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Integrating Family-Centeredness into a Pediatric Advanced Heart Failure/Heart
Transplant Model of Care

DNP Project
Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Nursing Practice
St. Catherine University
St. Paul, Minnesota

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ST CATHERINE UNIVERSITY
ST. PAUL, MINNESOTA

This is to certify that I have examined this
Doctor of Nursing Practice DNP project manuscript
Written by

Elizabeth Wagner-Preze

and have found that it is complete and satisfactory in all respects,
and that any and all revisions required by
the final examining committee have been made.

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Department of Nursing

Integrating Family Centeredness into a Pediatric Advanced Heart Failure/Heart Transplant Model of Care

Children with advanced heart failure face complex medical regimens and often require heart transplantation to survive. These children do not experience life with advanced heart failure alone; their families are also impacted. Although more pediatric transplants are being performed today than ever before, many families are required to move to be able to obtain a heart transplant for their child, and this disrupts family routines, roles, and can cause financial hardships (Williams, Eilers, Heerman & Smith, 2012).

Pediatric heart transplant is widely accepted as a life-saving treatment for end-stage heart failure in children, and make-up approximately 14% of the total number of heart transplants performed (Schweiger, Stiasny, Dave, Cavigelli-Brunner, Balmer, Kretschmar...Hubler, 2015). Survival rates for pediatric heart transplant recipients continue to improve with children now living on average 15 years after transplant (Thrush & Hoffman, 2014). However, serious illnesses in children can pose overwhelming challenges to families and impact their ability to cope long-term with the impact of the disease. Families of pediatric heart transplant patients face a significant amount of uncertainty, stress, and often post-traumatic stress from the experience of having a child undergo a heart transplant (Farley, DeMaso, D'Angelo, Kinnamon, Bustardi, Hill...Logan, 2007).

Because of the substantial impact pediatric heart transplant has on families, it was identified by the organization involved in this study that there was a need to understand the family's lived experiences of heart transplant before implementing a pediatric Advanced Heart Failure/Heart Transplant program. It has been demonstrated that when implementing a new pediatric heart transplant program, it can be beneficial to include the family's perspective into

program development to ensure the success of the program and improve patient outcomes (Williams, Eilers, Heermann & Smith, 2012). The organization in this study has a mission to improve children's health by providing the highest-quality, family-centered care, advanced through research and education with a vision to be every family's essential partner in raising healthier children throughout childhood (Children's Minnesota, 2017).

Background

Patient and family-centered care (PFCC) have been the hallmark of pediatric care in the United States (U.S.) since the 1950's when it was identified that children were negatively impacted when families were not allowed to visit a hospitalized child (Shields, Zhou, Pratt, Taylor, Hunter & Pascoe, 2012). PFCC is an approach to the planning, delivery, and evaluation of health care based on a model of mutually beneficial partnerships between healthcare providers, patients, and families. PFCC incorporates core concepts of dignity and respect, information sharing, participation, and collaboration (Abraham & Moretz, 2012). Collaboration encourages patients, families, and healthcare providers to work together in policy and program development, implementation, evaluation, design, and delivery of care (Abraham & Moretz, 2012). When families are facing heart transplantation for their child, a PFCC care model can foster relationships with healthcare providers, improve the family's ability to participate in the care of their child, and make health care decisions (Rostami, Hussan, Yaghmai, Ismaeil & Suandi, 2015).

There has been a national focus on improving healthcare by focusing on PFCC (Balik, Conway, Zipperer & Watson, 2011). One of the six aims identified for improvement of the healthcare system in the U.S is patient-centeredness (Committee on Quality of Health Care in America & Institute of Medicine Staff, 2001). Patient-centeredness focuses on the patient's

experience of illness, the healthcare systems, and the ability to meet the patient's needs (Committee on Quality of Health Care in America & Institute of Medicine Staff, 2001). In 2001 the Institute of Medicine (IOM) published "Crossing the Quality Chasm," a report that recommends a redesign of the U. S. healthcare system.

