

St. Catherine University

SOPHIA

Doctor of Occupational Therapy Doctoral
Projects

Occupational Therapy

12-2021

Family-Centered Support Through Storytelling: A Children's Book For Hypoplastic Left Heart Syndrome

Alissa Cooper
St. Catherine University

Follow this and additional works at: https://sophia.stkate.edu/otd_projects

Recommended Citation

Cooper, Alissa. (2021). Family-Centered Support Through Storytelling: A Children's Book For Hypoplastic Left Heart Syndrome. Retrieved from Sophia, the St. Catherine University repository website: https://sophia.stkate.edu/otd_projects/33

This Doctoral Project is brought to you for free and open access by the Occupational Therapy at SOPHIA. It has been accepted for inclusion in Doctor of Occupational Therapy Doctoral Projects by an authorized administrator of SOPHIA. For more information, please contact sagray@stkate.edu.

**Family-Centered Support Through Storytelling:
A Children's Book For Hypoplastic Left Heart Syndrome**

OCTH 8250: Doctoral Capstone Project Portfolio

Alissa Cooper

St. Catherine University

St. Catherine University
 Doctor of Occupational Therapy Entry Level
Certification of Successful Doctoral Capstone Portfolio Defense

We, the undersigned, certify that

Alissa Anne Cooper

Has successfully defended the occupational therapy doctoral capstone titled

Family-centered support through storytelling: A children's book for
hypoplastic left heart syndrome

_____	_____
Doctoral Capstone Faculty Advisor	Date
<i>Katherine Campbell</i>	<u>December 8, 2021</u>
Doctoral Capstone Mentor	Date
<i>Hannah Y. Oldenburg</i>	<u>December 9, 2021</u>
Doctoral Capstone Faculty Committee Member	Date

Certification of Approval for Final Copy of Doctoral Capstone Portfolio

I, the undersigned, approve the final copy of the doctoral capstone portfolio by

Alissa Cooper

Student Name

Paula Rabasy PhD., OTR/L

_____	_____
Doctoral Capstone Faculty Advisor	Date
	<u>Dec 14, 2021</u>

Contents

Chapter 1: Introduction.....	6
Background.....	6
Review of the Evidence.....	7
Significance and Innovation.....	12
Objectives.....	14
Chapter 2: Scoping Review.....	16
Introduction.....	16
Occupational Therapy Research Priorities.....	16
Scoping Review Question.....	16
Methods.....	17
Search Process.....	17
Results.....	18
Summary of Themes.....	22
Theme 1: Education Discrepancy.....	22
Theme 2: Biological and Psychosocial Content.....	24
Theme 3: Modes of Education Delivery.....	25
Theme 4: Efficacy of Educational Programming.....	26
Discussion.....	27
Implications for Practice.....	28
Recommendations.....	29
Conclusion.....	30
Chapter 3: Needs Assessment.....	32

Approach.....	32
Data and Themes.....	35
SWOT Analysis.....	37
Conclusion.....	38
Chapter 4: Goals, Objectives, and Approaches.....	39
Introduction.....	40
Process and Plan.....	39
Quality Improvement.....	40
Participants.....	42
Timeline.....	45
Chapter 5: Evaluation and Results.....	50
Project Evaluation.....	50
Data Collection.....	50
Parent and Clinician Feedback.....	50
Results.....	50
Data.....	52
Chapter 6: Discussion and Impact.....	54
Discussion.....	54
Limitations.....	55
Impact.....	56
Chapter 7: Conclusion and Reflection.....	58
Professional Development.....	59
References.....	62

Appendix A: *Flynn and Flora Prepare for the Fontan*.....68

Appendix B: Mayo Clinic Quality Improvement Memo.....104

Appendix C: Post-Fontan Parent Survey.....106

Appendix D: Parent Feedback Survey.....113

Chapter 1: Introduction

Background

Hypoplastic left heart syndrome (HLHS) is a life-threatening congenital heart defect (CHD) distinguished by an underdeveloped or nonfunctional left ventricle. About 1,000 babies are born annually with this condition (CDC, 2020). Infants with HLHS have the highest morbidity and mortality rates of any CHD (Nieves et al., 2017). An HLHS diagnosis requires parents to make many difficult decisions regarding the level of medical intervention for their child. Predominant treatment options range from pregnancy termination or palliative care, like perinatal hospice, to a more aggressive surgical approach focused on reconstructing the heart. Surgical intervention involves two open-heart surgeries in the first few months of life, followed by a third by the time the child is preschool-age (Feinstein et al., 2012). These surgeries are called the Norwood, the Glenn, and the Fontan.

Available medical interventions have serious lifelong implications for the child as well as the family unit. If left untreated, HLHS would be responsible for 25-40% of all neonatal cardiac deaths (Rempel et al., 2012). Throughout the three-stage surgical process, children with HLHS are extremely medically fragile. Collaboration among care team members is necessary to provide the ongoing assessment and surveillance required to ensure the child's safety throughout this interstage period (Nieves et al., 2017). Family involvement is a crucial component of the child's care plan, and parents must be aware of the early warning signs of cardiac distress. Managing all of this is profoundly taxing on parents, and often compromises their own wellbeing.

Mayo Clinic is well-respected as a leader in HLHS research. With more than 100 people seen annually with this rare condition, doctors there have unique experience in HLHS care (Mayo Clinic, n.d.). Mayo has been ranked among the best for heart surgery and has developed a

national network of HLHS researchers (U.S. News & World Report, 2021). “The HLHS Consortium drives innovation, discovery science and clinical expertise by investing local resources back into research” (Mayo Clinic, n.d., para. 4). With a fundamental value of evidence-based practice, Mayo’s rich environment provided the support and resources necessary to cultivate this capstone project. A scoping review and needs assessment yielded the insight necessary to understand current interventions targeting post-Fontan parents and identified specific ways to improve them. The product generated by this quality improvement (QI) project is expected to be utilized by Mayo and within the HLHS community to acknowledge and address caregiver needs to support long-term outcomes for HLHS.

Review of the Evidence

Research has highlighted a need for improved support for parents of children with HLHS (Landry et al., 2019). Because children with HLHS are so medically fragile during the early years of life, parents tend to report feeling a lack of control over their child’s ongoing survival (Meakins et al., 2015). The delicate interstage period between the three major open-heart surgeries is often the focus of parent education. After the third (and potentially final) operation (the Fontan), however, familial support from the care team tends to decrease. Parents often struggle during this shift from immediate, day-to-day functioning to long-term developmental needs (Rempel, et al., 2012). The care team provides specific guidelines and routines to follow between surgeries, but after the Fontan, parents are left without a clear roadmap for the future.

The post-Fontan period is often when parents feel the most overwhelmed while simultaneously receiving the least support from their care team. In a survey involving HLHS parents by Landry et al (2019), post-Fontan parent groups self-reported having the greatest need for psychosocial support. 35.7% of these parent participants indicated disagreement with the

statement “The care team anticipated my emotional needs as a parent and provided resources to help me cope”, which was significantly higher than parents who were at earlier points of surgical intervention (Landry et al, 2019). Without another operation to plan for, the reality of the long-term implications of life with this chronic condition begin to set in. They often feel unprepared to independently manage the ongoing care that their child will need and are frequently unaware of available services.

Parental stress across the lifespan of a child with CHD affects the home environment and ultimately impacts neurodevelopmental outcomes and overall family functioning (Lisanti, 2018). 25-50% of parents coping with the immense demands of CHD report parental anxiety, depression, and traumatic stress (Sood et al., 2018). This strain on parents may ultimately affect the developmental and behavioral trajectories of these children. Additionally, the ever-present fear of cardiac distress may restrict their child’s participation in normal childhood activities as well as the occupations of the entire family unit. Sood et al (2018) described ‘parent mental health and family functioning’ as “one key domain crucial to the advancement of cardiac neurodevelopmental and psychosocial outcomes research” (p. 874). Addressing the needs of parents within this context is a component of the multi-pronged approach necessary to mitigate impairment and maximize the lifelong outcomes of children with CHD (Sood et al., 2018).

Post-Fontan parents require ongoing and specific education to prepare them for their child’s development throughout the lifespan. Major gaps in parental support in dealing with HLHS have been identified as a lack of coping resources, unrealistic parental expectations, and unclear interprofessional team roles (Landry et al., 2019). Cassidy et al (2021) described the importance of follow-up programs to bolster resilience and provide support to families through the myriad transitions inherent to CHD. Occupational therapists (OTs) are in a unique position to

address the needs of post-Fontan parents through family education to orient caregivers toward appropriate informational and psychosocial resources.

A variety of frameworks, theories, and models were drawn upon to develop this capstone project. Figure 1 depicts a model created to describe the five main facets of parenting a child with HLHS (Rempel et al., 2012). Each side describes a different parenting style and attempts to conceptualize the needs of this parent population. This model provides guiding principles for the development of an educational intervention. This capstone project aimed to translate current knowledge into an education program to prepare parents for life after their child's Fontan operation. This involved understanding long-term HLHS outcomes as well as recognizing their own psychosocial needs as a caregiver. The intention was to set parents up with the knowledge and resources necessary to successfully address inevitable challenges throughout their child's development.

Figure 1

Theoretical model: Facets of parenting a child with HLHS (Rempel et al., 2012)

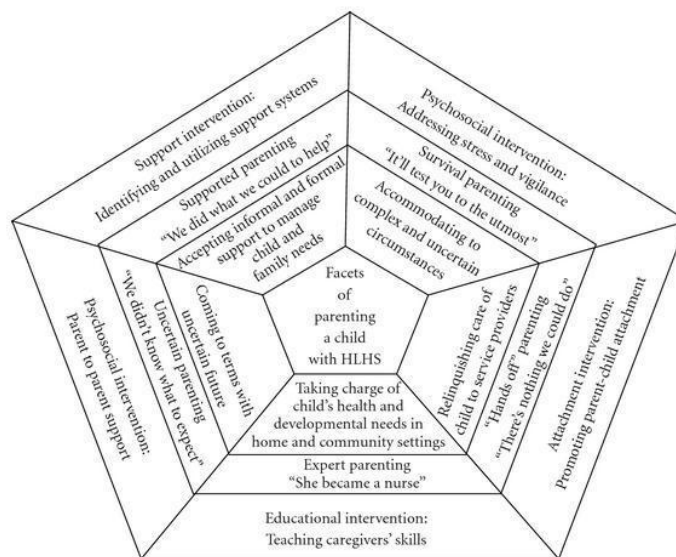


Figure 2 highlights constructs integral to the adjustment of families with a child who has a chronic illness (Lisanti, 2018). This theoretical framework was developed by Mussato (2006) through a literature review on child and family adaptation. In this review, Mussato (2006) posited that illness-related factors, anxiety, prior experience with stress, and the family's developmental stage influence the way parents perceive the stress of a CHD diagnosis. She goes on to suggest that the parents' ability to cope is impacted by their social support and resources, problem solving, hardiness, and communication skills (Lisanti, 2018).

Figure 2

Mussato's Family Stress Model (Mussato, 2006)

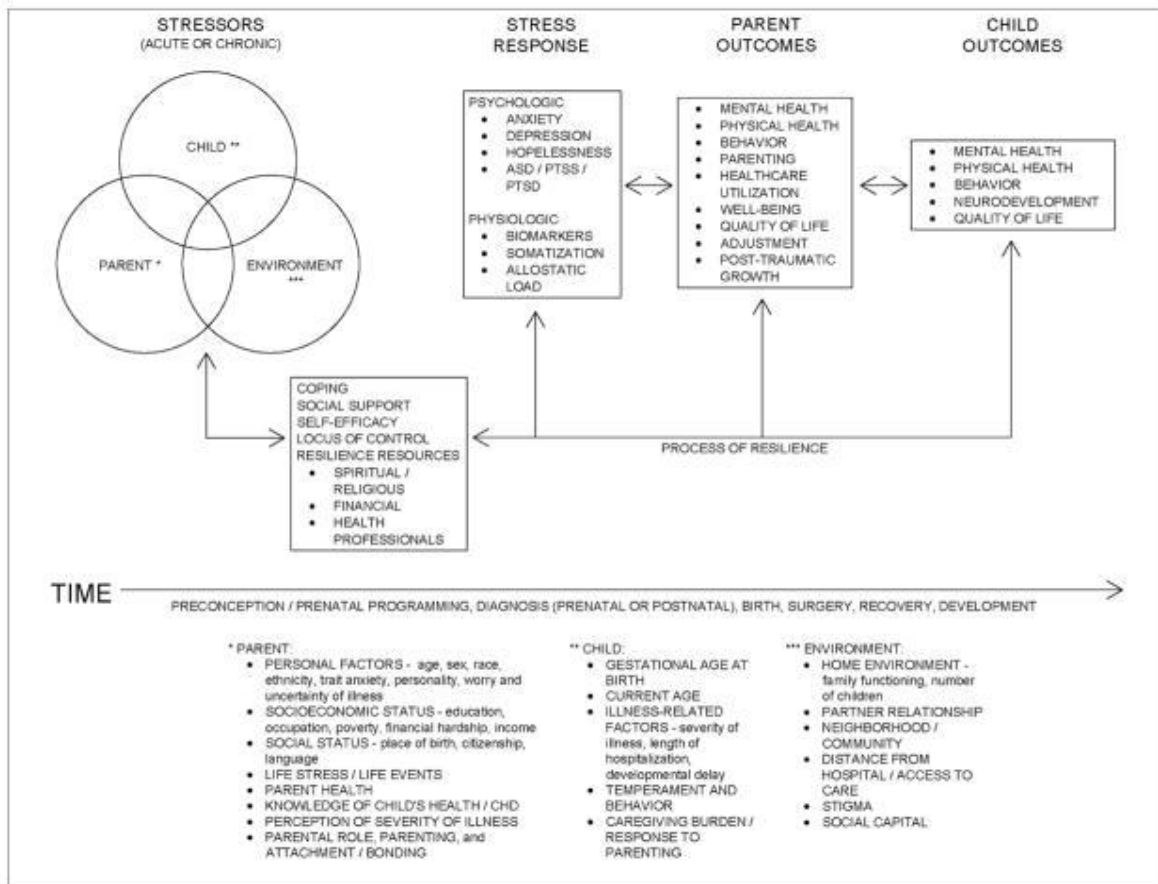


Figure 3 depicts the lifelong effects that prenatal factors can have on parents and children with CHD (Lisanti, 2018). There is a growing body of evidence suggesting that maternal biologic stress responses before and during pregnancy (specifically those relating to hypothalamic-pituitary-adrenal axis dysregulation) influence the future mental and physical health of the child (Lisanti, 2018). This model acknowledges the variety of social factors that contribute to the experience of stress like socioeconomic status, race, and stigma. The relationship between stress response, parent outcomes, and child outcomes described by this model is reminiscent of the Person-Environment-Occupation-Performance (PEOP) model - a

central tenet of OT practice which considers the complexities of human functioning and experience to inform individualized interventions (Strong et al, 1999).

Figure 3.

Parent Stress and Resilience in CHD Model (Lisanti, 2018)



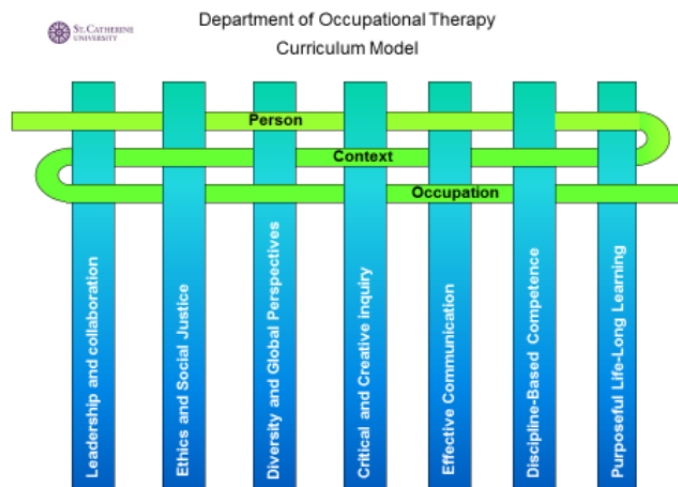
The contributions from this capstone project can be viewed as threads strengthening a metaphorical tapestry. Available information from a multitude of sources informed this project and ultimately served to improve existing educational interventions for post-Fontan parent groups utilizing services at Mayo Clinic in Rochester, Minnesota.

Education was the primary focus area of this capstone project. The St. Catherine University Department of Occupational Therapy (OT) Curriculum Model classifies education as an important occupation central to OT practice (St. Catherine University, 2017). Within this

model (Figure 4), education and effective communication are considered to be deeply intertwined concepts. This capstone explored the relationship between occupation and communication by improving the quality of post-Fontan HLHS educational materials and the manner in which they are communicated to parents.

Figure 4.

Department of Occupational Therapy Curriculum Model. (St. Catherine University, 2017)



Significance and Innovation

This capstone project related to concepts outlined through the Cardiac Neurodevelopmental Outcome Collaborative (CNOC) R13 initiative. This initiative involved the formation of different multidisciplinary working groups to identify significant knowledge gaps that affect CHD treatment (Sood et al., 2021a). Multiple critical questions (CQs) identified by these groups were particularly relevant to this project. The Neurodevelopmental and Psychosocial Interventions Working Group’s; CQ5 asked: “How do we develop systematic and effective approaches to optimize developmental transitions and transitions in care for individuals with CHD and their families?” (Cassidy et al., 2021, p. 3). This project fulfilled a required investigation of this question by aiming to “improve strategies to assist families in navigating

CHD-specific challenges and transitions” (Cassidy et al., 2021, p. 3). CQ5 from the Parent Mental Health and Family Functioning Working Group asked: “How and when should interventions be offered to bolster parent mental health and family adaptation, and optimize neurodevelopmental and psychosocial outcomes?” (Sood et al., 2021b, p.4). This project was based on existing knowledge that informed this CQ, more specifically, the need these parents have for “education on how to effectively communicate with medical teams, advocate for their child’s needs, and partner in their child’s medical and developmental care during hospitalisation” (Sood et al., 2021b, p. 8). This capstone contributed to the body of knowledge that informs care for CHD and ultimately supports the long-term outcomes for children with HLHS.

