminded you of the stressful experience?	0	1	2	3	4
5. Having strong physical reactions when something reminded you of the stressful experience (for example, heart pounding, trouble breathing, sweating)?	0	1	2	3	4
6. Avoiding memories, thoughts, or feelings related to the stressful experience?	0	1	2	3	4
7. Avoiding external reminders of the stressful experience (for example, people, places, conversations, activities, objects, or situations)?	0	1	2	3	4
8. Trouble remembering important parts of the stressful experience?	0	1	2	3	4
9. Having strong negative beliefs about yourself, other people, or the world (for example, having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)?	0	1	2	3	4
10. Blaming yourself or someone else for the stressful experience or what happened after it?	0	1	2	3	4

11. Having strong negative feelings such as fear, horror, anger, guilt, or shame?	0	1	2	3	4
12. Loss of interest in activities that you used to enjoy?	0	1	2	3	4
13. Feeling distant or cut off from other people?	0	1	2	3	4
14. Trouble experiencing positive feelings (for example, being unable to feel happiness or have loving feelings for people close to you)?	0	1	2	3	4
15. Irritable behavior, angry outbursts, or acting aggressively?	0	1	2	3	4
16. Taking too many risks or doing things that could cause you harm?	0	1	2	3	4
17. Being "superalert" or watchful or on guard?	0	1	2	3	4
18. Feeling jumpy or easily startled?	0	1	2	3	4
19. Having difficulty concentrating?	0	1	2	3	4
20. Trouble falling or staying asleep?	0	1	2	3	4

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VITA

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Her husband, Joe Elliott, provided selfless love, support, companionship, and editorial services throughout her academic career. They welcomed their greatest adventure, a son, Bentley Bear Hatch Elliott while Melissa was finishing her dissertation research study.