Problem Statement

The organization provides care to the majority of children with heart disease in the state. It does not currently offer advanced heart failure or heart transplant services requiring patients and families to be transferred to other institutions to receive these services. This transfer has caused patients and families significant dissatisfaction as most have been treated in the organization over the entire course of their illness. It has also resulted in a substantial financial loss to the organization, as average billable charges for a heart transplant in the U. S. are 1.3 million dollars per transplant (Bentley & Phillips, 2017). Additionally, with the absence of a pediatric heart failure and heart transplant program, the organization is unable to be ranked among The Best Children's Hospitals in the U. S. News & World Report for Cardiology and Cardiac Surgery service (Olmsted, Geisen, Powell, Murphy, Bell & Stanley, 2017). However, the organization's strategic plan now includes the development and implementation of a new pediatric Advanced Heart Failure and Heart Transplant program. Pediatric advanced heart failure and heart transplant patients and their families face unique challenges which need to be considered when developing a new program. Incorporating family feedback into a model of care can facilitate successful transplant outcomes and foster the patient and family's ability to thrive after transplant. Currently in the U. S. organ supply does not meet the demand, with more than 7,000 adult and pediatric candidates dying in 2016 while on the waiting list, or within 30 days of leaving the list without receiving an organ transplant (United Network for Organ Sharing

(UNOS), 2017). Therefore, it is the responsibility of every organization providing pediatric transplant services to work to ensure that patients and families emerge after transplant with the ability to appropriately manage the care of their child. Gaining an understanding of the family's needs and incorporating them into a model of care will be essential in developing a sustainable pediatric heart transplant program that fosters the success and well-being of the family.

Needs Assessment

In 2017 there were 431 pediatric heart transplants performed in the U. S. (U.S. Department of Health and Human Services, 2018). In 2017 ten patients were transferred out of the organization in this study for heart transplant evaluation. In the spring of 2016, a feasibility study was completed by an external transplant consulting firm, and the organization was found to have the foundational elements required to support a pediatric advanced heart failure and heart transplant program. The needs assessment concluded that the organization's logical next step would be to start a pediatric heart transplant program (Smith-Fields, 2016).

PICO Question

The PICO question that is the basis for this Doctor of Nursing Practice (DNP) project is: *What is the impact of integrating family centeredness into a project proposal to hospital administration when seeking approval of a new pediatric advanced heart failure and heart transplant model of care?* In 2017 a strategic initiative was introduced to develop and implement the Pediatric Advanced Heart Failure and Heart Transplant program to avoid patient transfers out of the organization for these services. It is optimal in the development of the Pediatric Advanced Heart Failure and Heart Transplant program to include a model of care which is family-centered, supports the mission of the organization, and meets the needs of its patients and families. Pediatric transplant patients and their families face unique challenges

associated with extended hospitalizations. These challenges create family needs that need to be considered when designing a family-centered advanced heart failure and heart transplant program. Gaining an understanding of these family's needs and incorporating them into a model of care will be essential for developing a sustainable, high-quality program.

Project Goals and Objectives

This DNP project's objectives include: to conduct six to eight interviews with parents/guardians of children who were treated in the organization for heart disease and transferred to another organization to undergo a heart transplant, to understand their lived experiences. Next, to identify common themes from the interviews and incorporate them into a family-centered advanced heart failure/heart transplant model of care. Finally, to present this model of care to organizational leadership for approval and implementation.

Theoretical Framework

There were two theories used to guide this DNP project, First, Roger's diffusion of innovation change theory (2002) and second Margaret Newman's Health as Expanding Consciousness (HEC) theory (1994). Roger's diffusion of innovation change theory was selected because it can be adapted to facilitate the change process needed to implement the advanced heart failure/heart transplant model of care. Roger's theory describes how over time an idea gains momentum, acceptance, and diffuses through a group (Rogers, 2002). Diffusion of innovation theory began in rural sociology with studies of farmers incorporating new agricultural techniques (Singhal, 2012). It has since been successfully applied in numerous areas such as communications, medical sociology, and health promotion with a significant impact on the use of medicines, medical techniques, and health communications (Berwick, 2003). Roger's diffusion of innovation theory can be utilized to guide this DNP project because of its success in

communicating and integrating change in the healthcare setting. Table 1 applies the five components of Roger’s theory to the stakeholders and demonstrates how each component will be operationalized to facilitate the change associated with the implementation of this DNP project.

Table 1
Operationalizing Roger’s Diffusion of Innovation Theory

Component of Roger’s Theory ^a	Stakeholder	Operational plan for project
Compatibility	Executive Leadership Clinical Staff	Review organizational values, mission, and vision statements and demonstrate how the model of care is congruent with these guiding principles of the organization.
Relative Advantage	Executive Leadership Clinical Staff	Present themes from family interviews to demonstrate the impact on families of the current practice of transferring patients outside the organization for advanced heart failure/transplant services.
Complexity	Executive Leadership Clinical Staff	Provide education on how the model of care will guide the care of a new patient population. Models of care are used when developing new ways of organizing and delivering care ^b and can ease the transition of learning a new patient population.
Trialability	Clinical Staff	Introduce the model of care before starting the heart failure/transplant program to allow for practice with the new model before using it to guide care on the new patient population.
Observability	Executive Leadership Clinical Staff	Successful outcomes and patient, family and staff satisfaction demonstrate observability of the change.