There is widespread demand for an intervention specific to this parent population to address the existing gaps in care and emotional support. While some parents seek support online through written educational materials and social media groups, these resources may fail to properly address their needs and could ultimately exacerbate stress. As a leader in treatment within this field, Mayo Clinic offers interprofessional expertise necessary to support the development and implementation of an intervention for this target audience. An educational intervention to best serve this population should be a far-reaching and cost-effective option for families looking to access information from the comfort of their home.

As surgeries for HLHS continue to improve with technological and scientific advancement, children are surviving beyond historical trajectories (Pundi et al., 2015; Rempel et al., 2012). As a child with CHD grows, their abilities and interests evolve which may increase parental uncertainty. There is a need to identify strategies to build and sustain parental confidence over time. The role of OT in this context is to ultimately support participation by increasing parental confidence in caregiving through caregiver education on psychosocial resources.

Family-centered care for this population involves equipping parents with the skills and knowledge they need to be more confident caregivers. This education could ultimately improve the long-term occupational participation of children with HLHS as well as the entire family unit.

Objectives

The primary objective of this capstone project was to create an educational tool to support the psychosocial health of post-Fontan parents. The first step involved probing for additional information from staff, parents, and other stakeholders to identify the specific educational needs post-Fontan. Gathering information related to this topic involved utilizing an interdisciplinary and trauma-informed approach that centered around the needs of this vulnerable parent population. Institutional Review Board (IRB) approval was not required for this project as it was determined to be a quality improvement project by Mayo Clinic and St. Catherine University. A survey was designed and administered to parent participants who met the following criteria:

1. Have a child who completed the Fontan operation
2. Have discharged from the hospital since the Fontan operation
3. Identify as primary caregivers
4. Consent to participate

Optimizing outcomes for children with HLHS requires evidence-based programming that focuses on parents as primary caregivers. While theories have emerged concerning effective ‘special needs parenting’, there is a great need to improve the methods by which these ideas are translated into practice (Rempel et al., 2012). The Knowledge-to-Action Framework was used to guide the process of knowledge translation (KT) to generate the educational content of this project. KT is defined as “The synthesis, exchange, and application of knowledge by relevant stakeholders to accelerate the benefits of global and local innovation in strengthening health

systems and improving people's health." (WHO, 2020, para. 4). This specific framework assumes a systems perspective and aims to develop a responsive and adaptive approach to knowledge (Field et al., 2014).

The input of these parents coupled with the expertise of relevant healthcare professionals and scoping review findings informed the content of this project. Educational materials and resources were compiled and an appropriate and promising educational tool was developed. The specific format of this educational intervention was designed based on information from current, relevant literature explored through a scoping review. The information was disseminated to participants and a follow-up survey was sent to gauge satisfaction and recognize suggestions for future direction. This feedback was crucial for refining this intervention to be more useful for parents. This capstone project aimed to develop an interprofessional intervention tool to address the needs of parents and ultimately support the entire family unit through improvement in the long-term outcomes of children with HLHS.

Chapter 2: Scoping Review

Introduction

The intent of this scoping review was to identify the most effective method of educational intervention for the post-Fontan parent population. The specific format of the resulting educational intervention was designed based on information from relevant peer-reviewed literature. To provide for a broader evidence-base, the literature was reviewed for findings related to CHD in general, as the needs of parents within this larger population are closely related. The findings informed an interprofessional intervention that addresses the needs of parents and ultimately supports the entire family unit through improvement in the long-term outcomes of children with HLHS.

Occupational Therapy Research Priorities

The World Federation of Occupational Therapy (WFOT) (2016) has highlighted the importance of advancing research pertaining to chronic conditions and knowledge translation for improving participation in everyday life. Occupational therapy (OT) can support the long-term participation of children with HLHS by providing parents with education pertaining to care for these children throughout their lifespan. As surgeries for HLHS continue to improve with technological and scientific advancement, children are surviving beyond historical trajectories (Pundi et al., 2015; Rempel et al., 2012). Further research is needed to identify strategies to build and sustain parental confidence over time.

Scoping Review Question

Initially the scoping review question was: What *virtual* educational interventions can be used to support parents of children with HLHS?

After meeting with stakeholders, however, the scoping review question was altered to encompass a broader range of education delivery modes. This supported a more eclectic approach to addressing the needs of HLHS parents.

The question was revised to: What educational interventions can be used to support parents of children with HLHS?

Methods

Search process

An array of databases and search engines were utilized to research existing information related to parental education concerning CHD. Databases searched included CINAHL, Wiley Online Library, PubMed, TRIP Database, Google Scholar, SOPHIA Database, Mayo Clinic, American Heart Association (AHA), American Journal of Occupational Therapy (AJOT), SAGE Journal, and the EBSCO Dissertation Database. Journal articles and dissertations were the primary forms of documentation explored and provided a comprehensive perspective on the topic.

Common keywords used throughout these searches included: ‘parent education’, ‘congenital heart disease’, and ‘virtual’. Articles were selected based on their relevance to the search terms, date of publication (within five years preferred), degree of academic review, and consideration of HLHS as well as CHD in general. Of the 27,195 total peer-reviewed journal articles that were identified through the search process, 37 were considered to be relevant based on this criteria. The 37 articles were narrowed down to the 13 most relevant. Grey literature searches yielded 165,649 total hits, 1,016 of which were relevant. These were narrowed down to the 10 most relevant texts based on the scoping review question and keywords. After reviewing the literature, 11 peer-reviewed journal articles and four pieces of grey literature, utilizing a wide

range of study designs and levels of evidence, were considered to be most closely related to the research question. These writings were explored in greater depth through initial appraisal and three of them were chosen for a critical appraisal.

While there was an overwhelming amount of research supporting the need for an educational intervention with this parent population, there were limited findings regarding the most effective method of translating this clinical knowledge into practice. Website materials targeting parent populations of children with CHD as the primary audience often require a high level of health literacy to comprehend. This indicated that virtual forms of education may still be inaccessible to families if not executed effectively. There was a lack of information concerning the long-term outcomes and daily occupations of children with HLHS, as well as psychosocial resources for parents and families. Much of the literature involved information about the diagnosis and surgical treatment options. The results of this extensive process yielded findings that guided the future direction of the scoping review.

Results

Removing grey literature from the 15 selected articles left 11 available for scoping review. Inclusion criteria for the selected studies involved at least one of these three areas:

- Parents of children with CHD or specifically HLHS
- Parent education and psychological support related to care for children with chronic-illness
- Modes of education delivery

All of the selected articles were published in reputable scholarly peer-reviewed journals related to pediatric nursing, cardiology, CHD, neurosurgery, and medicine between 2012 and 2020. Ten were primary research studies and one was a review of research, which included a literature

review. Of the ten primary research studies, five were qualitative, four were quantitative, and one was mixed-methods. Six of the studies were conducted in the US, one in Canada (Rempel et al., 2012), one in India (Staveski et al., 2016), one in China (Ni et al., 2019), one in Korea (Lee & Koo, 2020), and one in Saudi Arabia (Azhar et al., 2018).

Qualitative study designs included two descriptive studies, one content analysis, one grounded theory analysis, and one cohort study. Quantitative studies included one descriptive, one experimental, one correlational, and one quasi-experimental study. A t-test was included in all four quantitative studies for statistical analysis of survey responses. The mixed-methods study consisted of a systematic review, quantitative analysis, and interviews (see Table 1).

All 11 primary research articles included parents of children with chronic illness, nine of which were specific to CHD and two of those were HLHS. Three of the primary research articles included healthcare providers as participants such as nurses, physicians, and cardiologists and two included grandparents (Rempel et al., 2012; Wray et al., 2018). Sample sizes of studies including healthcare providers ranged from 38 - 63 and those with family participants ranged from 22 - 171. Three studies specified having diverse participant pools in regards to literacy, education, technology skills, age and ethnicity while the others were more homogenous or did not include demographic information (Azhar et al., 2018; Lane et al., 2019; Wray et al., 2018). Children with other health complications were excluded to control for confounding variables.

The qualitative articles incorporated focus groups, interviews, and open-ended questionnaires whereas quantitative articles used Likert scales and rating systems for data. Research questions related to the amount of CHD education provided by the child's care team, the educational needs of parents, and the psychological effects of being the primary caregiver for a child with CHD. Topics such as medical complexity, parental stress, and web-based education

were considered. Four of the selected studies involved questionnaires that were used to gather insight into parent knowledge of CHD and to further understand the specific areas that needed to be addressed (Arya et al., 2013; Azhar et al., 2018; Ha et al., 2018).

Educational interventions involved a variety of methods including clinician-led teaching programs, written reference guides, teach-back method, an interactive DVD, and a smartphone application (Ha et al., 2018; Lane et al., 2019; Staveski et al., 2016). Educational interventions were made accessible to parents by using simple language written at a low reading level and incorporating content in a variety of forms for different learning styles. The information often contained a combination of text, pictures, icons, pictograms, and video that were visually engaging. None of the articles demonstrated strong evidence to support one format of education delivery over another. Three of the qualitative articles led to the development of models that can be used to support knowledge translation related to CHD (Lane et al., 2019; Meakins et al., 2015; Rempel et al., 2012). These models can be used to inform an education intervention for parents of children with CHD.

Table 1

Study Design

Criteria	Number
Qualitative	5
Descriptive	2
Content analysis	1
Grounded Theory analysis	1
Cohort	1
Quantitative	4

	Descriptive	1
	Experimental	1
	Correlational	1
	Quasi-experimental	1
Mixed-Methods		1
	Systematic review, quantitative analysis, interview	1
Research Review		1
	Literature review	1
<hr/>		
Sources of Publication	Pediatric nursing	5
	CHD	2
	Cardiology	2
	Medicine	2
	Neurosurgery	1
<hr/>		
Participants	Parents of children with “CHD”	5
	Parents of children with “HLHS”	2
	Grandparents	2
	Caregivers	2
	Nurses	1
	Cardiologists	1
	Interprofessional group (designers and clinicians)	1
<hr/>		
Education Delivery Mode	Multi-modal: mobile application, reference guide, & in-person	1
	In-person	1

DVD	1
Online forum	1
At-home monitoring	1

Summary of themes

The purpose of this scoping review was to identify the most effective form of education delivery for parents of children with CHD. Four major themes emerged, including, (a) education discrepancy, (b) biological and psychosocial content, (c) modes of education delivery, and (d) the efficacy of educational programming. Studies conducted in America, Canada, India, Saudi Arabia, China, and Korea have revealed global trends in the information needs of these parent populations. A variety of forms of education delivery have the potential to yield promising results.

Theme 1: Education Discrepancy

Clinicians often misinterpret the educational needs of parents who have children with CHD. This message was conveyed across seven of the 11 studies through various formats and analyses of survey and interview data. This theme was explored within a literature review, correlational and descriptive quantitative studies, a qualitative content analysis, a descriptive qualitative study, a grounded-theory analysis, and a quasi-experimental quantitative study (Abernathy, 2018; Arya et al., 2013; Azhar et al., 2018; Lane et al., 2019; Lee & Koo, 2020; Rempel et al., 2012; Staveski et al., 2016). The findings from these studies indicated that parents of children with CHD want more information pertaining to their child's condition and psychosocial resources.

The educational opportunities offered after discharge are often insufficient compared to the needs of parents (Lee & Koo, 2020). Arya et al. (2013) demonstrated this education

discrepancy through a cross-sectional survey of 38 cardiologists and 41 parents of children over age three with CHD at Morgan Stanley Children's Hospital in New York. Survey responses revealed that parents tended to rank topics such as follow-up care and the child's quality of life as more important than cardiologists considered them to be ($p < 0.03$) (Arya et al., 2013). This trend was shown to extend beyond regional and cultural borders. Variation between parental needs and clinical practice was described in a Korean study by Lee and Koo in 2020. This online survey of 171 parents of children with CHD indicated that 97.1% of parents wanted educational programming related to providing care to their child after discharge, while 16.4% reported receiving any (Lee & Koo, 2020). There is a widespread need for improved educational programming for this population.

Providers may fail to address the needs of parents for a variety of reasons. Arya et al. (2013) suggested that a difference in lived experience between providers and parents affects the perception of what information is needed to care for a child with CHD. Another reason could be that clinicians try to avoid overwhelming parents with too much information all at once (Arya et al., 2013). Both of these explanations result in missed educational opportunities for parents which affects their ability to confidently provide care to their child.

Failure to address these educational needs can affect the psychosocial functioning of parents. According to Rempel et al.'s (2012) grounded theory analysis, many studies provide evidence of pathology associated with parental fear, stress, and anxiety, and contribute to feelings of hopelessness and depression. Rempel et al.'s (2012) research suggested that health care practitioners offer evidence-based interventions to parents at all stages of their child's illness trajectory to reduce 'uncertain parenting' and address the wide range of parent needs. Providing

high-quality educational content to these parents can ultimately serve as a means to support their psychosocial functioning.

Theme 2: Biological and Psychosocial Content

An effective educational intervention for this parent population must include content related to both the biology of CHD and psychosocial support. The need for psychosocial support was acknowledged in seven of the 11 studies whereas biological information was discussed in all of them (Abernathy, 2018; Azhar et al., 2018; Meakins et al., 2015; Ni et al., 2019; Rempel et al., 2012; Staveski et al., 2016; Wray et al., 2018). Azhar et al.'s (2018) survey of 120 caregivers of children with CHD in Saudi Arabia found that caregivers tended to have a good understanding of the CHD diagnosis, its nature, and the effects of the disease (64.2%), but still wanted more information concerning biological and psychosocial issues associated with the diagnosis. Parents participating in Lane et al.'s (2019) focus groups described the need for information related to symptoms and risk factors associated with CHD, the effects on child maturation, coping mechanisms, as well as social and service resource information. Parent participants consistently demonstrated a range of educational needs.

While the need for psychosocial support was less represented in the studies, there was strong evidence supporting the importance of it. A quasi-experimental study by Staveski et al. (2016) revealed that families of children with CHD in India have higher stress levels when lacking social support. Ni et al. (2019) also found that parent stress associated with caring for a child with CHD was high. This demonstrated that effective programming must include coping strategies to best support these parent groups (Ni et al., 2019). The psychological toll of CHD on parents was studied by Wray et al. (2018) through use of an online parent forum for CHD. Isolation was a common theme identified and was experienced by parents in a variety of forms

(physical, social, knowledge) (Wray et al., 2018). The need for both educational and psychosocial resources was conceptualized through the development of the 5-Facet Model (Rempel et al., 2012). Different types of HLHS parenting were acknowledged by this model, including survival parenting, hands-off parenting, expert parenting, uncertain parenting, and supported parenting (Rempel et al., 2012). This model can be used to guide the educational and psychosocial interventions needed to support this parent population.

Examination of current educational practices highlighted the specific ways in which they can be improved. Focus groups in a study by Lane et al. (2019) conducted focus groups in which parents indicated they valued existing educational programming and identified areas where they need additional support. Areas they found the value in included diagrams, posters, handouts, and in-app content that described the anatomy of the affected heart. Parents clarified several opportunities for improvement related to home care education, providing daily care for their child at home, the role of care team members, and how to monitor for red flags. Parents as well as clinicians who participated in this study exclaimed that the information should be accessible all in one place, such as a reference guide that could be customized for the specific diagnosis (Lane et al., 2019).

Theme 3: Modes of Education Delivery

When utilized properly, virtual technology can be an effective tool for education delivery. Four of the 11 articles involved some form of virtual education, all of which supported the use of this mode of intervention (Abernathy, 2018; Ha et al., 2018; Lane et al., 2019; Wray et al., 2018). Lee and Koo (2020) surveyed Korean parents and noted that they want information that is accessible from home. Lane et al. (2019) had similar findings in their U.S. study in which clinicians suggested that an interactive web-based platform for home care educational materials

would be useful for families, particularly once they are discharged from the hospital. Parents in this study reported a preference for mobile applications, face-to-face questions, presentations, websites, and e-mail for information delivery (Lane et al., 2019). These findings were used to inform the evidence-based Home Care for Heart Health intervention, a multi-modal educational intervention consisting of a reference guide, a smartphone application, and in-person clinician education. This intervention can be used as a model for home-based education delivery for parents of children with different types of chronic illness (Lane et al., 2019). Ha et al. (2018) used an interactive DVD to provide CHD education, which was found to be effective and rated highly for its ease of use. Wray et al. (2018) showed that social media has the potential to be used to provide support to families by connecting them with others sharing a similar experience. The online forum for this study demonstrated the ability to provide a community for parents, resulting in a reduction in feelings of isolation (Wray et al., 2018). There are many routes of education delivery that have potential to support parents of children with CHD.

Theme 4: Efficacy of Educational Programming

Overall, all 11 studies demonstrated the benefits of educational programming to varying degrees. Azhar et al. (2018) found that CHD education for parents enabled good understanding of the disease and alleviated psychological distress. Educational DVDs were found to improve parental knowledge and health websites were able to meet information needs and offer supportive resources (Ha et al., 2018). An online forum created a safe space for parents to share stories and offer support to others dealing with similar stressors (Wray et al., 2018). Educational interventions and mindfulness were able to provide anxiety relief and the use of illustrated materials supported the efficacy of the intervention (Azhar et al., 2018; Bishop, 2016). At-home

monitoring programs during the interstage period between surgeries were shown to be cost-effective and decreased morbidity and mortality (Abernathy, 2018).