Note.
^a Rogers, E. M., 2002, ^b Agency for Clinical Innovation, 2013

Rogers also outlines five adopter categories which identify the characteristics of one’s target population that can facilitate or hinder the adoption of the innovation (Rogers, 2002). These characteristics can also influence the rate at which innovation is adopted (Hadorn, Comte, Foucault, Morin & Hugli, 2016). In the change process, it is essential to understand the five adopter categories and engage staff in key groups to influence the rate of change. Tailoring interventions to engage staff at each level using Rogers’ diffusion of innovation theory is

essential in the change process. Table 2 outlines the strategies to employ each of the five categories of adopters in integrating the advanced heart failure/heart transplant model of care.

Table 2
Strategies to Engage Adopters

Roger's Adopter Categories ^a	Characteristics of the Adopter ^b	Engagement Strategies
Innovators	This group wants to be first to try the innovation. They are interested in new ideas, willing to take risks and are the first to develop new ideas.	-Provide regular updates on the project plan; communicate timelines and any delays in the project.
Early Adopters	This group is comprised of opinion leaders. They are aware of the need for change, enjoy leadership and are comfortable adopting new ideas.	-Provide information on the model of care and how to implement it with the patient population. -Encourage "super user" from this group; provide extra training on the model of care. -Utilize this group as preceptors or charge RNs.
Early Majority	This group adopts new ideas before the majority, but need evidence that innovation works before trying it. They rarely are leaders.	-Discuss the success stories using the model of care and outcomes. -Engage "super users" to discuss their success in using the model of care with other staff.
Late Majority	This group is skeptical of change and adopt the change only after the innovation has worked with the majority.	-Provide information on the successful integration of the model of care with other patients and families. -Facilitate precepted or role modeling experiences to enhance comfort with the model of care.
Laggards	This group is very traditional and conservative, skeptical of change and the hardest group to engage in change.	-Engage "super users" to share their success & effectiveness in using the model of care. -Offer additional education on the model of care and resources. -Monitor use of the model with this group and intervene with performance issues as needed for non-compliance.

Note.
^aRogers, 2002, ^bLeMonte, 2016

The second theory in this DNP project was Margaret Newman's theory of health as an expanding consciousness (1994). Newman's theory is based on a unitary process and involves the recognition of patterns as the identifier of wholeness and the transformative process of change (Newman, 2005). It was used in this DNP project to facilitate the family interviews and to understand the lived experiences of families who had a child undergo a heart transplant. The use of the HEC model allowed the researcher to recognize evolving patterns of what families found meaningful in their lives and how those experiences impacted the family as a whole (Pharris, 2015) during their child's heart transplant experience. The recognition of patterns by

the researcher facilitated the development of a family-centered pediatric advanced heart failure/heart transplant model of care. Additionally, HEC theory gave a framework to the transformative process of change that occurs within the experience of a heart transplant and the advanced heart failure/heart transplant model of care.

The family experience was the focal point of this DNP project and the essential element in developing a pediatric advanced heart failure/heart transplant model of care. Family-centered care is part of the mission of the organization implementing the advanced heart failure/heart transplant program. Therefore, an extensive literature review was conducted before implementation of this study to understand the concept of family-centered care and its impact on providing health care to children and their families.

Literature Review

The search strategy to answer the PICO question, “What is the impact of integrating family centeredness into a project proposal to hospital administration when seeking approval of a pediatric advanced heart failure and heart transplant model of care?” included the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, SAGE, and Cochrane Review. The articles selected from these searches included those in which patient-centered care (PCC) or family-centered care (FCC) was implemented on a pediatric inpatient unit, literature reviews of PCC or FCC studies with a pediatric focus, meta-synthesis, and meta-analysis completed on pediatric PCC or FCC studies. Studies which only concentrated on a single intervention around patient and family-centered rounds or family presence were not included in the final selection of articles appraised; however, some of these studies were included in the meta-analysis. A selection of 12 articles for appraisal resulted from the searches described (Appendix B). Additional evidence was identified through a web-based search and

review of the selected article reference lists, and three other sources of evidence were included from the Institute for Patient and Family-Centered Care, Institute for Healthcare Improvement, and Registered Nurses Association of Ontario, for a total of 15 sources of evidence.

Appraisal of the Evidence

The appraisal of the evidence was conducted using The Johns Hopkins Hospital/The Johns Hopkins University Research Evidence Appraisal Tool and the Non-Research Evidence Appraisal Tool (Dearholt & Dang, 2012). The search of the evidence did not produce a significant number of high-level evidence quantitative research studies. Most of the literature found on PFCC was qualitative or non-experimental (Shields et al., 2012). The Cochrane review article selected for this appraisal included one randomized controlled trial in its systematic review because of the lack of quantitative research available; identifying a need for quantitative research to test the effectiveness of FCC (Shields et al., 2012). Three of the fifteen sources of evidence were single study qualitative research, one in the form of a questionnaire and two interviews. These three studies had limitations in that one study had a relatively homogenous group that included only female nurses and all but one was white, which did not represent the population of nurses in that county. Also, the parents in the study were 71% Latino who did not accurately describe the ethnicity in the county (Baird, Davis, Hinds, Baggott & Rehm, 2015). In the second study, the manner in which questions were worded in the questionnaire for nurses sensitized the nurse's awareness of family-centered knowledge and may have influenced nurses' answers (Coyne, O'Neill, Murphy, Costello & O'Shea, 2011). In the third study participants may have had recall bias because parents were interviewed at different time points from the date of their child's illness (Moore, Robinson, Mink, Hudson, Dotolo, Gooding...Vavilala, 2015). The remainder of the nine articles included: literature reviews, meta-

analysis, or meta-synthesis of studies on PFCC. Four of these reviews identified that their studies were not generalizable to non-tertiary care practices (Foster, Whitehead & Maybee, 2016; Foster, Whitehead, Maybee & Cullens, 2013; Gallo, Hill, Hoagwood & Olin, 2016; Harrison, 2010). However, for this appraisal, the information was explicitly sought to include PFCC provided in a pediatric Intensive Care Unit (ICU) or acute care setting. Finally, additional evidence selected on PFCC included two clinical practice guidelines and a white paper.

Synthesis of the Literature for Intervention

In synthesizing the evidence selected to address the intervention in the PICO question, studies were rated on the strength of their evidence as defined by The Johns Hopkins Hospital/The Johns Hopkins University Research Evidence Appraisal Tool and the Non-Research Evidence Appraisal Tool (Dearholt & Dang, 2012). The strength of the evidence is based on a five-point scale, with level I studies demonstrating the strongest evidence from randomized controlled trials, and level V is the weakest evidence and includes literature reviews, quality improvement projects and case studies (Dearholt & Dang, 2012). The majority of the articles, 13 out of 15, were appraised in the range of level III-V. There were five studies which appraised at a level III. Four studies appraised at a level IV. There were four level V studies. Finally, of the two remaining studies, one was a level I and one was a level II. The quality of the evidence of the 15 studies in this synthesis included the majority of the studies, 10 out of 15, earning a B quality rating and the remaining five receiving an A quality rating. Overall, the quality of the evidence synthesized was of good quality according to Dearholt and Dang's (2012) rating categories, and this is consistent with the review of the literature available on PFCC. The majority of the PFCC evidence is not in the form of quantitative research studies, but rather qualitative research studies. Most of the studies recommend a need for further research in PFCC

focused on outcomes of the care model (Jolley & Shield, 2009; Butler, Copnell & Willetts, 2014). However, the qualitative and non-research evidence available on PFCC does demonstrate that PFCC initiatives are effective and continues to be the preferred model of care in pediatrics (Harrison, 2010; Butler, Copnell & Willetts, 2014).

In analyzing the evidence for synthesis, it is compelling that there are a wide variety of studies, and sources of evidence in this synthesis including qualitative phenomenology and case studies, systematic reviews with meta-analysis, meta-synthesis, and other sources of evidence such as clinical practice guidelines and a white paper and many of the outcomes of these studies and evidence sources were similar in their conclusions. Communication and the need for leader support when implementing PFCC initiatives were the two findings most closely aligned with the PICO question and consistently found in the evidence.

The FCC literature identifies communication and providing information to families as fundamental in operationalizing FCC concepts in hospitals (Foster, Whitehead & Maybee, 2016). According to guidelines developed for FCC in the neonatal, pediatric, and adult ICU's, regular communication with family members in family conferences can reduce any miscommunication between clinicians and family members (Davidson, Aslakson, Long, Puntillo, Kross, Hart, et al., 2017). Additionally, using a structured approach in communicating with families is recommended, and clinicians should receive FCC communication training as one element of their critical care training (Davidson, Aslakson, Long, Puntillo, Kross, Hart, et al., 2017). In a meta-synthesis of 30 qualitative research studies, honesty, respect, time, and relationships were identified by parents, health care providers, and hospitalized children as essential factors that facilitate communication during critical illness (Foster, Whitehead, Maybee & Cullens, 2013). Parents also report that communication from the healthcare team needs to be clear, consistent,

and often repeated (Foster, Whitehead, Maybee & Cullens, 2013). In Foster, Whitehead and Maybee's (2016) qualitative synthesis of 59 FCC studies, parents identified that communication impacted stress levels, satisfaction, the care and treatment of their child, decision making, and health outcomes of their children. All 59 studies included communication as a common component referenced in the studies. However, less than half identified in their findings that communication was a common theme (Foster, Whitehead & Maybee, 2016).