Findings from other studies also demonstrated ways in which educational interventions could be improved. Dedicating more than ten minutes to provide medical education to parents of children with CHD was found to alleviate anxiety in 70.8% of parents surveyed in Saudi Arabia (Azhar et al., 2018). Two studies noted that education supported parents' abilities to provide complex care to children with CHD and that parents can develop expertise in this over time (Meakins et al., 2015; Wray et al., 2018). Standardized parental discharge teaching was found to be associated with increased knowledge, confidence, parental perception of readiness for discharge, and better coping in developed countries (Staveski et al., 2016). Staveski et al. (2016) found in their study of parents in India that educational programming after discharge decreased parental uncertainty and ambiguity, but also made parents more nervous because they became aware of resources they'd need but didn't have access to. This reflects the need for region-specific educational programming to support families at the community level.

Discussion

The findings of this scoping review have generated implications regarding the delivery of educational content to parents of children with HLHS. Clinicians have often underestimated the educational needs of this population, and the routinely provided education often lacks components needed to support psychosocial functioning (Arya et al., 2013; Lee & Koo, 2020). Illness-related parenting stress often leads to isolation and can negatively affect the entire family unit (Meakins et al., 2015; Ni et al., 2019; Wray et al., 2018). This scoping review revealed that the experience of stress and the informational needs of parents of children with CHD are similar around the world.

Post-Fontan parent groups have indicated the greatest need for coping resources (Landry et al., 2019). The focus in parenting a child with HLHS tends to be on immediate, day-to-day functioning rather than on long-term developmental needs (Rempel et al., 2012). After the final Fontan operation, communication with the care team tends to decline, and the role of parents begins to shift. Parents had previously been provided with specific guidelines and routines to follow between surgeries, but after the Fontan they are left without a clear roadmap for the future. This is often when parents feel the most overwhelmed and receive less communication from their care team.

While little is known about how improved parental education affects the long-term outcomes of children with HLHS, an educational intervention providing both scientific and psychosocial-related content could support these parents' caregiving abilities (Azhar et al., 2018; Meakins et al., 2015; Ni et al., 2019; Rempel et al., 2012; Staveski et al., 2016). Occupational therapy (OT) can support the long-term participation of children with HLHS by providing parents with education pertaining to the chronic care for these children throughout their lifespan.

Research has shown that parents are motivated to utilize interactive educational material and there is strong evidence supporting the efficacy of modes of delivery that include these features (Ha et al., 2018; Lane et al., 2019). Content presented in a variety of written and visual formats have the most supporting evidence (Azhar et al., 2018; Lane et al., 2019). The research from this scoping review indicated that an engaging educational intervention may support the psychosocial functioning of post-Fontan parent groups.

Implications for Practice

Findings from this scoping review have specific implications for education venues for parents of children with CHD. Failing to address the educational needs of parents of children

with HLHS can prevent them from feeling successful within their role as a caregiver. When parents are ill-prepared to provide lifelong homecare, it can result in isolation, psychological distress, medication errors, hospital readmission, and limitations on the child's growth, development, participation in ADLs, and life expectancy (Lane et al., 2019). Currently, the limited face-to-face and written educational content provided to this population is lacking critical information concerning the biology of CHD and psychosocial support. Optimizing care for children with HLHS must be accessible and include increased attention to the informational and resource needs of the parents supporting them. Post-Fontan parent groups have been identified as the group most in need of additional resources to cope with their child's diagnosis (Landry et al., 2019).

While expertise is developed over time, parents can be setup to be successful with their roles through improved educational interventions. OTs are in a unique position to address the needs of these parents. The interactive components of interventions may allow for a more individualized educational experience. Specific content should be incorporated in both written and visual formats to account for different learning styles. There is strong research supporting the need for and potential efficacy of this kind of intervention.

Recommendations

The findings of this scoping review can be used to improve the quality of education provided to post-Fontan parent groups. The following recommendations were conceptualized through analysis of the 11 peer-reviewed journal articles selected.

- Identify gaps in biological and psychosocial educational programming at Mayo Clinic through parent and clinician interviews and/or surveys

- Utilize Mayo Clinic's collaboration with HLHS Consortium to reach post-Fontan parent groups (Mayo Clinic, 2020)
- Explore research concerning post-Fontan child development and identify ways in which educational programming can support lifelong outcomes
- Create written and visual educational content specifically for post-Fontan parents that includes information related to HLHS and psychosocial resources
- Educate HLHS care team members on the information needs of post-Fontan parent groups
- Identify ways in which interprofessional groups can support families coping with HLHS
- Continue researching the effects of educational interventions on the long-term wellbeing of children with HLHS

Conclusion

Initial appraisals were completed for all 15 of the articles selected for this scoping review, which involved a variety of scholarly and grey literature. Peer-reviewed articles included qualitative, quantitative, and mixed-method designs as well as one research review. Nine of these were specific to CHD, two of which to HLHS. Grey literature consisted of electronic dissertations from educational institutions. Critical appraisals were completed on the three scholarly, peer-reviewed articles which most closely aligned with the scoping review question.

Overall, there was strong evidence supporting the need for educational interventions for parents of children with CHD. Survey responses, interview transcripts, and focus groups were frequently utilized to gauge parent and stakeholder needs and interests. Studies involving educational delivery incorporated online forums, at-home monitoring, mobile applications, reference guides, and in-person training. All of these routes demonstrated promising results for

improving parent understanding of CHD and the unique needs of their child. Less was documented about the long-term benefits these types of interventions may have on child and parent wellbeing. Parents consistently reported high levels of caregiver-related stress and indicated a need for improved educational programming, specifically when returning home, post-discharge. Unfortunately, however, there was little acknowledgement of available psychosocial resources to support familial wellbeing.

While the main focus of this scoping review involves HLHS, broadening the research question to encompass other CHD generated significantly more research findings. There was more relevant literature to pull information from and it became clear that the need for parental education is not unique to HLHS - there is a need for parental interventions across CHD diagnoses. Many parents utilized online resources for information and did not seem to have difficulty using virtual/digital education tools. Smartphone applications have shown potential for education delivery as well as improvement in communication between parents and provider. Several existing models and programs described throughout the literature can serve as a guide for educational programming development for parents and should reflect their need for psychosocial resources.

Chapter 3: Needs Assessment

Approach

A needs assessment was conducted over the course of one month in an entirely virtual format. Electronic data from relevant organizations were reviewed to identify accessible materials and resources for parents. Interviews provided another important source of information; Mayo clinic physicians, prominent leaders within the pediatric cardiology and cardiac neurodevelopmental research community, as well as one parent affected by HLHS participated in 1:1 interviews. Their unique lenses provided a comprehensive perspective on this topic by drawing upon both personal and professional experience. All of this valuable information was analyzed and used to inform the future directions of this project.

Findings from previous research by Landry et al (2021) was the primary motivation for this capstone project. The intention of their research was to identify existing gaps in support for HLHS parents. A mixed methods approach was utilized to understand the nuances of this topic through the lens of interprofessional care team members and parents affected by HLHS (Landry et al., 2021). Survey results from over 600 HLHS parents around the world revealed that post-Fontan parent groups were in the greatest need of support - they perceived having the least support from the care team and were in the greatest need of coping resources (Landry et al., 2021). These findings identified the need for interventions that specifically target this population, which this capstone project aimed to address.

The research conducted by Landry et al. was made possible through Mayo Clinic's Todd and Karen Wanek Family Program. The website for this program provides information on available support and resources, as well as ways to contribute to research. This foundation is composed of a multidisciplinary team of clinicians and researchers who collaborate with the

HLHS Consortium. The focus of the Consortium is to streamline the execution of clinical trials involving HLHS in a financially sustainable manner (Mayo Clinic, n.d.).

The Mayo Clinic website has links to both of the aforementioned organizations as well as the educational tools given to parents by Mayo Clinic providers. The primary resource given to parents is the HLHS pamphlet. This pamphlet simplifies a lot of complex medical information for parents to understand the diagnosis, but fails to acknowledge the mental health and long-term needs of parents and families affected by HLHS. The most detailed and beneficial identified throughout the needs assessment was the Mended Little HeartGuide. Mended Little Hearts is another relevant organization that aims to support parent education of CHD. The HeartGuide has information ranging from diagnosis to long-term care for children with CHD (Mended Little Hearts, n.d.). It acknowledges the struggles faced by parents and offers solutions for coping with some of the common issues like finding support groups (Mended Little Hearts, n.d., p. 9).

Mayo Clinic has a partnership with Sisters By Heart, a volunteer-led organization that aims to educate families coping with HLHS and other single-ventricle diagnoses (Sisters By Heart, n.d.). Sisters By Heart is the parent organization of The National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC). NPC-QIC utilizes its connections with over 60 pediatric cardiology care centers to improve health outcomes of children affected by cardiovascular disease (NPC-QIC, n.d.). Mayo's elaborate web of connections supports a comprehensive understanding of the resources available to parents of children with HLHS.

All of these websites and tools possess an abundance of information for families. The most beneficial resources identified for the intentions of this capstone project were those which were informed by the perspectives of actual parents who had a child undergo the Fontan procedure. The most notable included: "What I Need as a Fontan Parent" a blog page on the

Mended Little Hearts website and three handouts made through collaboration between Sisters By Heart, NPC-QIC, and parents affected by HLHS which were titled: “Raising a Toddler”, “Preparing for Fontan” and “Fontan Hospitalization”. All of these materials acknowledged the importance of support resources that address the mental health of the family unit. A two-hour long phone conversation with an HLHS parent on 8/17/21 was another method of gaining insight into the needs of post-Fontan parents. This mother has two children with HLHS, which is extremely rare. She is an devout advocate for the CHD community and has dedicated her life to supporting the mental health of caregivers as a Life Coach. Virtual meetings with two different neuropsychologists involved in CHD research on 8/12/21 and 7/16/21 contributed a clinical perspective to the assessment. Both of these individuals have been involved in many publications related to supporting parents of children with CHD. Additionally, a virtual meeting with a pediatric cardiologist at Mayo Clinic on 8/23/21 added the pertinent perspective of a pediatric cardiologist to the conversation. Table 1 shows the list of interview questions discussed with all of these individuals. These 1:1 conversations with a diverse mix of relevant stakeholders provided important information relevant to this needs assessment.

Table 2*Informational Interview Questions*

Questions for Stakeholders

1. How have parents been surveyed formally or informally at Mayo about the care they receive for their children with HLHS?
2. What are the main complaints/concerns you hear from families?
3. How do/can they express their frustrations?

-
4. What quality indicators are used to measure the efficacy of services? Any system for checks and balances?
 5. How can you provide appropriate long-term education for parents when technology and treatments are changing so rapidly?
 6. What do you view as the biggest hurdles to parent education for HLHS?
 7. How is HLHS education different from other CHDs?
 8. When do you think the appropriate time would be to introduce a post-Fontan educational intervention?
 9. What specific information and resources do you think this population would benefit from the most? Which are parents actually using? Why/why not?
 10. What do you view as pros/cons of a virtual/app-based educational intervention?
 11. What are the most common comorbidities you see in children with HLHS?
 12. What common symptoms do you see that affect day-to-day functioning which don't meet criteria for a specific diagnosis?
 13. Examples of diversity and health inequities affecting patient care/outcomes?
-

Data and Themes

Research from Landry et al. (2019) coupled with parent and professional interviews and a review of existing literature and resources indicated a widespread need for post-Fontan parent support which Mayo Clinic is in a position to appropriately address. Capstone mentors and stakeholders including a child psychologist and an HLHS parent reiterated the sentiments of the Landry et al. (2019) article in various ways, citing a range of systemic problems that contribute to the disconnect between providers and patients. It became clear that after the Fontan, parents are left to navigate through a complex medical system on their own and are expected to know when and how to access various resources for support. When this was discussed with one pediatric cardiologist at Mayo Clinic, he purported that post-Fontan parents were not in as much

need for support as parents earlier along in the surgery process. When findings from the Landry et al. article were shared with him, he noted that he had been unaware of the needs of this population and was appreciative of the information. This demonstrates how even the most involved clinicians on an HLHS care team may be unaware of the needs of this parent population. An article alluding to the creation of HLHS app called “HLHS Health Journal” by Mayo Clinic was discovered, but it is unclear if this app actually came to fruition as no further information was available and it does not appear to be accessible on any platform (Ferguson, 2016).

While the need for support was clear, the appropriate method and timing of an intervention to support this population was less straightforward. It seems that post-Fontan family success is affected by many forces that come into play well before the actual Fontan operation. The aforementioned HLHS parent involved in this project described in detail some of the trauma that she and her child experienced throughout earlier surgeries; returning for the Fontan was triggering for her and she struggled with knowing how to prepare herself and her child. She and various parent resources including blog posts and the Mended Little HeartGuide acknowledged the importance of finding opportunities for parents to bond and connect with their child throughout the challenges posed by the Fontan. Some of the procedures leading up to and following the Fontan can be scary for children; this puts parents in a position where they may feel like they are violating their child’s trust by complying with necessary aspects of hospitalization. Protecting and promoting positive parent-child relationships should be at the center of any intervention targeting this population.

SWOT Analysis**Table 3**

SWOT Analysis: Strengths, Weaknesses, Opportunities, and Threats to Post-Fontan Parent

Education at Mayo Clinic

Internal		External	
Strengths	Weaknesses	Opportunities	Threats
Preceded by a related research project with relevant information and connections to draw upon	Care for post-Fontan parents drops off after final operation – decrease in communication	A lot of existing research on CHD to inform intervention and justify need for this capstone project	Lack of research on interventions specific to HLHS population of CHD
Post-Fontan parent population is accessible through Mayo	Findings from other studies on CHD may not be generalizable to post-Fontan parent group	Many evidence-based interventions exist for related diagnoses/situations (kids w/cancer, disabilities)	Lack of trauma-informed care resources specific to this population
HLHS care at Mayo involves an interdisciplinary team - provides for a variety of perspectives	Clinicians do not receive extensive training on trauma-informed care	Families demonstrated motivation to participate in related studies	Timing of intervention – parents may be less receptive to new information at certain points due to stress & etc.
CNOC Identified this research topic as an area of need - priority question #3	Parents focus on the most critical information during the time of the surgeries and do not retain information about available resources	Many HLHS online groups and message boards available to disseminate information or surveys	Internet accessibility may be limited for some families)

Dr. Cassidy has connections to the major organizations that provide resources to these families	Lack of information related to the efficacy of the HLHS app used at Mayo – unsure how widespread it is used or what specific information it has	Clinicians have an opportunity to be proactive, rather than reactive when it comes to educating this parent population	May be difficult to provide individualized intervention – some families may have different needs than others
Mayo is currently completing three different clinical trials related to HLHS and are actively trying to improve methods of treatment and care	Use of harmful language reported by many families	Several optimistic studies have been published that indicate these children have the potential to have a normal quality of life and levels of emotional functioning	Location-specific information and resources may be difficult to provide as the capstone project will produce a tool for generalized information

Conclusion

Setting up parents of children with HLHS to be successful after the Fontan operation is a multifaceted issue that requires a trauma-informed approach. Acknowledging the significance of the parent-child relationship is an important aspect of supporting the mental health of these caregivers. Because HLHS is such a rare condition, getting information from this parent population can be challenging. This small community is often bombarded with requests to participate in research; attempts to connect with these families must be well-planned and considerate of the painful experiences they may have endured. Potential interventions for this population must acknowledge both the complexities of this surgical procedure and the lasting impact it can have on families. The specific needs of these parents should be further explored in order to work towards optimizing family outcomes.

If executed correctly, an educational tool could be useful to educate both parents and their kids to prepare them for the Fontan and beyond. A resource supporting parents and children as they prepare for the Fontan procedure can set these families up well to anticipate, cope, and thrive in life post-Fontan. The need for psychosocial interventions for this population has been well established and Mayo Clinic is in a unique position to tackle this challenge as a leader in HLHS research.

Chapter 4: Goals, Objectives, and Approaches

Introduction

This chapter outlines the process that led to the development of an educational tool for parents of children with HLHS. The final product was a children's book that focused on child and parent education and included psychosocial resource pages. The need for this type of tool was uncovered throughout the process of the capstone experience and it was executed in a way that has a practical application. While the scoping review had an emphasis on virtual routes of education delivery, the literature indicated that in general, these parents tend to prefer tools they can access in the home environment. The specific format seems to be less important than the content and the way in which it is communicated. This book provides a way for parents to connect with their child in a comfortable setting and deepen their own understanding of a complex topic. The finalized version of the book can be found below in appendix A.

Process and Plan

The primary goals and objectives for this capstone project included the following:

1. Gather additional information from stakeholders to identify key educational needs post-Fontan stage
2. Design an educational tool to support parent and child education and wellbeing
3. Distribute product to parent population
4. Gather feedback from relevant stakeholders via survey and/or 1:1 virtual meetings

Quality Improvement

St. Catherine University and Mayo Clinic both reviewed details related to this capstone and determined that it constituted as a quality improvement project. Mayo Clinic hosts an IRB Wizard website which allows designated staff to enter specific information about projects and

research and it provides an immediate response as to what level of review is necessary. With the details entered into IRB Wizard, this capstone project was officially qualified to be considered a quality improvement project for Mayo on 8/24/21 (see appendix B for the official memo).

Because there were only eight questions involved in this process for Mayo Clinic, St. Kate's IRB committee requested completion of a full IRB application to ensure thorough review. St.

Catherine provided confirmation of this QI project on 8/31/21. On 9/30/21, an amendment to the initial application was requested to allow for an additional question to be added to the survey.

This addition involved asking parents to enter their email addresses for follow up if they were interested in providing feedback on the final product. This would allow for parents to be involved in the evaluation portion of the capstone process. Their input on the efficacy of the product is an important aspect of creating a practical tool for this population. The IRB amendment was approved on 9/30/21. Evidence used to inform the direction of this project was obtained in a variety of ways. The initial needs assessment revealed an additional need to gather feedback from parents. A virtual survey was designed to gather information from parents of children with HLHS. Information about survey design was reviewed to ensure questions were presented in a way that produced authentic responses. Individual meetings with relevant clinicians and one HLHS parent took place to ensure the survey addressed the appropriate items.

Initially the pre-intervention survey was intended for parents of children who had the operation specifically at Mayo Clinic, Rochester. These criteria were changed due to the fact that it would be too restrictive and limit participation. As mentioned in chapter 1, HLHS is a very rare condition and Mayo Clinic does not do a large number of Fontan operations annually. For this situation, it seemed that the location of the operation is less important and creating an

applicable tool for this population would require a lot of input from parents coping with an HLHS diagnosis.

The pre-intervention parent survey was shared in a digital format using Google Docs for convenience. The survey was shared among major Facebook parent groups for HLHS and related organizations. These groups can be rather exclusive due to the sensitive nature of the topic, not all of the pages contacted were willing to share the survey with parents for this reason. See Table 5 for pre-intervention parent survey questions and responses. The Facebook pages that did post the survey included HeartWorks and Sisters By Heart (see survey questions in appendix C).

Participants

39 participants completed the parent survey. The participant pool was mostly composed of highly educated Caucasian mothers. Most of these participants had a child that experienced the Fontan over five years ago, and most of the children were hospitalized for two weeks following the operation. See Table 4 for demographic details. Figures 5 and 6 illustrate further demographic and educational details.

Table 4

Quantitative Data from Initial Parent Survey

Survey question	Most common response (percentage of participants, n=39)
Racial/ethnic heritage	Caucasian (94.87%)
Parental role	Mother (89.7%)
Relationship status	Married (97.4%)
Educational background	Bachelor's degree (35.9%)
Time passed since Fontan	Five years or greater (43.6%)
Duration of hospitalization	Two weeks (38.5%)
Self-reported preparedness to	5/5 Likert scale rating (56.4%)

return home as child's
post-Fontan caregiver

Self-reported access to
developmental services and
supports for child

5/5 Likert scale rating (51.3%)

Self-reported access to parental
mental health services and
supports

2/5 Likert scale rating (28.2%)

Care team communication
rating

5/5 Likert scale rating (35.9%)

Ability to provide care team
feedback

Yes (47.4%)

Figure 5

Google Forms Survey Responses: Demographic Information

Demographic Information: Before you begin, we would like to know a bit about your background.
Select the parent role that best describes you:
39 responses

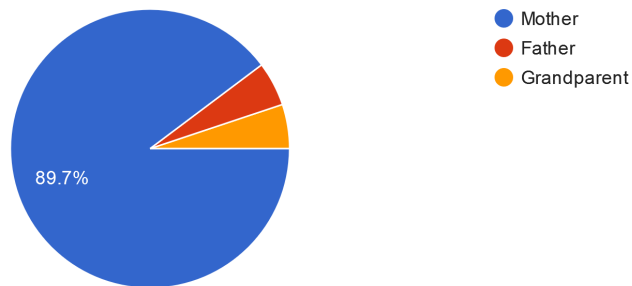


Figure 6

Google Forms Survey Responses: Educational Background

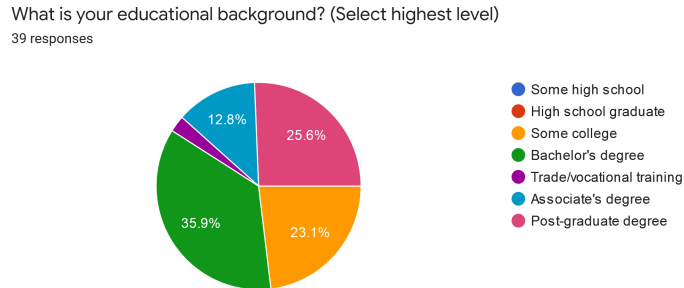


Table 5.

Qualitative Data From Initial Parent Survey

Question	Common Parent Responses (Number of mentions, n=39)
Is there anything that would have helped you feel more prepared?	Dietary restrictions (4) Education on warning signs (3) Similar to first two surgeries (2) Connection to support groups (2) “It would have been very helpful to have some kind of established strong support group or outreach program in place.” “More education about CHD.”
What supports and services did you access, if any?	None (7) OT (5) Pediatric cardiology (5) PT (4) Speech (4) “We were not told of any, just if medical issues to call doc.” “Early intervention to help him catch up developmentally.”

What resources have been the most helpful since your child's Fontan operation?

Mental health therapy (4)
Social media (4)

“Once discharged, I had no clue who to contact.”

“Facebook chatting with other parents.”

How was feedback for the care team collected?

Survey (6)
Follow up appointments (5)

“Not in depth feedback, just basically answering the cardiologist's questions during follow up appointments.”

“Mayo Clinic sends out yearly survey.”

In what ways did your child's care team communicate well?

Informing them of the plan (8)
Taking time to explain things (4)
Phone calls (4)

“I was always included everyday at rounds, they listened and answered all my questions and suggestions each day, they ask for my thoughts on her care and treatment with new meds.”

“Always informing us of the plan and how we could be a vital part of our child's recovery.”

In what ways did your child's care team communicate poorly?

Didn't listen to parent concerns (4)
Poor interprofessional team communication (3)

“Parents are left to navigate it themselves.”

“Sometimes there were many rotations of nurses and residents and it was hard to keep track.”

Do you have any suggestions for parents of children with HLHS preparing for the Fontan operation?

Dietary preparations (4)
Getting psychological help early (2)
Connecting with other families (2)
Prioritize parent health (2)

“Knowledge, prepare yourself and home, have help, take it day by day and prioritize your health as the parent.”

“Your child is older and will remember more and may need support processing the trauma of being hospitalized.”

What do you wish the healthcare team knew about your mental health?

Effects of trauma (13)
 COVID-19 restrictions make it difficult (4)
 Lack of parent resources (3)

“We need more materials and guidance.”

“Parents will not speak up and admit when they are having a hard time coping when their child needs them at a time like this.”

Timeline

The following meetings were essential to the development of the capstone plan:

- On 6/21/21 there was an initial virtual meeting bridging St. Catherine and Mayo staff to discuss the overall goal of the capstone project.
- On 7/7/21 there was a meeting with the doctoral advisor and cohort members to discuss details of the capstone experience. The pillars of this experience were outlined at length and expectations for communication and productivity were discussed.
- A meeting on 7/21/21 took place with doctoral students and St. Catherine University’s capstone coordinator. At this meeting, requirements for on- and off-site hours were explained in detail.
- On 7/30/21 an introductory meeting with Mayo Clinic site mentor. Student and mentor roles were discussed and ways to collaborate were identified.

Bi-weekly check-ins with mentor based at St. Catherine University on 8/1/21. As the liaison between St. Catherine’s Women's Integrative Research Center and Mayo Clinic, meetings with this mentor involved discussing ways of utilizing this connection and associated resources to create a unique and useful product. The second of two capstone project mentors, a neuropsychologist at Mayo Clinic, also provided mentorship via bi-weekly virtual meetings to review capstone progress and determine future plans. He provided insight into the application of

capstone plans in ways that were congruent with Mayo Clinic's methods and values. While no on-site visits to Mayo took place due to the COVID-19 pandemic, "on-site" time logged involved completing tasks related to the development of a capstone product. This primarily involved reviewing literature related to the topic, connecting with experienced clinicians, and searching for appropriate platforms and venues for which to disseminate the content involved in the capstone product.

Starting week 1, there was an emphasis on meeting preparation, practice with clear and concise communication, and inquiry into the IRB approval process for Mayo Clinic. By week 3, the focus was on identifying online tools and platforms to contact the target population and disseminate materials. By week 4, meetings with Mayo Clinic staff members were arranged and effort was made to identify potential parent participants. At this time the idea of making online educational modules was considered, however, it became apparent that there were better alternative routes to communicate health information to this population. While researching existing resources to improve parental competence concerning HLHS, very few children's books were available. This was what sparked the idea to create a children's book that could convey information to both children and parents simultaneously. This would be a more client-centered way of connecting with this population and conveying complex information in a simplified manner.

By week 5, an outline of necessary content and a list of priority areas was created. Information related to survey design strategies was reviewed and the pre-intervention survey was created which involved both quantitative demographic questions and qualitative open-ended responses. The link for the survey was shared with capstone advisor, mentors, and another neuropsychologist involved in CHD research. Edits were made as needed and the survey was

sent out to parents in relevant Facebook groups via posts by the page admins. It was hoped that having the survey shared by someone within the group could maximize engagement. Over the following weeks, the results from the surveys were reviewed and themes from the data were identified. Virtual meetings with other relevant stakeholders took place including a psychologist and pediatric cardiologist who both work closely with HLHS families. The outline for necessary content was updated based on parent feedback and clinician interviews. Table 5 shows common parent responses to qualitative survey questions.

The trajectory of the project evolved based on the information provided by stakeholders between weeks 5 and 11. Multiple parents expressed frustration that despite participating in multiple research projects, their feedback was never used to create a tangible product that addressed their concerns. An OT lens was used to consider forms of education delivery that hadn't been utilized yet to support this population. An outline of necessary content was created based on parent feedback and the idea for a kid's book came to fruition. The book *Flynn and Flora Prepare for the Fontan* was created using Google Slides and illustrated with tools from AdobeFresco. It was shared with parents and clinicians using a downloadable pdf file via email.

The content for the book was created based on the information gathered and an initial draft was sent to mentors and capstone advisor for review by week 11. Language and cultural considerations were an important aspect of this task as the goal of this intervention is to be accessible and appropriate for all parents affected by HLHS. When describing complex aspects of HLHS medical care, the specific language used by parents, clinicians, and relevant organizations was incorporated into the book for familiarity to this population. Paulo Freire's Empowerment Education Model was referred to while developing the book content, which has been used in studies involving caregiver education pertaining to CHD and other chronic

conditions (Ni et al., 2016). This model supports caregiver knowledge and incorporates resources to improve caregiving abilities. It aims to cultivate a reciprocal relationship between educator and client to establish and meet learning goals and has been found to improve caregiver abilities as well as the child's recovery from a high-risk heart surgery (Ni et al., 2016). Suggestions for developing parent-education materials with lower readability levels from Menghini's (2005) article were referred to throughout this process. Additionally, the font size and color contrast were designed for maximal accessibility. These kinds of perceptibility considerations are strategies central to universal design, a research-based framework which aims to reduce learning barriers (American Occupational Therapy Association [AOTA], 2015).

A post-intervention survey was created and shared with parents for feedback on the book. Of the 25 parents who provided their email addresses on the initial survey, six of them ultimately responded to the post-intervention survey to review *Flynn and Flora*. This feedback survey can be found in appendix D. In addition to parent participants, mentors, and capstone advisor, various clinicians including a Child Life Specialist and a pediatric cardiologist provided feedback via email and/or 1:1 virtual interviews. Changes to the book content, phrasing, and illustrations were made per recommendations. Modifications were made to the book content and images as needed and the final version was shared with patient education at Mayo Clinic for review. Results will be discussed in chapter five.

Chapter 5: Evaluation and Results

Project Evaluation

Data collection

Evaluation data was collected from a variety of relevant stakeholders. Feedback from volunteer parent participants was collected via post-intervention surveys. Data from clinicians was provided via email communications and/or 1:1 virtual chat. The clinicians involved in the review process were affiliated with institutions including Mayo Clinic and Cincinnati Children's Hospital, and Nemours Cardiac Center. Collecting feedback from both parents and multi-disciplinary clinicians allowed for a broad range of constructive comments concerning the utility of this tool. Feedback questions were intentionally left open-ended to provide for a rich and diverse pool of qualitative data to inform the future directions of the product.

Parent and clinician feedback

Feedback was incorporated on a case-by-case basis and was dependent on factors including whether it was mentioned by multiple people and how significant and practical the suggested change would be to implement. For parent participant data, responses were transferred to an Excel spreadsheet; if multiple parents made a similar comment it was highlighted with comments made by the greatest number of parents taking precedence. Clinician feedback was documented on a spreadsheet as well and suggestions similar to either other clinicians or other parents were highlighted. This method allowed for common themes to emerge throughout the evaluation.

Results

The most pertinent feedback questions related to the reader's opinions on the book's strengths and weaknesses. Some of the most common aspects mentioned by parents related to a

lack of information on pre-op procedures and challenges associated with walking after the operation. Because of this, a pre-op page and a page about walking for the first time afterwards were added. Multiple parents found the format of the book to be problematic; each illustrated page had a corresponding parent information page and some thought it would be better to make two separate books - one for kids and one for parents. This may have been a limitation of the digital format of the book; if the book had been printed and spiral bound on the top, the illustrated and content-heavy pages would be separated (with kids only looking at one side, and parents looking at the other side) and they may not have viewed it as much of a potential issue.

Many of the parent suggestions contained specific information that was not necessarily generalizable to a broader population. For example, multiple parents thought it would be important to include specific tips they found to be helpful for getting their child to eat after the Fontan. Because the intention of this capstone project was to support parent education and not provide specific medical recommendations, rather than including these tips, information about speech and OT services was included. This provided parents with the information needed for them to know who to reach out to for more individualized advice.

Clinicians focused more heavily on increasing interdisciplinary representation throughout the book and frequently identified potential health literacy barriers for parents. Incorporating this feedback involved the addition of pages describing the roles of various relevant care team members and rephrasing certain explanations to make them more straight-forward. These changes made the book more thorough and reader-friendly. One piece of feedback mentioned by multiple clinicians (and no parents) related to the ethnicity of the physician in one of the illustrations. It was recommended that the image of an older Caucasian physician be altered to be

intentionally more inclusive to avoid implicit bias. This unexpected piece of feedback demonstrated the inclusive and forward-thinking nature of the involved clinicians.

Data

A wide range of positive and constructive comments were provided by relevant stakeholders. Multiple revisions to the book were made based on the feedback summarized in Tables 6 and 7. The final version of the book can be found in appendix A.

Table 6

Thematic Analysis of Post-Intervention Parent Survey

Questions	Common Parent Feedback (Number of mentions, n=7)
How much time did you spend reading through the book?	10 mins (4)
Was there anything you didn't understand throughout the book?	No (7)
What did you like about the book?	<p>Deep Dive sections for parents (2) Additional resources for coping (2)</p> <p>“Many of them we were aware of [coping resources] but I liked they were all in 1 place.”</p> <p>“Great idea with aiming it toward children, but having the “dive deep” sections to help educate parents further!”</p>
What did you dislike about the book?	<p>The format (2)</p> <p>“I think it would be more useful to have a companion guide or to have the parent pages at the end so the story flows nicely for the kiddos.”</p> <p>“I think the concept of pumping blood and why it's important is still a hard concept [for kids].”</p>
Is there anything missing from the book?	<p>Pre op information (3) Walking for the first time afterwards (2)</p>

“I think explaining what is going to happen when they get to the hospital besides meeting the care team. IV lines, having to leave mom & dad, etc....”

“It might be good to mention how they might feel funny when they wake up.”

Would this be helpful for parents of children with HLHS who are about to undergo the operation?

Yes (7)

Table 7

Thematic Analysis of Clinician Feedback

Department (number of providers)	Clinician Feedback (number of mentions)
Pediatric Neuropsychology (2)	Update image of physician (2) Update character facial expressions (1) Describe more forms of “support” (1) Describe more sensory concerns (1) “The image [of the surgeon] may fit the statistical stereotype...”
Nursing (1)	“I love the energy and creativity of it, so different than so much of the literature that goes out...”
Child Life (1)	Acknowledge lack of therapy dog availability (1) “I do wonder if the deep dive pages are on the long side and include an amount of detail that could be overwhelming to parents/caregivers.”
Pediatric Cardiology (3)	Update image of physician (1) Change specific wording (2) Describe role of nursing (1) “I’m very excited to have it as a resource.”
Occupational Therapy (1)	Describe roles of other disciplines (1) Prepare for standing up for the first time (1) “I think it will be a wonderful resource for parents and children going through the Fontan.”

Chapter 6: Discussion and Impact

Discussion

The children's book created through this capstone experience is unlike anything that is currently available to HLHS parents. As discussed in earlier chapters, there is strong evidence supporting the need for psychosocial support for post-Fontan parent groups who have specific educational needs. While this gap in service has been well-established, specific ways of addressing the problem were less clear. The book, *Flynn and Flora Prepare for the Fontan*, took a creative approach to fill this need in an engaging way that supports the bond between parent and child. Overwhelmingly positive feedback was provided by a variety of stakeholders whose input was incorporated throughout revisions of the book. The community support for this tool indicated that it is worth printing and distributing as it is something that has the potential to make a difference in the lives of people affected by HLHS.

Many aspects of *Flynn and Flora* encompassed themes previously identified in the scoping review. While specific aspects of the book format were critiqued, both parents and clinicians agreed overall that it was a helpful way to communicate a wide breadth of information. This idea was reminiscent of Lane et al.'s description of a 'reference guide' (2019). While clinicians and parents both considered the book to be a potentially beneficial resource, there was variation in the type of content they thought should be included, as outlined in chapter 5. This kind of parent-clinician discrepancy was a common trend throughout the literature and may be attributed to differences in lived experience (Arya et al., 2013). Survey responses indicated that parents wanted a combination of both educational and psychosocial resources, which could be conceptualized with the use of the 5-Facet Model outlined in chapter 1 (Rempel et al., 2012). Clinician feedback often included suggestions related to simplifying phrases to avoid

overwhelming parents with information, an idea previously described by Arya et al., (2013). Overall, the content and illustrations for *Flynn and Flora* were designed to acknowledge the complexities of stress in relation to personal and environmental factors identified by Mussato's Family Stress Model and the Parent Stress and Resilience in CHD Model (Lisanti, 2018; Mussato, 2006). The efficacy of this educational tool could ultimately be measured through post-Fontan parent reports of increased knowledge, confidence, parental perception of readiness for discharge, and better coping (Staveski et al., 2016).