Leader support in PFCC initiatives was another significant theme identified in the synthesis of the studies and sources of evidence. According to the Institute for Patient and Family Centered Care (2017), hospitals that have been successful in PFCC initiatives have leaders who understand that their commitment and support is paramount. Some of the explicit roles identified for leaders include: making a commitment to PFCC and serving as role models, providing resources and support of PFCC initiatives, providing oversight of partnerships with patients and families in strategic initiatives, implementing systems to measure the outcomes of PFCC efforts, and recognizing that organizational change to incorporate PFCC can take time (Institute for Patient and Family-Centered Care, 2017). In a review of 19 studies, Mastro, Flynn, and Preuster (2014) identified that evidentiary support existed for PFCC contributing to the improvement of patient satisfaction, staff satisfaction, and enhanced staff-patient communication. They recommended that nurse executives implement PFCC principles and strategies within organizations (Mastro, Flynn & Preuster, 2014). Additionally, Coyne, O'Neill, Murphy, Costello, and O'Shea (2011) conducted a qualitative study exploring what FCC means to pediatric nurses and how it can improve practice. The nurses identified that they have a clear understanding of what is involved in FCC from a broad perspective. However, they recognized that a lack of organizational and managerial support and inadequate resources contributed to

challenges in fully implementing FCC (Coyne, O'Neill, Murphy, Costello & O'Shea, 2011). The nurses also identified that management could develop comprehensive policies around FCC with staff involvement as an enhancement in providing FCC (Coyne, O'Neill, Murphy, Costello & O'Shea, 2011).

An interesting difference in PFCC exists between the research evidence, white paper, and clinical practice guidelines appraised. The quantitative research evidence identifies the need for additional experimental research to test the effects and outcomes of PFCC (Shields et al., 2012). However, the white paper determined that there is evidence available to support that PFCC is effective (Balik, Conway, Zipperer & Watson, 2011). It is vital to consider incorporating both the evidence from research studies and other sources of evidence when developing a PFCC initiative.

The intervention of presenting a family-centered advanced heart failure/heart transplant model of care to organizational decision makers when developing the pediatric heart transplant program is supported by the literature review. From the review and synthesis of the evidence highlighted, there is a demonstrated need to engage leader support before developing PFCC initiatives. Engaging leadership support will increase the likelihood of success of the initiative (Institute of Patient and Family Centered Care, 2017). The synthesis of the evidence also shows that communication is a central component of all PFCC initiatives, and understanding a family's experience is fundamental to communicate with patients and families especially when attempting to improve access to care and services (Registered Nurses Association of Ontario, 2015). Including patient and family input with the available evidence on PFCC and enlisting hospital leadership support will be key in successfully developing a family-centered pediatric advanced heart failure/heart transplant model of care.

Synthesis of Literature for Outcomes

The evidence available on PFCC is consistent and recognizes that PFCC is essential in providing care to hospitalized children (Shields, et al., 2012). PFCC has been the hallmark of pediatric care in the U. S. since the 1950's when it was identified that children were negatively impacted when families were not allowed to visit a hospitalized child (Shields et al., 2012). Despite this, there continues to be a lack of randomized controlled studies in which FCC models are compared with standard models of care to test the effectiveness of FCC (Shields et al., 2012). However, PFCC evidence is growing and gaining acceptance among hospitals because of its close ties with patient and family engagement and the continued significance this has for hospitals competing for patients and reimbursement dollars today (U. S. Centers for Medicare & Medicaid Services, 2017).

The PFCC evidence indicates that implementing a family-centered pediatric advanced heart failure/heart transplant model of care that incorporates principles of PFCC is beneficial. Additionally, input from patients and families who have experienced receiving heart transplant care for their child can contribute to greater understanding of the experiences of a prolonged hospitalization for patients and families undergoing heart transplantation in the organization. Despite the fact that few experimental research studies exist on the effectiveness of FCC (Shields et al., 2012), there were no studies in this review of the literature that discussed potential harm to participants associated with incorporating PFCC concepts. Moreover, the Institute of Medicine report (2001), *Crossing the Quality Chasm: A New Health System for the 21st Century*, included patient-centeredness as one of its six aims for improvement in healthcare, where patient experience was suggested as a measure of patient-centeredness (Institute of Medicine (U.S.) Committee on Quality of Health Care in America, 2001). Also, the Centers for Medicare &

Medicaid Services (CMS) supports transparency in patient experience ratings and has indicated that patient experience rankings will be compared between hospitals and higher patient experience rankings will influence reimbursement (Balik, Conway, Zipperer & Watson, 2011). CMS is a primary payer of transplant reimbursement and supports patient-centeredness influencing reimbursement. In 2017 CMS weighted patient and caregiver-centered experience of care at 25% of its value-based purchasing domains (Department of Health and Human Services Center for Medicare & Medicaid Services, 2017). The sources of evidence are compelling, and can significantly influence the change process. Finally, presenting a family-centered pediatric advanced heart failure/heart transplant model of care to hospital administration is supported based on the evidence reviewed here.