Limitations

Certain limitations may have hindered the utility of this educational tool. There was a relatively small participant pool: 39 parents responded to the initial survey and only seven parents actually reviewed the book. Greater participation could have allowed for more diverse perspectives. The parent participants were from a narrow demographic group consisting predominantly of educated, Caucasian mothers who may have had different experiences than individuals with other ethnic and educational backgrounds. The majority of the feedback came from parents who had a child undergo the Fontan operation over five years ago; they may have been influenced by standard procedures, care team roles, and modes of communication that are now outdated and have changed dramatically. This could have made their feedback less applicable to parents who are now preparing for the Fontan. Additionally, the methods utilized for designing the illustrations and incorporating stakeholder feedback were subject to the author's own personal biases.

Mayo Clinic's patient education department used a generator that indicated the finalized version of the book is rated at a grade 7.5 reading level. This assessment was based on tests including the Flesch-Kincaid, Flesch Reading Ease, Gunning Fog, New Dale-Chall, and New

Fog Count. These tests look at different aspects of readability including the number of words per sentence, word length and complexity, and word familiarity. As a general rule of thumb, most health-education materials aim to score at about a 6th grade reading level. In practice, however, most are currently at an eighth to ninth-grade level (Menghini, 2005). While a rating of 7.5 could still make the book less valuable for parents with lower health literacy, it is of note that some of the medical terminology used throughout the book that influenced the reading level would likely be more familiar to this specific parent population. By the time parents read *Flynn and Flora Prepare for the Fontan*, it is expected that they have gone through two prior surgeries with their child and have had greater exposure to complex medical phrases related to this diagnosis.

Impact

This book offers a unique approach to occupation-based educational intervention for families and children with HLHS. The combination of separate child and parent pages allows for clinicians to support parental roles while providing pertinent educational material in an engaging way. Sharing this resource with parents prior to the surgery may empower them by consolidating information about the diagnosis and psychosocial resources all in one place. Based on stakeholder feedback, this resource is expected to be well-received by both care team members and HLHS parents alike.

Steps were made toward printing and disseminating the book to the target population. A meeting was held with one of Mayo Clinic's patient education representatives on 11/4/21. At this meeting the book's potential for printing was discussed. The representative was supportive of this endeavor and said they would work towards printing it and making it available at Mayo Clinic locations. Since many Fontan operations happen outside of Mayo Clinic, however, Mayo Press was contacted to discuss the possibility of publishing the piece to make it more widely

available. Mayo Press has decided to review the book for potential publication in January of 2022 and at that time it will be determined if they have editorial authority to make ongoing updates to the book as needed. Until then, follow up with the patient education department may yield the greatest chances of getting the book printed and distributed.

Chapter 7: Conclusion and Reflection

The book, *Flynn and Flora Prepare for the Fontan*, is intended to be an accessible educational tool for parents and children affected by HLHS. Because this diagnosis is so rare, the specific needs of HLHS families are often overlooked or get lumped into the broader CHD category. Throughout this capstone project, addressing an identified gap in service affecting the post-Fontan parent population within this community involved many pillars of the AOTA's 2025 Vision; a plan which outlines the guiding principles of the profession and emphasizes efficacy, leadership, collaboration, accessibility, and equity (AOTA, n.d.). The specific methods used to develop the book reflect an inclusive approach to maximizing health, well-being, and quality of life for diverse communities (AOTA, n.d.).

The Henrietta Schmoll School of Health at St. Catherine University aims to cultivate socially-responsible leaders through team-oriented healthcare education (St. Catherine University, n.d.). *Flynn and Flora* was created through collaboration with pertinent stakeholders directly affected by HLHS, in either daily life or clinical practice. Feedback from both parents and interdisciplinary team members increased the utility of the book. Cultural inclusivity was at the forefront of the decisions related to the design of the content and illustrations used. As a result, the images and wording are suitable for families of a wide range of ethnic and educational backgrounds. Accessibility of the book will be maximized through both printing and making it available for virtual download. This capstone project reflects the importance of interdisciplinary initiatives central to the university's teachings.

The Department of Occupational Therapy at St. Catherine University strives to prepare students to promote occupational wellbeing while respecting the dignity of every individual (St. Catherine, n.d.). *Flynn and Flora* utilized creative methods to support the daily roles and

occupations of HLHS parents through educational intervention. The content of the book is delivered in a way that validates the lived experiences of these parents and addresses their psychosocial needs in a dignified manner, an approach which is in line with the overall mission of the OT department at this institution. Ultimately, the book was created by utilizing the unique lens of OT to support the long-term outcomes of children with HLHS and their families through education.

Professional Development

This capstone project provided myriad opportunities for professional development. At the start of the capstone experience, a Memorandum of Understanding (MOU) was initially signed by project author, mentors, and capstone advisor to establish an outline for anticipated goals. The goals mainly related to communication, utilization of feedback, and the development of a capstone “product”. Initially this product was expected to involve virtual education modules for parents but shifted toward a children’s book after becoming more aware of existing (and nonexistent) resources available to parents. It was ultimately determined that the book could be a more effective mode for education delivery. This demonstrated the importance of being open and adaptable when creating person-centered interventions. Extensive experience with the IRB approval process was necessary to gather pertinent stakeholder feedback. A nuanced understanding of the challenges faced by families affected by HLHS was needed to approach the affected community to ask sensitive questions about traumatic experiences in a respectful manner. Additionally, the book illustrations required a lot of creativity, thoughtful input, and attention to detail to make them appealing to children and culturally appropriate.

Mayo Clinic provided the necessary connections to make this project possible. Offering access to well-respected leaders within the field which encouraged mindful communication, a

skill which was further challenged by the virtual context required by the ongoing COVID-19 pandemic. With patient education being a core value, Mayo Clinic has cultivated an environment of clinicians willing to participate in interdisciplinary work to support patient outcomes. This collaborative culture allowed for the diversified input that enriched the product. While Mayo Clinic is heavily involved in supporting HLHS families and pushing research initiatives further, few Fontan operations are actually performed here annually. Mayo Clinic's ties to other institutions through the HLHS Consortium provides a network that is expected to support the dissemination of the book and more effectively deliver it to the target population. By publishing and printing *Flynn and Flora*, Mayo Clinic can further exemplify their dedication to patient education by providing needed support to HLHS families in a new and forward-thinking way.

Overall, this multi-faceted project is a unique contribution to the field of OT. The process of creating *Flynn and Flora* honed many professional skills and illuminated both the challenges and rewards of supporting an underserved community. The intention for the use of this book is to empower caregivers to perform their role-related occupations to the best of their ability. While interdisciplinary collaboration is discussed throughout healthcare, it can often be difficult to pinpoint what it actually looks like. This book is a tangible representation of what clinicians can accomplish when they pool their unique knowledge and experiences together. While research indicated the need for post-Fontan parent support, it was difficult to conceptualize what that would actually look like. The twists and turns throughout creating *Flynn and Flora* exemplified the importance of going into projects with an open mind because the final form may be different than the initial vision. The biggest takeaway from this experience was gaining an understanding of how to address complex challenges both personally and professionally; oftentimes there is no way to predict what an end product will actually look like, finding a small place to start and

building onto it from there may be the best approach. These lessons have set me up to confidently begin my career as an OT and have empowered me to continue advocating for underserved communities.

References

- Abernathy, J. (2018). Home monitoring in patients with HLHS: A literature review. *Pediatric Nursing, 44*(2), 68-76.
- American Occupational Therapy Association [AOTA]. (2015). *Occupational therapy and universal design for learning*.
<https://www.aota.org/-/media/corporate/files/aboutot/professionals/whatisot/cy/factsheets/udl%20fact%20sheet.pdf>
- American Occupational Therapy Association [AOTA]. (n.d.). *Vision 2025*.
<https://www.aota.org/AboutAOTA/vision-2025.aspx>
- Azhar, A. S., Zaher, Z. F., Abu-Ouf, N. M., Al-Ata, J., & Alsheblie, S. (2018). Determinants of successful medical education of caregivers of children with congenital heart diseases. *Journal of the Saudi Heart Association, 30*(1), 28–39.
<https://doi.org/10.1016/j.jsha.2017.03.006>
- Cassidy, A., Butler, S., Briend, J., Calderon, J., Casey, F., Crosby, L., . . . Butcher, J. (2021). Neurodevelopmental and psychosocial interventions for individuals with CHD: A research agenda and recommendations from the Cardiac Neurodevelopmental Outcome Collaborative. *Cardiology in the Young, 31*(6), 888-899.
[doi:10.1017/S1047951121002158](https://doi.org/10.1017/S1047951121002158)
- Centers for Disease Control [CDC]. (2020). *Facts About Hypoplastic Left Heart Syndrome*.
<https://www.cdc.gov/ncbddd/heartdefects/hlhs.html>
- Feinstein, J.A., Benson, D.W., Dubin, A.M., Cohen, M.S., Maxey, D.M., Mahle, W.T., ... Martin, G.R. (2012). Hypoplastic left heart syndrome: Current considerations and

- expectations. *Journal of the American College of Cardiology*, 59(1, Suppl.), S1-S42.
doi:10.1016/j.jacc .2011.09.022
- Ferguson, S. (2016). *HLHS Health Journal: New App to Keep Track of Health*.
<https://connect.mayoclinic.org/blog/hlhs/newsfeed-post/hlhs-health-journal-new-app-to-keep-track-of-health-26632e/>
- Ha, D., Hay, M., & Menahem, S. (2018). Educational DVD for parents of children with congenital heart disease - a pilot study. *Journal of Visual Communication in Medicine*, 41(1), 18–23. <https://doi.org/10.1080/17453054.2017.1399792>
- Landry, M., Katers, M., Olson, E., Cern, L., Nelson, T., & Campbell, K. (2019). *Identifying gaps in parental support for families with hypoplastic left heart syndrome*. [Poster]. St. Catherine University.
- Lane, B., Hanke, S. P., Giambra, B., Madsen, N. L., & Staveski, S. L. (2019). Development of a clinician-parent home care education intervention. *Cardiology in the Young*, 29(10), 1230–1235.
<https://doi-org.pearl.stkate.edu/10.1017/S1047951119001318>
- Lee, B. & Koo, H. (2020). Needs for post-hospital education among parents of infants and toddlers with congenital heart disease. *Child Health Nursing Research*, 26(1), 107–120. <https://doi-org.pearl.stkate.edu/10.4094/chnr.2020.26.1.107>
- Lisanti A. J. (2018). Parental stress and resilience in CHD: a new frontier for health disparities research. *Cardiology in the young*, 28(9), 1142–1150.
<https://doi.org/10.1017/S1047951118000963>

Mayo Clinic. (n.d.). *Hypoplastic left heart syndrome care at Mayo Clinic*.

<https://www.mayoclinic.org/diseases-conditions/hypoplastic-left-heart-syndrome/care-at-mayo-clinic/mac-20350608>

Meakins, L., Ray, L., Hegadoren, K., Rogers, L. G., & Rempel, G. R. (2015). Parental vigilance in caring for their children with hypoplastic left heart syndrome. *Pediatric nursing, 41*(1), 31–50.

Mended Little Hearts. (n.d.). *What I need as a Fontan parent: From diagnosis to future*.

<https://mendedhearts.org/needs-fontan-parent-diagnosis-future/>

Menghini, K. (2005). Designing and evaluating parent educational materials. *Advances in Neonatal Care, 5*(5), 273-283. doi: 10.1016/j.adnc.2005.07.003.

Mussatto, K. (2006). Adaptation of the child and family to life with a chronic illness. *Cardiology in the Young, 16*(S3), 110-116. doi:10.1017/S104795110600103X

National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC). (n.d.). *Our network*. <https://www.npcqic.org/our-network>

Ni, Z., Chao, Y., & Xue, X. (2016). An empowerment health education program for children undergoing surgery for congenital heart diseases. *Journal of Child Health Care, 20*(3), 354–364. <https://doi.org/10.1177/1367493515587057>

Ni, Z. H., Lv, H. T., Ding, S., & Yao, W. Y. (2019). Home care experience and nursing needs of caregivers of children undergoing congenital heart disease operations: A qualitative descriptive study. *PloS one, 14*(3), e0213154.

Nieves, J. A. (2017). Interstage home monitoring after newborn first-stage palliation for hypoplastic left heart syndrome: Family education strategies. *Critical Care Nurse, 37*(2), 72–88. <https://doi-org.pearl.stkate.edu/10.4037/ccn2017763>

Norton Children's. (2020). *COVID-19 update*.

<https://nortonchildrens.com/news/covid-19-implications-for-children-and-adults-with-congenital-heart-disease/>

Pundi, K., Johnson, J., Dearani, J., Pundi, K., Li, Z., Hinck, C., Dahl, S... Cetta, F. (2015).

40-year-follow-up after the Fontan operation. *Journal of the American College of Cardiology*, 66(15), 1700–1710. <https://doi.org/10.1016/j.jacc.2015.07.065>

Rempel, G. R., Rogers, L. G., Ravindran, V., & Magill-Evans, J. (2012). Facets of parenting a child with hypoplastic left heart syndrome. *Nursing research and practice*, 2012, 714178. <https://doi.org/10.1155/2012/714178>

Sisters By Heart. (n.d.). *About us*. <https://www.sistersbyheart.org/>

Sood, E., Jacobs, JP., & Marino, BS. (2021a). *Optimising neurodevelopmental and psychosocial outcomes for survivors with CHD: a research agenda for the next decade*. *Cardiology in the Young* 31: 873–875. doi: 10.1017/S1047951121002171

Sood, E., Lisanti, A. J., Woolf-King, S. E., Wray, J., Kasparian, N., Jackson, E., Gregory, M. R., Lopez, K. N., Marino, B. S., Neely, T., Randall, A., Zyblewski, S. C., & Brosig, C. L. (2021b). Parent mental health and family functioning following diagnosis of CHD: a research agenda and recommendations from the Cardiac Neurodevelopmental Outcome Collaborative. *Cardiology in the young*, 31(6), 900–914. <https://doi.org/10.1017/S1047951121002134>

Sood, E., Karpyn, A., Demianczyk, A. C., Ryan, J., Delaplaine, E. A., Neely, T., Frazier, A. H., & Kazak, A. E. (2018). Mothers and fathers experience stress of congenital heart disease differently: Recommendations for pediatric critical care. *Pediatric critical care medicine: A journal of the Society of Critical Care Medicine and the World*

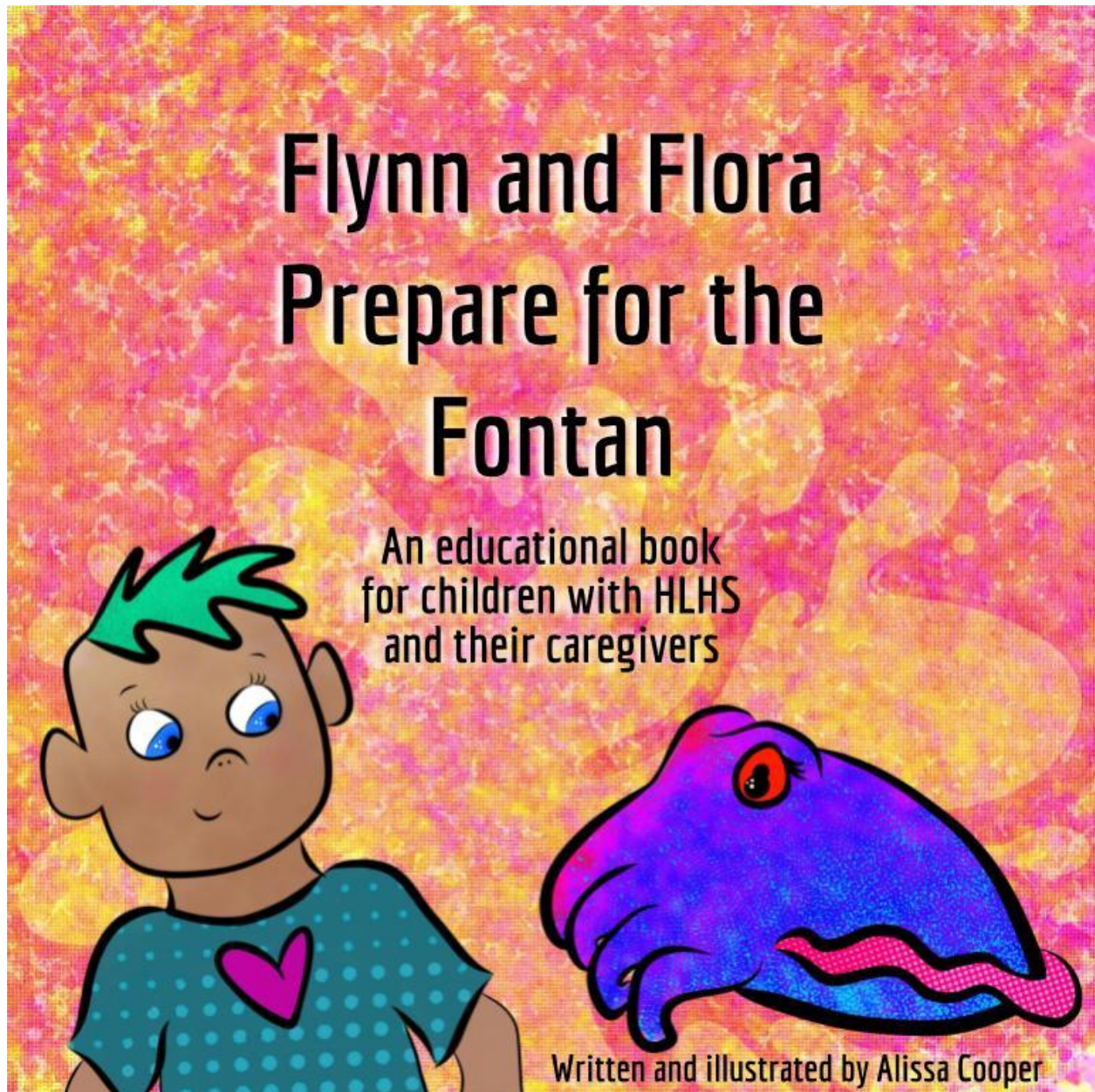
- Federation of Pediatric Intensive and Critical Care Societies, 19(7), 626–634.*
<https://doi.org/10.1097/PCC.0000000000001528>
- Staveski, S. L. (2014). An Evaluation of the Parent Education Discharge Instruction Program for Care of Children After Cardiac Surgery in Southern India. [Doctoral Project].
- Staveski, S. L., Parveen, V. P., Madathil, S. B., Kools, S., & Franck, L. S. (2016). Nurse and parent perceptions associated with the Parent Education Discharge Instruction Programme in southern India. *Cardiology in the Young, 26(6), 1168–1175.*
<https://doi-org.pearl.stkate.edu/10.1017/S1047951115002164>
- Strong, S., Rigby, P., Stewart, D., Law, M., Letts, L., & Cooper, B. (1999). Application of the Person-Environment-Occupation Model: A practical tool. *Canadian journal of occupational therapy. Revue canadienne d'ergotherapie, 66(3), 122–133.*
<https://doi.org/10.1177/000841749906600304>
- St. Catherine University. (2017). Doctor of Occupational Therapy Entry Level Program Student Handbook (p. 19).
<https://stkate.app.box.com/s/pw8figymfggtr467lkom0lxm7waq4gas>
- St. Catherine University. (n.d.). *Henrietta Schmoll School of Health.*
<https://www.stkate.edu/academics/hssh>
- St. Catherine University. (n.d.). *Occupational therapy.*
<https://www.stkate.edu/academics/academic-programs/gc-occupational-therapy-entry-level>
- U.S. News & World Report. (2019). *U.S. News Releases 2021-22 Best Hospital Rankings.*
<https://www.usnews.com/info/blogs/press-room/articles/2021-07-27/us-news-releases-2021-22-best-hospitals-rankings>