Project Implementation

This DNP project was designed to answer the PICO question: *What is the impact of integrating family centeredness into a transplant project proposal to hospital administration when seeking approval of a pediatric advanced heart failure and heart transplant model of care?* Family input was needed to develop a family-centered pediatric Advanced Heart Failure/Heart Transplant program in the organization in addition to a modeling a return on investment. The DNP project included interviewing families of patients who had received services for their heart disease in the organization but were transferred to receive a heart transplant to understand their lived experiences. The themes identified from the interviews were then incorporated into the development of an advanced heart failure/heart transplant model of care. The model was then presented to organizational leadership for approval. Approval was obtained from organizational leadership and the model of care will be implemented in the Cardiovascular Care Center (CVCC). Since this model of care would be new to the staff of the CVCC, project

implementation includes providing a one-hour education session to all staff in the CVCC. This project is consistent with the patient and family-centered literature in that the development of the model of care was presented to organizational leadership for approval. The literature indicates the engaging leadership in patient and family-centered initiatives increase the likelihood of success of the initiative (Institute for Patient and Family Centered Care, 2017). Additionally, communication was identified consistently in the patient and family-centered literature as a key component of all PFCC initiatives, understanding a family's experience is a fundamental component in communicating with patients and families especially when improving access to care and services (Registered Nurses' Association of Ontario, 2015). The model of care focuses specifically on effectively communicating with families in each of the transplant phases of care.

Ethical Issues, Social Justice Issues

There are social justice issues related to the organization's current practice of sending patients out of the organization for a heart transplant evaluation. The organization's patient population includes 40% of patients insured through Medicaid (Children's MN, 2018). Medicaid is a jointly funded federal and state health insurance program for low income, needy people including children (Centers for Medicare and Medicaid Services, 2018). The transplant options are not equal for all families being referred out of the organization for a heart transplantation. Those with more financial means can travel a greater distance and perhaps receive a heart transplant sooner if they go to a program with shorter waiting times. Patients could also be listed at a transplant center with better outcomes if they can travel to those programs rather than being limited to those programs closer to the patient's home. The implementation of the Advanced Heart Failure/Heart Transplant program would allow patients and families to receive a heart transplant in the same organization they have chosen to receive their child's cardiac care.

Providing advanced heart failure/heart transplant care in the organization will allow all patients the same access to this service.

Methods

This DNP project's study utilized a qualitative, phenomenological approach to understand the lived experiences of families who have had a child undergo a heart transplant. This project was approved by Children's Minnesota and St. Catherine University's Institutional Review Board, and study participants were parents or guardians of patients who underwent a pediatric heart transplant from 2010-2017. Potential participants were sent a letter of invitation to participate in the project and were provided with a response form to indicate their interest in participating in the project. Informed consent was obtained before conducting parent/guardian interviews. Face-to-face or telephone interviews were conducted for data collection. Parents were interviewed using open-ended structured questions used to elicit information about their family's experience (Appendix A).

Sample

All patients from the organization who were transferred for heart transplant evaluation between 2010 and 2017 were identified from an internal organizational database by the researcher. Once the patient's names were obtained from the database, to maintain the confidentiality of patient data the researcher's site mentor accessed the organization's electronic health record (EHR) to obtain parent/guardian contact information for the researcher. The patient list was further reduced by the site mentor as only parents or guardians of patients who met the inclusion criteria of being English speakers, whose child had undergone a heart transplant, and was still living. There were 47 patients who met the inclusion criteria and parent/guardian contact information was obtained from the organization's EHR. There were

seven potential participants who were excluded for distance (i.e. >100 miles to patient’s residence from Children’s MN), as all interviews were planned to be conducted face-to-face. The exclusion criteria included parents/guardian of patients who were transferred for heart transplant evaluation but had not undergone heart transplantation, the child was no longer living, or whose parents did not speak or understand English. Interview participant demographics are included in Table 4.

Table 4
Interview demographics

Interview	1	2	3	3	4	5	6	AVG
Interviewee	Mother	Mother	Mother & Father	Mother & Father	Mother	Mother	Mother	
Patient Diagnosis	DCM	DCM	DCM	DCM	LVNC	Tricuspid Atresia	HCM	
Wait time	2 weeks	6 weeks	1 day	2 days	2 weeks	6 months	2 months	
Age at transplant	8.5 months	8 months	2.5 years	2.5 years	28 days	8 years	6 months	
Location of Transplant	Mayo MN	U of MN	Mayo MN	Mayo MN	Mayo MN	Lurie Children’s Chicago IL	Mayo MN	
Wait time (days)	14	42	1	2	14	180	73	47
Age at transplant (months)	8	8	30	30	1	96	6	26

Note. DCM= Dilated Cardiomyopathy HCM=Hypertrophic Cardiomyopathy LVNC=Left Ventricular Non-Compaction AVG=Average

Data Collection

There were forty invitations to participate in the project mailed to parents/guardians of patients who met the inclusion criteria. Eleven responses were received, nine acceptance, two declined, and three letters were returned as undeliverable. Six interviews were scheduled and completed; three were not able to be scheduled despite multiple attempts to make contact via telephone and email or were canceled by the participant. The participants included six mothers and one father who had a total of seven children undergo heart transplant; one family had two

children undergo a heart transplant. Open-ended questions were used to elicit the information from the participants (Appendix A). Five face-to-face interviews were completed and one interview was completed via telephone. Data were collected from November 2017 to January 2018. Interviews lasted on average 67 minutes; they ranged between 58-81 minutes and were audiotaped and transcribed. To protect the confidentiality and privacy of the participants the interviews were recorded on the organization's internal dictation line and then were transcribed by a Health Insurance Portability & Accountability Act (HIPPA) compliant transcription service with a business services agreement with the organization. Parent interview transcripts were verified with the actual interview by the researcher for accuracy.

Data Analysis

The transcripts were initially read by the researcher to immerse into the data. The transcripts were then re-read, line-by-line, to identify words or phrases that described the family's lived experience of having a child undergo a heart transplant. These words and phrases were recorded in a "codebook," i.e., excel spreadsheet. The words and phrases were organized by individual interview. The list of codes was reviewed to identify commonalities between the six interviews completed. The ten most common codes were then identified and categorized by similarity. There were three common themes determined from the ten most common codes. The researcher then returned to the data to verify that keywords and phrases describing families lived experiences were able to be categorized into the three identified themes. Once this step was completed the three themes were further reduced to a single word label that described the theme. This data analysis is consistent with Colaizzi's analytic method of phenomenological studies except for the last step, returning to the study participants to validate the findings of the study (Abalos, Rivera, Locsin & Schoenhofer, 2016). This step eliminated because the purpose of the

study was to focus on families their lived experiences, not on evaluating how it was said. Other phenomenological methods indicate that the researcher completes the phenomenological analysis of the data, rather than the participants. Returning to the participants to validate the findings has participants focusing on what was said rather than describing their experiences (Kleiman, 2004). To further ensure rigor of the qualitative data analysis, the steps of the phenomenological research process and data analysis was strictly followed, and field notes, a codebook, and audit trail were maintained (Averill, 2014). Margaret Newman's theory of health as expanding consciousness (1994) was employed understand the meaning and common patterns of families' experiences and to develop the pediatric advanced heart failure/heart transplant model of care.

Results

The data represented patients who underwent a heart transplant at three different institutions. Six interviews were conducted in this phenomenological quantitative study as Sandelowski (1995) recommends that when conducting phenomenological studies aimed at understanding participant's experiences that six participants be included. The six interviews provided rich qualitative data for the study and data saturation was achieved after the fifth interview when the lived experiences of families of children who had undergone heart transplantation became redundant. The analysis of the interview transcripts provided identification of three themes which described the families' lived experiences of having a child undergoing heart transplant. These themes included: Transition from life as it was (Transition), Adaptation to a new normal (Adaptation) and Remodeling and building a new normal (Remodeling). The themes identified in the interview data coincided with the transplant phases of care, including the pre-transplant/evaluation phase, transplant phase and post-transplant phase. The wording chosen for the three themes that emerged from the interview data was based on the

most common words or phrases used by families, and their experiences in each of the particular transplant phases.