Wray, J., Brown, K., Tregay, J., Crowe, S., Knowles, R., Bull, K., & Gibson, F. (2018).

Parents' experiences of caring for their child at the time of discharge after cardiac surgery and during the postdischarge period: Qualitative study using an online forum. *Journal of Medical Internet Research*, *20*(5), e155.

<https://doi.org/10.2196/jmir.9104>

Appendix A: Flynn and Flora Prepare for the Fontan



About the book

This book was created by an occupational therapy student from St. Catherine University in partnership with Mayo Clinic. It is intended to be used for the education and empowerment of parents, caregivers, and children affected by Hypoplastic Left Heart Syndrome (HLHS). For specific medical advice, diagnoses, and treatment, consult your child's doctor.

Adults should read through this book independently before reading to kids. The Deep Dive pages are dedicated to helping parents prepare for surgery and talk to their child about the Fontan operation with confidence.

Information provided by:

National Pediatric Cardiology Quality Improvement Collaborative,
Sisters by Heart, and Mended Little Hearts

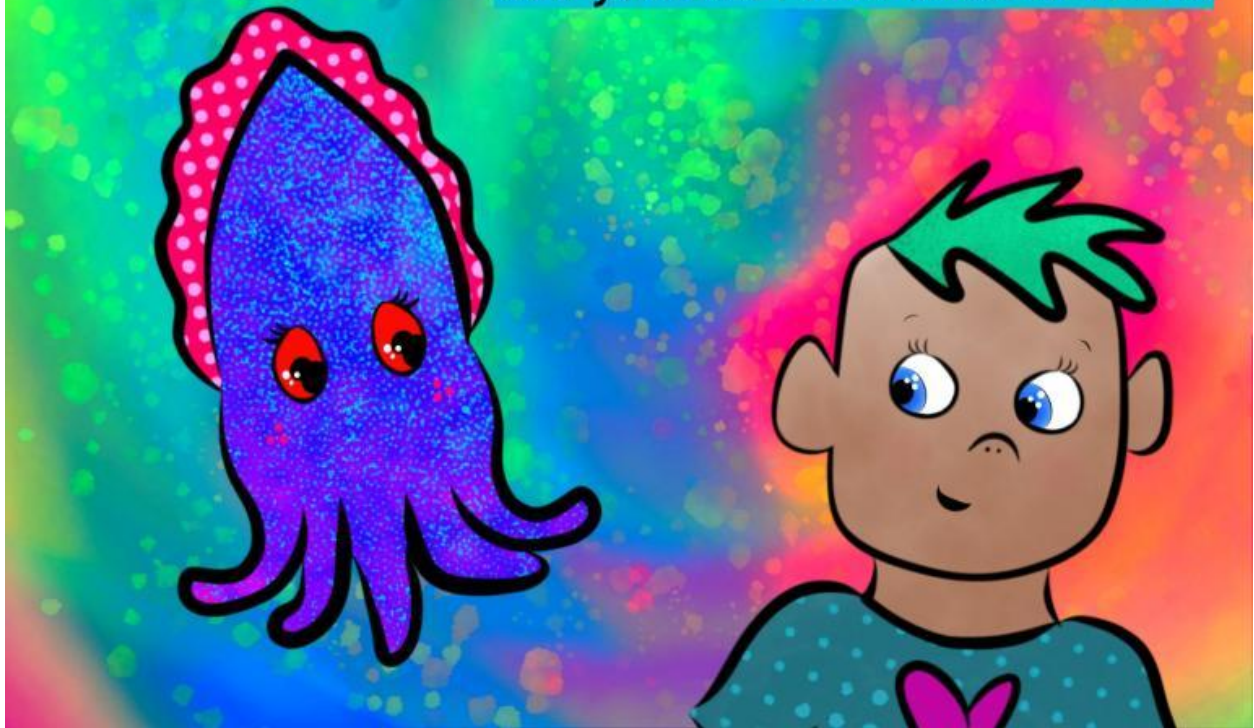
A special thanks to:

Adam Cassidy (Ph.D., L.P.), Katie Campbell (Ph.D.),
Paula Rabaey (Ph.D. OTR/L), Erica Sood (Ph.D.), and
Christina DeShaw (J.D) - heart mom ♡

Meet Flynn and Flora. Flynn was born with HLHS,
just like you!

Flora is his best friend. She is a cuttlefish. Flora
has never heard of HLHS before.

Can you tell Flora what HLHS is?



Deep Dive: Defining HLHS

The previous page is intended to have children practice talking about their diagnosis. Understanding what it is helps justify the need for the operation and encourages self-advocacy skills.

Here is one way to phrase it:

“Everyone’s body is different. Most babies are born with a heart that uses 2 sides. But some babies, like you, are born with a heart that uses 1 side.”

Flynn had two heart surgeries when he was a tiny baby. Now he's getting ready for his third one.

This is called the Fontan operation.

Flynn needs surgery to help make his heart stronger.

Can you flex your muscles like Flynn?



Deep Dive: Preparing for Surgery

Experience from previous surgeries can be good preparation for the Fontan. One thing that makes this operation different, however, is the age of your child. They are likely old enough now to understand a bit about their condition and remember more about the hospital experience. This means that as a caregiver, you can help prepare them beforehand and encourage them to be an active participant throughout the healing process.

Preparation tips:

- Talk
 - All kids process things differently. For some, talking about the operation only a few days beforehand can minimize anxiety leading up to the surgery date.
 - If your child asks something that you don't have an answer to, you can always say "that's a good question, let's ask the doctor together".
- Play
 - Use medical play through books, TV shows, and apps to acquaint your child with medical experiences.
- See
 - Contact Child Life Services at the hospital in advance to see if they have any materials to send home like pictures of the facility, video tours, and medical equipment they'll encounter.

(NPC-QIC, n.d.)

Did you know that your heart is a muscle? When it flexes, it pumps blood through your body. This gives you the strength to run and play.

Sometimes the heart has to work really hard!



The Fontan operation makes it easier for the heart to pump blood.

Deep Dive: The Fontan

The Fontan operation reconstructs the heart in a way that makes it more efficient for oxygen to reach muscles of the body. Before this surgery, your child's heart pumps a mixture of high- and low- oxygen blood. The Fontan reroutes blood flow so that the heart can pump more high-oxygen blood out to the body. This is done by connecting blood vessels from the lower body directly to the lungs.

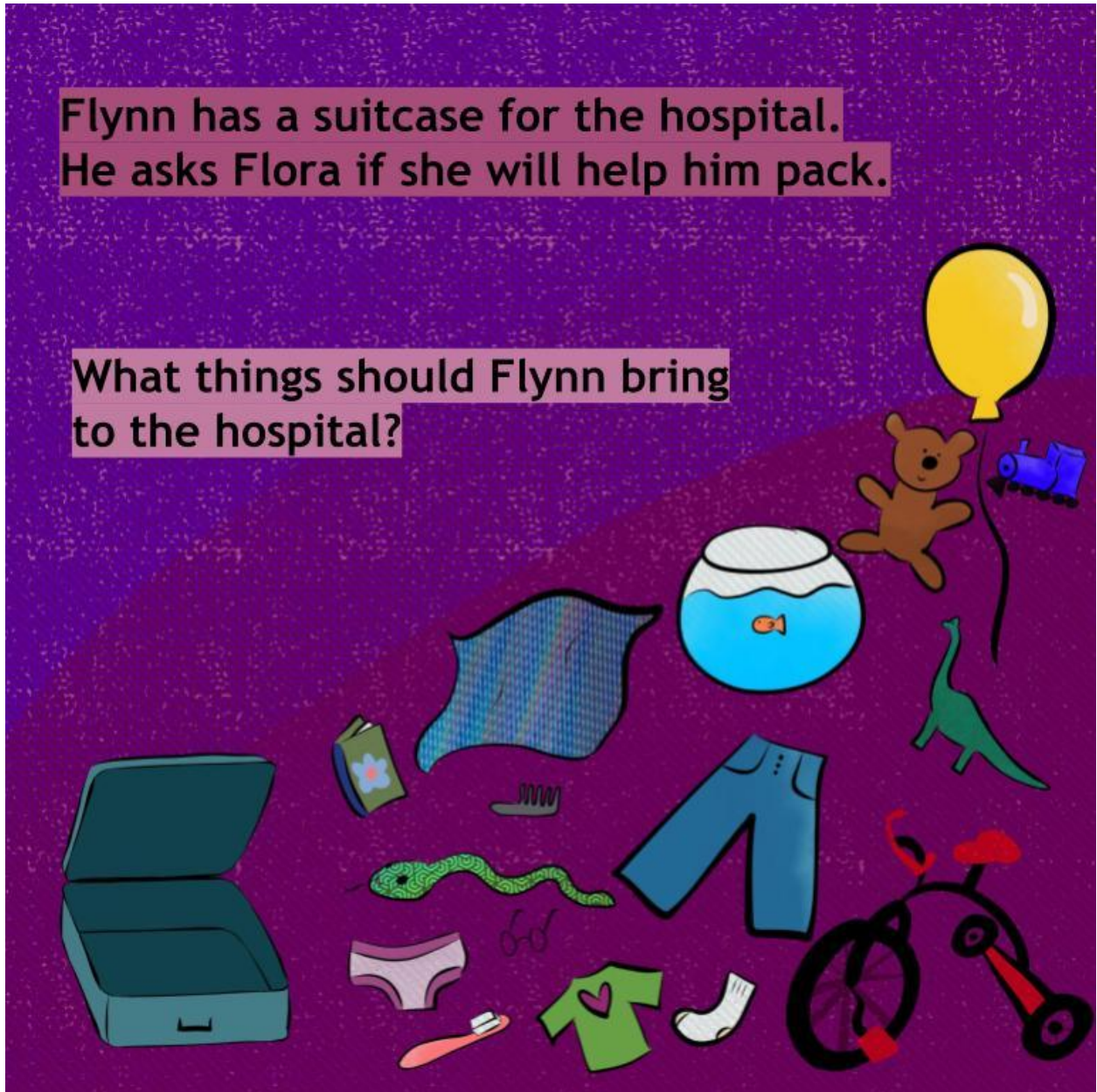
When describing the Fontan, try using words like “help” and “make stronger” instead of “sick” or “broken”. You can remind your child that their heart works extra hard because it uses 1 side instead of 2 sides. Explain that this operation should give them energy to do things like run without getting as tired and play longer on the playground.

Pointing to veins in the hand is one way to show them how blood moving through the body is pumped by the heart.

(Mayo Clinic, 2019; NPC-QIC, n.d.)

Flynn has a suitcase for the hospital.
He asks Flora if she will help him pack.

What things should Flynn bring
to the hospital?



Deep Dive: Packing

Fontan operation is usually followed by a 1-2 week hospital stay. It may end up being longer or shorter, depending on what your child needs. To help your child feel safe and comfortable during this time, make sure to pack some of their favorite items such as:

- Stuffed animals
- Blankets, pajamas, and slippers
- Movies, games, and headphones
- Familiar utensils, sippy cups, and plates
- Night lights
- Snacks (only give as advised)

Choose clothing with snaps or buttons rather than zippers or Velcro so that wires and tubes can fit through the holes.

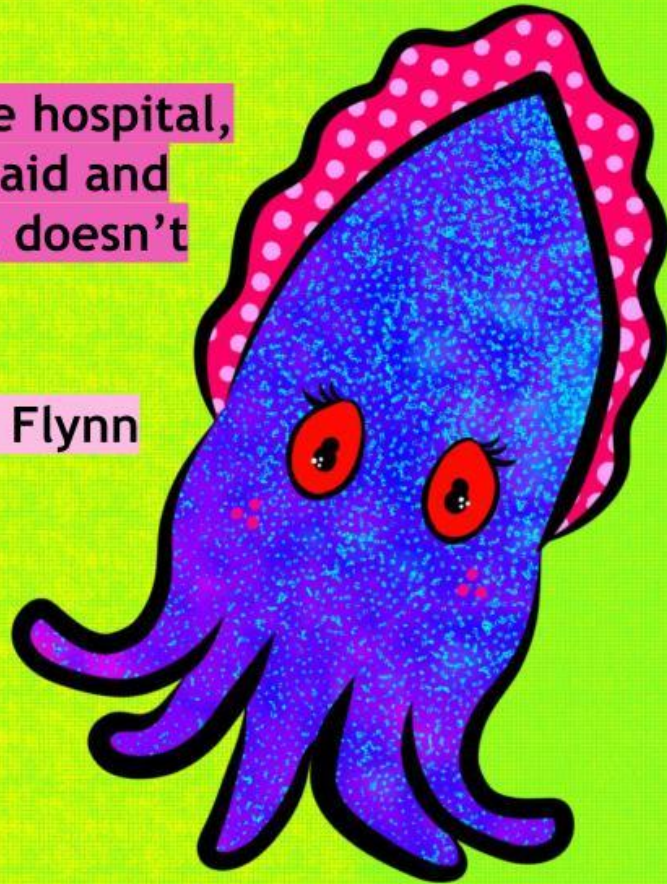
Packing is a good opportunity to get siblings involved!

(Mended Little Heart Guide, n.d.)

On the morning of surgery, Flynn wakes up feeling brave. Can you tell me about a time when you were brave?

When he gets to the hospital, he starts to feel afraid and begins to cry. Flora doesn't know how to help!

How can Flora help Flynn feel calm?



Deep Dive: Coping

Parents can encourage healthy coping strategies such as:

- Hugging a favorite stuffed animal
- Doing deep breathing exercises
- Closing eyes and counting to 10
- “Taking 5” to cool down in a safe spot
- Listening to music
- Playing with fidget toys

Try to provide reassurance and let your child know that it’s okay to be afraid:

- “Sometimes I feel afraid too. What’s something you can do when you’re afraid?”
- “I’ll be right there with you before the operation.”
- “You will be safe with the doctor, they want to take good care of you.”

(NPC-QIC, n.d.)

Flora tells Flynn to take 3 deep breaths. Will you try it with him? Pretend you're blowing bubbles!

Flynn feels very calm now, how do you feel?



Deep Dive: Behaviors

Many children show an increase in behaviors like temper tantrums and thumb sucking around hospitalization. This is normal and temporary! Consider which challenges are the most important and which you can let go of during this time.

Remember to shower them with positive verbal and physical attention.

Use visual tools like sticker charts to map progress and celebrate the small steps toward getting home. Beads of Courage is a program available at many hospitals - it provides a visual way to track milestones along the care journey.

(NPC-QIC, n.d.)

Deep Dive: The Care Team

This is an opportunity to familiarize yourself and your child with the people who will be involved in their care at the hospital. Consider looking online or asking the hospital for headshots of the care team in advance.

Effective communication with your team is critical. Find ways to establish and maintain open lines of communication, whether it be in-person or virtual. Being included in daily rounds is one way parents can feel involved in their child's recovery. Remember that they are there to help you, don't be afraid to let them know what you need.

Frequent shift and staffing changes can make it difficult to keep track of everyone entering and exiting the hospital room. It can also be draining to answer many of the same questions for each provider; if you or your child feel overwhelmed by this, talk to the care team about minimizing intrusions and creating more opportunities for your child to rest.

(Landry et al., 2021; Mended Little Hearts, n.d.)

Deep Dive: Pre-Op

Distracting kids while they're getting an IV placed can minimize the stress and pain of the procedure. Consider implementing any of the following strategies if necessary:

- Singing songs
- Counting
- Blowing bubbles
- Using a tablet or toy

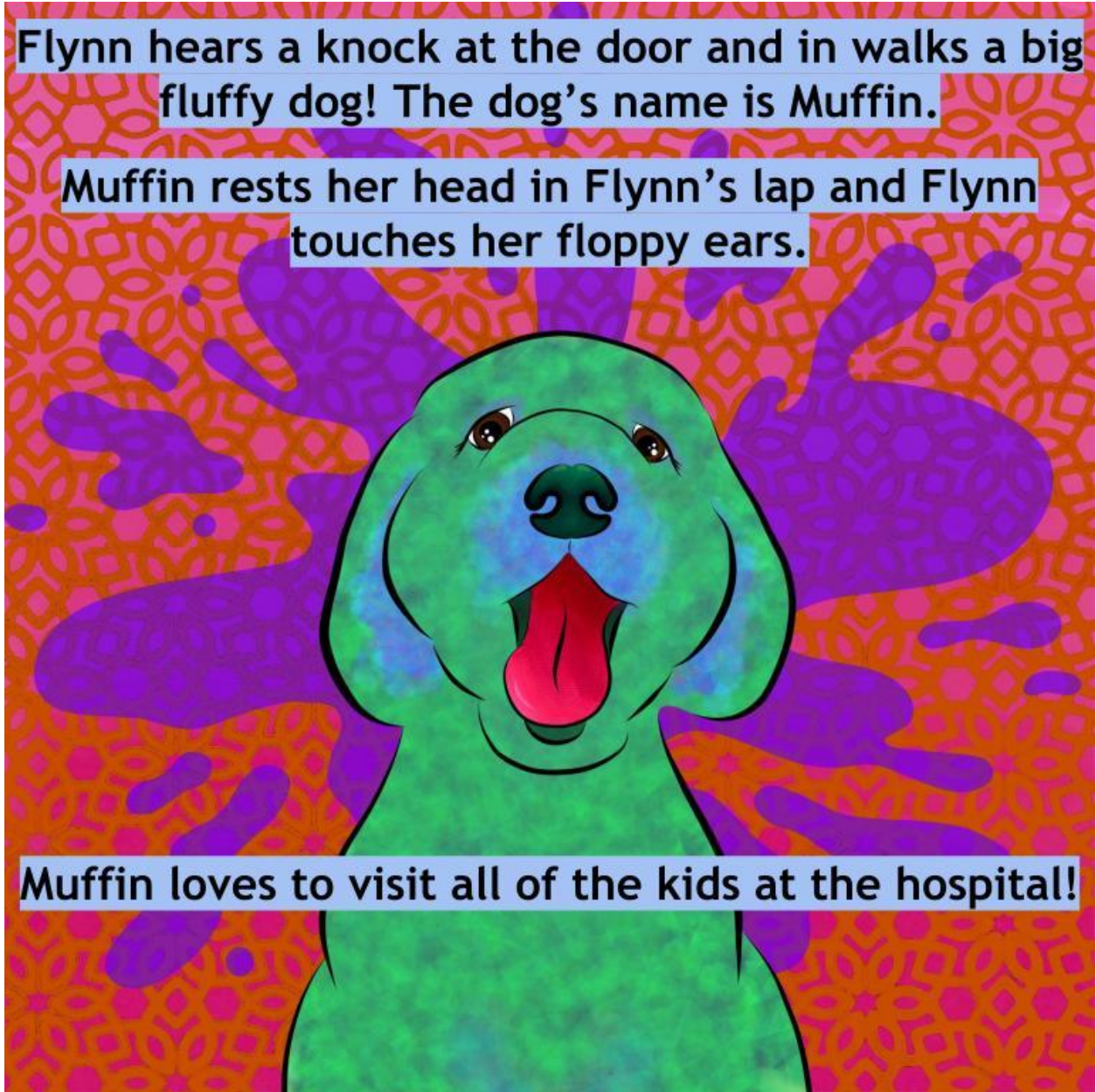
Saying goodbye to your child before they head to the operating room can be difficult. Remind them that you will be right outside and waiting for them when they wake up.

(Burns-Nader, Atencio, & Chavez, 2016)

Flynn hears a knock at the door and in walks a big fluffy dog! The dog's name is Muffin.

Muffin rests her head in Flynn's lap and Flynn touches her floppy ears.

Muffin loves to visit all of the kids at the hospital!



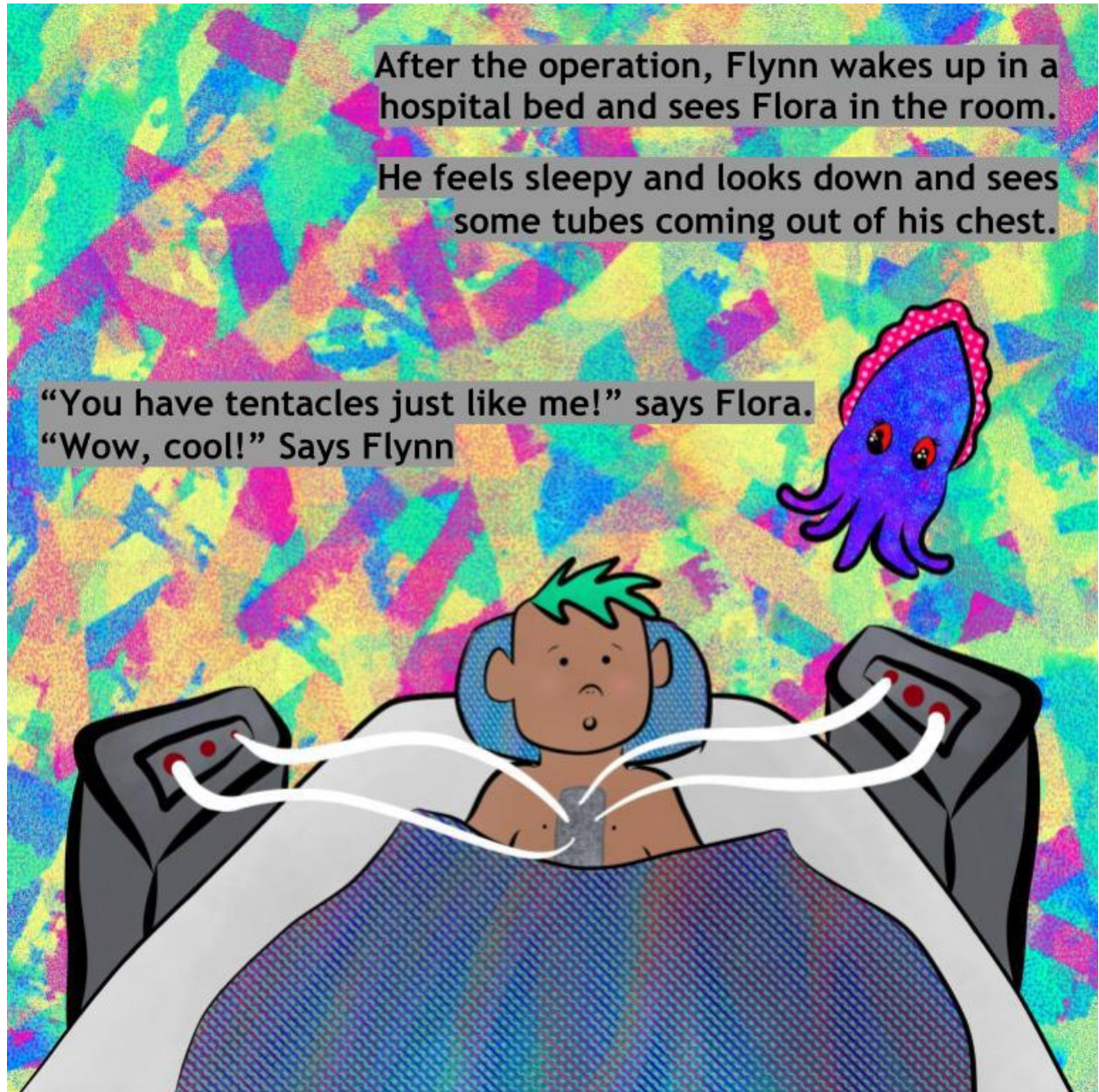
Deep Dive: Therapy Dogs

Therapy dogs can be a great tool to help kids relax. If your child is having a difficult time with certain procedures, see if you can arrange for the hospital's therapy dog to be present during that time.

Unfortunately, these pets might not always be available and you may need to utilize other techniques to encourage your child to cooperate. Being consistent with the situations in which you make commands and give them options is one way to prepare for this potential challenge. Giving kids choices when possible helps give them a feeling of control:

- “Would you like your blood pressure taken on your left or right arm?”
- “Would you like to take your medicine with water or juice?”

(Mended Little Hearts, n.d.; NPC-QIC, n.d.)



Deep Dive: Waking Up After Surgery

After surgery it can be scary for kids to see tubes, wires, and lines covering their body. The tubes remove air and fluid from the space between the lungs and the chest wall. Pulling on them can lead to complications so it is important to remind kids that the tubes help them breathe and need to stay in place.

Be mindful of your child's sensory needs in the hospital. They may feel overstimulated by frequent beeps and flashing lights on the monitors around their bed. Remember to use headphones as needed and dim the lights to create a more relaxing environment. Keeping the lights on during the day and off at night can help them stay oriented and establish a regular sleep schedule. You can communicate any sensory needs to the bedside care team.

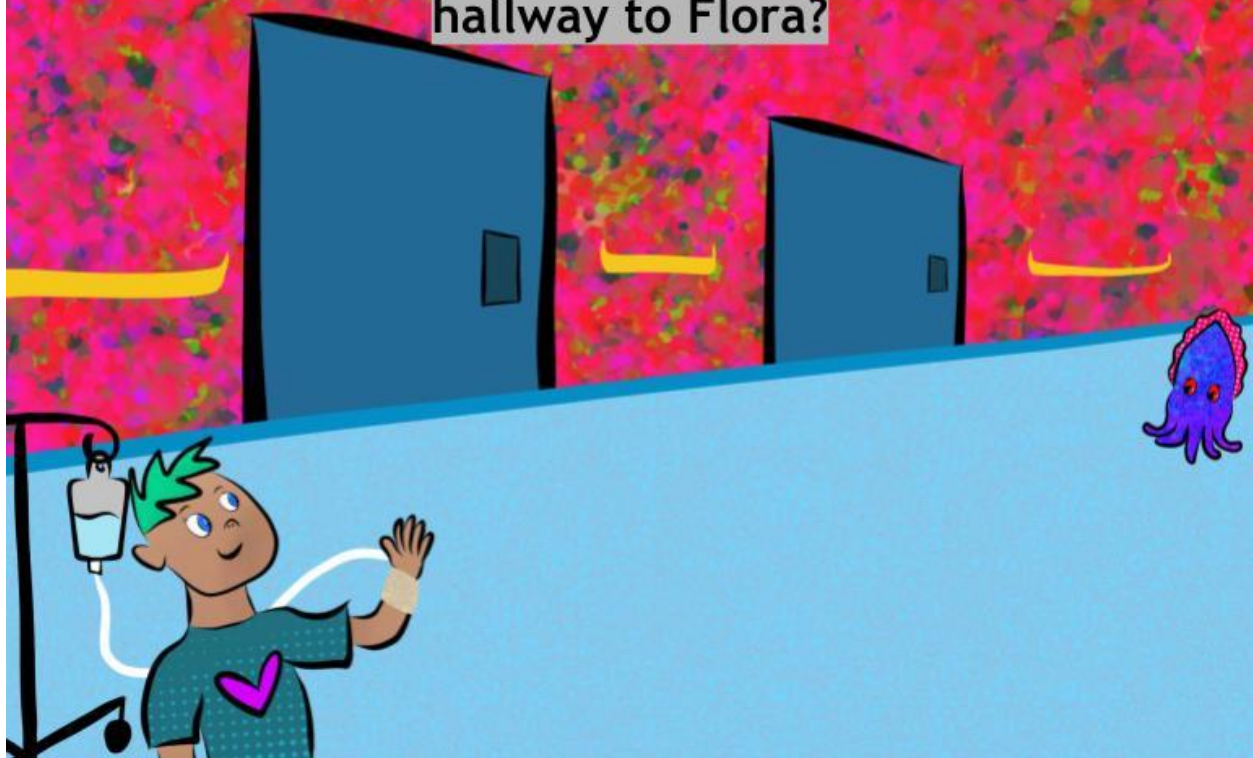
ICU nurses are heavily involved throughout the Fontan recovery process. Their primary tasks include drawing blood, medication administration, pain management, and implementing necessary dietary changes.

(Memorial Sloan Kettering Cancer Center, 2021; Taylor, Bates, & Kipps, 2018)

Flynn's physical therapist helps him get out of bed for the first time since the operation.

He feels wobbly but he knows he can ask for help if he feels like he's going to fall.

Do you think he can walk all the way down the hallway to Flora?



Deep Dive: Post-Op

Physical therapists will help your child walk safely when advised. They usually encourage kids to get out of bed once they are medically stable, despite having attached lines. Getting up and moving as soon as possible aids in the recovery process.

Standing up after the Fontan operation can be intimidating for kids; they may be woozy from medication and their body may feel very different. Remind them that this is because their body is healing and provide them with any necessary reassurance.

(Memorial Sloan Kettering Cancer Center, 2021)

In order to get better and go home, Flynn knows he needs to take his medicine - just like he did before the operation.

Do you take any medicine?



Deep Dive: Recovery

After the operation, your child will have around-the-clock care with frequent medications to help their heart and improve blood flow.

What we eat and drink have an effect on circulation and the way our bodies heal. Your child's food and liquid intake will be monitored closely after the Fontan operation to help ensure the best possible outcome. The doctor may put them on a special diet for this reason. If eating is difficult for your child, talk with the occupational therapist and speech therapist about strategies for mealtime and swallowing.

In order to be an effective advocate for your child during this time, remember to take care of your own health. Take regular breaks and leave the hospital room, eat regular meals, sleep when possible, and allow yourself to experience your emotions; **It's okay to admit when you're not okay.** The care team understands that this is a very difficult time for parents. The hospital social worker should be able to help connect you with a support group or other resources.

(Childrens Minnesota, 2021; Mended Little Hearts, n.d.; Ozbek & Tanrikulu, 2019)

Flynn is having a hard time thinking of something fun to do in his hospital room.

Quick, point to something you'd like to play with while in bed!



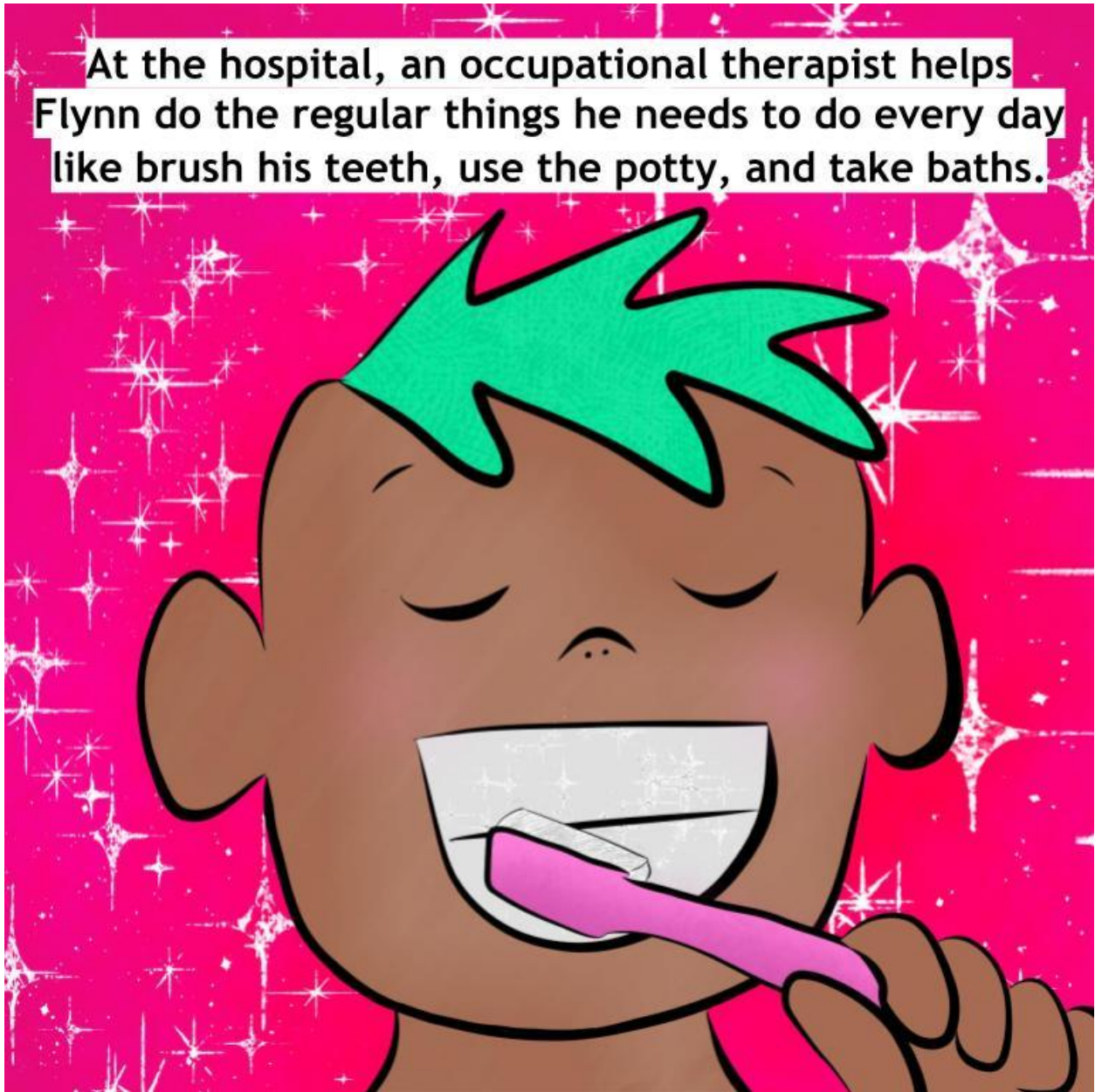
Deep Dive: Play

At the hospital, ask your child's occupational therapists and certified Child Life specialists about finding ways to play that reduce fear, anxiety, and pain while adhering to sternal precautions. Kids can often take part in many of their favorite activities with adaptations like lap desks, card holders for playing games, and grippers for markers or paint brushes. The hospital may also have resources like music therapy to promote therapeutic play.

Sometimes kids need to be motivated by toys and various activities to get out of bed. If possible, introduce your child to the hospital's playroom before surgery as an incentive. Therapy dogs are another great way to encourage kids to move when needed.

(NPC-QIC, n.d.)

At the hospital, an occupational therapist helps Flynn do the regular things he needs to do every day like brush his teeth, use the potty, and take baths.



Deep Dive: Ongoing Care

Your child may be involved in a variety of different therapy services at the hospital throughout their recovery. There are many ways these types of services can continue to help your child even after discharge. Children with HLHS often experience behavioral and emotional challenges throughout life. Early intervention through various therapies can help set your child up to be successful at school and beyond. Talk to your child's care team if you are interested in a referral to a range of outpatient services including:

Occupational therapy

- Skills related to activities of daily life: feeding, thinking, playing, hand-eye coordination, sensory needs, and fine motor strength
- Education and training on adaptive equipment
- Postural control and positioning

Physical therapy

- Abnormal movement patterns
- Muscle weakness or rigidity, fatigue
- Delays in gross motor skills like running and playing

Speech therapy

- Expressive and receptive language skills
- Swallowing and oral aversion

(Cincinnati Children's, 2021)

After a few weeks in the hospital,
Flynn feels strong and is ready to
return home.



Deep Dive: Post-Fontan Monitoring

Specific follow-up details are determined at the time of discharge. Doctors may want to see your child after a week or two to check on their healing progress. This is often followed by regular 6 month check ups. Your child will return home with sternal precautions - these may be more complex than those following previous operations since the child is older and more mobile.

As your child continues to recover from the Fontan, it is important to be aware of warning signs that warrant medical counsel such as:

- Blue coloration of lips or nails
- Loss of appetite or vomiting
- Changes in breathing (too fast or increased difficulty)

You know your child best. If something just doesn't seem quite right, trust your instincts as a parent and reach out for help.

**Flynn feels better now that he has recovered
from surgery.**

He's excited to play with his friends!



Deep Dive: Parent Wellbeing

When you return home with your child, you should feel proud of the important role you played during their hospitalization. Supporting them through this journey requires an extreme amount of energy and patience. Your child is not the only one who will need time to heal afterwards.

Adjusting to being back home can be challenging for parents. Returning to the role of primary caregiver after continuous clinician involvement may feel abrupt and jarring. It may take some time to get back into your normal routines again - hospitalization may change patterns related to sleep, mealtime, and medication.

These stressors highlight the importance of establishing a solid network of support. The following pages have information about the wide range of resources available to HLHS parents.

Parent Resources

Taking care of yourself

- Returning to the hospital for the Fontan operation may trigger emotions from past trauma related to your child's condition. Physical and mental self-care is an essential part of preparing for this operation so that you can be a strong advocate for your child.
- Leading up to the operation, try to spend time with supportive family and friends and establish healthy routines that include exercise, mindful eating, and rest.
- Ask the hospital about any mental health resources available to you as a caregiver (such as parent groups, peer mentor programs, massages, etc.).
- Visit kidshealth.org/en/parents and search for "Taking Care of You: Support for Caregivers" for tips on avoiding burnout.
- Book of Hope - HLHS Stories of Hope and Inspiration from Parents and Patients. Free copies available at empoweredbykids.com

Connecting with others

- Sisters by Heart - sistersbyheart.org - Offers community support and provides Fontan care packages for children.
 - "Linked By Heart" feature helps families connect regionally
- Mended Little Hearts - mendedlittlehearts.org - Support, education, and awareness for families affected by CHD.
- Conquering CHD - conqueringCHD.org - Offers "State Chapters" to connect with local families.
- Facebook has many HLHS parent communities - Find an appropriate group using search terms like "HLHS parent" and "CHD parent".
- Cardiac Neurodevelopmental Outcomes Collaborative (CNOC) - cardiacneuro.org - Partner with healthcare professionals to support neurodevelopmental research initiatives.

Additional Preparations

Housing

- If you will need support with this during hospitalization, contact the hospital social worker for a referral to the Ronald McDonald House or any hospital-specific programs.
- Hotels often provide lower rates for families in need of housing for a hospital-related stay.
- Ask your hospital if they offer parent sleeping rooms and if you need to sign up in advance to reserve one.

Helpful Apps

- Headspace - Guided Meditation and Mindfulness
- Mindfulness Daily
- Baby Connect - Tracks children's medications

Talking to Siblings

- SistersByHeart.org - Go to "News/Resources", select "Practitioner Posts" and scroll down to "Helping Siblings Adjust, Cope, and Thrive".
- Child Life offers on- and off-site sibling support.

Resources for Kids

Websites

- Therapeutic toys and accessories: ChildLifeMommy.com
- Anesthesia: Visit kidshealth.org/en/parents, search for “Preparing your child for anesthesia”
- Surgery: Visit kidshealth.org/en/parents, search for “Preparing your child for surgery”
- Contact the hospital’s Child Life team for support with preparation and tours prior to surgery.

Other books

- *At the Hospital* by Carron Brown (A Shine-A-Light book)
- *My Brother Needs an Operation* by Anna Marie Jaworski
- *Super Heart Hero* by Samantha Kelly
- *Thump! Ouch! Marcus Gets Hurt* a book about pain management by SpellBound

TV

- Doc McStuffins

Mindfulness apps

- For younger children: Breathe, Think, Do with Sesame Street
- For older children: Stop, Breathe & Think Kids

References

- Burns-Nader, S., Atencio, S., & Chavez, M. (2016). Computer tablet distraction in children receiving an injection. *Pain Medicine, 17*(3), 590-595. <https://doi.org/10.1111/pme.12877>
- Children's Minnesota. (2021). *Hypoplastic Left Heart Syndrome: The Fontan procedure*. <https://www.childrensmn.org/educationmaterials/parents/article/17716/hypoplastic-left-heart-syndrome-surgery-the-fontan-procedure/>
- Cincinnati Children's. (2021). *Occupational Therapy for pediatric heart patients*. <https://www.cincinnatichildrens.org/patients/child/encyclopedia/treat/ot>
- Landry, M., Katers, M., Olson, E., Cern, L., Nelson, T., & Campbell, K. (2021). Identifying gaps in parental support for families of children with hypoplastic left heart syndrome. *Cardiology in the Young, 1-8*. doi: 10.1017/S1047951121001736
- Memorial Sloan Kettering Cancer Center. (2021). *Staying active before and after surgery for pediatric patients*. <https://www.mskcc.org/cancer-care/patient-education/staying-active-peds>
- Mended Little Hearts. (n.d.). *Four on the Floor*. <https://mendedhearts.org/story/four-on-the-floor/>
- Mended Little Hearts. (n.d.). *Mended Little Heart Guide*. <https://mendedhearts.org/toolsresource/mh-and-mlh-heartguides/>
- National Pediatric Cardiology Quality Improvement Collaborative [NPC-QIC]. (n.d.). *Fontan hospitalization bulletin*. <https://www.npcqic.org/tools-resources>
- National Pediatric Cardiology Quality Improvement Collaborative [NPC-QIC]. (n.d.). *Preparing for Fontan bulletin*. <https://www.npcqic.org/tools-resources>
- National Pediatric Cardiology Quality Improvement Collaborative [NPC-QIC]. (n.d.). *Raising a toddler bulletin*. <https://www.npcqic.org/tools-resources>
- Ozbek, B., & Tanrikulu, N. (2020). A Simple Predictive Factor for Mortality in Fontan Surgery: Serum Hypo-Osmolality. *Brazilian journal of cardiovascular surgery, 35*(2), 155-159. <https://doi.org/10.21470/1678-9741-2019-0325>
- Sisters By Heart. (n.d.). *Guides and toolkits*. <https://www.sistersbyheart.org/guides-toolkits-nd>
- Taylor, A., Bates, K., & Kipps, A. (2018). Variability in paediatric cardiac postoperative chest tube management. *Cardiology in the Young, 28*(12), 1471-1474. doi:10.1017/S104795111800152X
- Zentner, D., Celermajer, D. S., Gentles, T., d'Udekem, Y., Ayer, J., Blue, G. M., Bridgman, C., Burchill, L., Cheung, M., Cordina, R., Culnane, E., Davis, A., du Plessis, K., Eagleson, K., Finucane, K., Frank, B., Greenway, S., Grigg, L., Hardikar, W., ... Wood, A. (2020). Management of people with a Fontan circulation: A cardiac society of Australia and New Zealand position statement. *Heart, Lung and Circulation, 29*(1), 5-39. <https://doi.org/10.1016/j.hlc.2019.09.010>

Appendix B: Mayo Clinic Quality Improvement Memo*Memo*

Date: 8/24/2021
From: Mayo Clinic Institutional Review Board
Re: A Virtual Educational Intervention for Parents of Children with HLHS
To: Adam R. Cassidy, PhD, LP, ABPP

The Mayo Clinic Institutional Review Board (IRB) acknowledges that based on the responses submitted for this new activity through the Mayo Clinic Quality Improvement Wizard tool, and in accordance with the Code of Federal Regulations, 45 CFR 46.102, the above noted activity does not require IRB review.

Other Federal, State and local laws and/or regulations may apply to the activity. This activity may be reconsidered for submission to the IRB if any changes are made.

The Project Leader is responsible for the accuracy and reliability of the information submitted through the Quality Improvement Wizard tool, for following all applicable Federal, State and local laws and/or regulations, and is also responsible for submitting research studies to the IRB when required.

Retain either a paper or electronic copy for your records.

Your responses to the Quality Improvement Wizard, listed below, indicate that the project is a Quality Improvement activity not requiring IRB review.

1. Does the project involve the prospective evaluation of a drug, device or clinical procedure that is not currently approved by the FDA for general use (including "off-label" indications)? **NO**
2. Has the project received funding (e.g. federal, industry) to be conducted as a human subjects research study? **NO**
3. Will any project activities take place outside of Mayo Clinic? **NO**
4. Does the project involve prospective assignment of patients to different procedures or therapies based on a predetermined plan such as randomization? **NO**
5. Will the project occur regardless of whether individuals conducting it may benefit professionally from it? (If you couldn't publish would you still do it?) **YES**
6. Is this project designed with the intent to contribute to generalizable knowledge? In other words, is the primary intent to contribute to the field of study and benefit other researchers? **NO**
7. Is the primary intent of the project to specifically improve an institutional process with the intent of the conclusions to be most directly applicable to Mayo Clinic? **YES**
8. Will patients or personnel be exposed to additional discernible risks or burdens beyond those of standard of care? **NO**

Should you have questions regarding the outcome of this submission, please contact the IRB Knowledge and Navigation through the Research Service Center at 6-4000

[Mayo Quality Academy](#) provides quality improvement education across the enterprise.

Resources for publication of quality improvement projects may be found at:
[Office of QI Scholarship >> SQUIRE](#) (Standards for Quality Improvement Reporting Excellence)

Appendix C: Post-Fontan Parent Survey

11/22/21, 1:22 PM

Post-Fontan Parent Survey

Post-Fontan Parent Survey

Developing educational materials for parents of children with HLHS

1. This survey is designed for post-Fontan parents of children with HLHS who identify as primary caregivers. This is a component of a quality improvement project for Mayo Clinic. Responses will be anonymous and no personally identifying information will be shared. Your participation is voluntary and your decision whether or not to participate will not affect your relationships with the researchers, Mayo Clinic, or St. Catherine University. The responses will be used to further develop educational materials for parents of children with HLHS as they prepare for recovery from the Fontan procedure. You may decide to stop taking the survey at any time, for any reason. You may also skip any item that you do not want to answer. No guarantees can be made regarding the interception of data sent via the Internet by any third parties. Check the box below if you agree to participate. By responding to items on this survey you are giving us your consent to allow us to use your anonymous responses for research and educational purposes. Estimated time to complete this survey: 15 minutes.

Mark only one oval.

- I consent to participate
- I do not consent to participate (do not proceed to next question)

2. Demographic Information: Before you begin, we would like to know a bit about your background. Select the parent role that best describes you:

Mark only one oval.

- Mother
- Father
- Grandparent
- Other: _____

11/22/21, 1:22 PM

Post-Fontan Parent Survey

3. Which of the following best represents your racial or ethnic heritage? Choose all that apply

Check all that apply.

- Non-Hispanic White or Euro-American
 Black, Afro-Caribbean, or African American
 Latino or Hispanic American
 East Asian or Asian American
 South Asian or Indian American
 Middle Eastern or Arab American
 Native American or Alaskan Native

Other: _____

4. What is your educational background? (Select highest level)

Mark only one oval.

- Some high school
 High school graduate
 Some college
 Bachelor's degree
 Trade/vocational training
 Associate's degree
 Post-graduate degree

11/22/21, 1:22 PM

Post-Fontan Parent Survey

5. What's your marital status?

Mark only one oval.

- Single
- Married/Domestic partnership
- Widowed
- Separated
- Other: _____

6. How long ago was your child's Fontan surgery?

Mark only one oval.

- 0-6 months ago
- 7-11 months ago
- 1-2 years ago
- 3-4 years ago
- 5 years or greater
- Other: _____

7. How long was your child hospitalized after the Fontan surgery?

Mark only one oval.

- 0-6 days
- 1 week
- 2 weeks
- 3 weeks
- 4 weeks
- 5 weeks or greater

11/22/21, 1:22 PM

Post-Fontan Parent Survey

- 8. On a scale from 1-5, how much do you agree with the following statement: "After the Fontan surgery, I felt prepared to return home as my child's primary caregiver"

Mark only one oval.

	1	2	3	4	5	
Strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Strongly agree

- 9. Is there anything that would have helped you feel more prepared? Describe below.

- 10. On a scale from 1-5, how much do you agree with the following statement: "After the Fontan surgery, I was able to access the supports and services needed to help with my child's development"

Mark only one oval.

	1	2	3	4	5	
Strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Strongly agree

- 11. What supports and services did you access, if any?

11/22/21, 1:22 PM

Post-Fontan Parent Survey

12. On a scale from 1-5, how much do you agree with the following statement: "After the Fontan surgery, I was able to access the supports and services to support my mental health as a caregiver"

Mark only one oval.

	1	2	3	4	5	
Strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Strongly agree

13. What resources have been the most helpful since your child's Fontan surgery?

14. On a scale from 1-5, how would you rate the care team communication you've received since your child's Fontan surgery?

Mark only one oval.

	1	2	3	4	5	
Poor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Good

15. Were you able to provide the care team with any feedback about your experience post-Fontan?

Mark only one oval.

Yes

No

Unsure

11/22/21, 1:22 PM

Post-Fontan Parent Survey

16. If yes, how was your feedback collected?

17. In what ways did your child's care team communicate well?

18. In what ways did your child's care team communicate poorly?

19. Do you have any suggestions for parents of children with HLHS preparing for the Fontan surgery?

11/22/21, 1:22 PM

Post-Fontan Parent Survey

20. What do you wish the healthcare team knew about your mental health?

21. Please provide any additional comments or suggestions below:

22. Next steps: An informational web page will be created based on the recommendations provided in this survey. If you are willing to review the content of the website and provide feedback, please enter your email address below. Thank you!

This content is neither created nor endorsed by Google.

Google Forms

Appendix D: Parent Feedback Survey

11/22/21, 1:28 PM

Post-Fontan Parent Feedback

Post-Fontan Parent Feedback

1. This survey is designed for post-Fontan parents of children with HLHS who identify as primary caregivers. Responses will be anonymous and no personally identifying information will be shared. Your participation is voluntary and your decision whether or not to participate will not affect your relationships with the researchers, Mayo Clinic, or St. Catherine University. The responses will be used to further develop educational materials for parents of children with HLHS as they prepare for recovery from the Fontan procedure. You may decide to stop taking the survey at any time, for any reason. You may also skip any item that you do not want to answer. No guarantees can be made regarding the interception of data sent via the Internet by any third parties. Check the box below if you agree to participate. By responding to items on this survey you are giving us your consent to allow us to use your anonymous responses for research and educational purposes. Estimated time to complete this survey: 15 minutes.

Mark only one oval.

- I consent to participate
- I do NOT consent to participate (do not proceed to next question)

2. Please review the pdf file of the book "Flynn and Flora Prepare for the Fontan"

Check all that apply.

- I have reviewed the materials

3. How much time did you spend reading through the book?

11/22/21, 1:28 PM

Post-Fontan Parent Feedback

4. Was there anything that you didn't understand throughout the book?

5. What did you like about the book?

6. What did you dislike about the book?

7. Is there anything that was missing from the book?

11/22/21, 1:28 PM

Post-Fontan Parent Feedback

- 8. Would this be helpful for parents of children with HLHS who are about to undergo the Fontan surgery?

- 9. Any final thoughts or suggestions?

This content is neither created nor endorsed by Google.

Google Forms