Transition from Life As It Was (Transition)

The participant's experience of having a child undergo a heart transplant is described in the interviews as a transition from life as they knew it. The majority of the participants received an unexpected diagnosis, and the families were thrust into the journey of heart transplantation suddenly. This experience was most often associated with the evaluation or pre-transplant phase of care and describes how the diagnosis and beginning their journey through heart transplantation with their child impacted their family:

"We stopped working, we stopped everything, it was a totally different life experience." (Participant #1)

"That was totally devastating, kind of blew us away, it kind of took us off this familiar path into unknown territory." (Participant #2)

"It's a complete change in your life." (Participant #4)

"Our plan for our family was that we would move to wherever gave her the best opportunity to live, and survive." (Participant #5)

This Transition period was associated with significant change, stress, and anxiety for families. Many of the participants were required to relocate to be near the hospital where their child would receive their heart transplant. This resulted in families either being separated or uprooting the entire family and moving to be together during the heart transplant. Caring for other children and marital relationships were particularly impacted during this period and are described by the participants:

"I missed so much of her babyhood because I had to, I had no choice, so I think finding some way to be able to support the whole family in that aspect and having, you know, ways for the parents to have the siblings with them." (Participant #3)

"We felt that staying together as a family was critical, for us, and I have seen other friends and stuff, that that's been very hard to separate, and I think that was one of our, the best decisions that we made was doing everything we could to stay together, because it is, there's so many ups and downs." (Participant #4).

"Then you never spend time with your partner, and you are passing ships, and so your relationship basically falters." (Participant #5)

"...if you leave, and you take turns, you're exhausted physically, mentally, emotionally. You go back to your other children, who need you, who you feel guilty with, that you are never spending enough time, and their emotional needs that are not being met at all." (Participant #5)

"....siblings need a lot more support than they get because parents can only give them so much in a life situation like that." (Participant #5)

"Monday, Tuesday, Wednesday my husband was there, and then I would stay there Wednesday, Thursday, Friday and my husband would bring my other son down, and we could as be as a family on the weekends." (Participant 6)

"I couldn't talk to my best friend; I couldn't talk to sometimes my own husband, cuz we were grieving differently." (Participant #6)

Adaptation to a New Normal (Adaptation)

A second theme identified from the participant interviews was the period of Adaptation to a new normal, this theme was most often associated with the child's transplant phase or early post-transplant phase. This theme was associated with a significant need for information, support, and resources. As families entered the transplant phase of their child's journey, they identified that their world had changed and identified what was needed to help them adapt to this

new phase of life; the phase where they would begin to learn to live with a child who had a transplanted heart. This theme was identified through the following:

"...in that time, I only wanted to hear success stories....I think success stories are really good."

(Participant #1)

"I was happy to always be a part of rounds. I was happy they were family-centered, and I could always be there." (Participant #2)

"I think it is really important to for everyone to have all options." (Participant #2)

"So, to have the care encompass the whole family is really important; to have a counselor available if you are really feeling hopeless would be nice." (Participant #3)

"I think all transplant centers should have in-house specially trained psychological help for the whole family." (Participant #3)

"I went to the CALM mom's support group, and then I would head down to Rochester. That was my therapy." (Participant #6)

Remodeling and Building a New Normal (Remodeling)

The third theme identified from the participant interviews was Remodeling and building a new normal. This theme was identified in the post-transplant phase where families began to remodel their lives after their child's heart transplant. This period included a need for communication, developing trust, and relationships with the transplant team. Participants indicated a need for clear, consistent communication about the post-transplant care

"I think that we've been pretty fortunate, our providers picking up on our style where like, you know, the doctors know that we come with a list of questions and we want precise answers and, I think that that is nice about having like the longer-term relationships." (Participant #1)

"So, to have a really good team that the parents feel confident calling is huge." (Participant #3)

"I'm the type of person that I want to know, just give it to me straight, don't beat around the bush, treat me with compassion and kindness....please tell me the truth and just be straightforward." (Participant #3)

"Communication, open communication; that first year, in particular, I called the transplant center so many times, because as prepared as you think you are when you leave, we were not prepared." (Participant #4)

"I think one of the key things to being a successful transplant facility, is communication, communication, communication. Listening to families, validating their feelings....and honoring what they have to say and making adaptations to each individual case..." (Participant #5)

The three themes identified; Transition, Adaptation, and Remodeling coincided with the phases of the heart transplant process. Transition occurs during the pre-transplant/evaluation phase, Adaptation in the transplant phase, and Remodeling during the post-transplant phase of heart transplantation.

In nursing, the application of Margaret Newman's theory of health as expanding consciousness (1994) can reveal further insight in the results of this DNP project and supports the development of the advanced heart failure/heart transplant model of care. Newman's theory enables nurses to identify with patients during challenging situations to help patients focus on the meaning of their situation, and how it fits into their lives (Pharris, 2015). Finding meaning in challenging conditions allows both the patient and nurse to grow despite the situation (Bateman, & Merryfeather, 2014). Newman's theory identifies that the absence of disease or disability is not always possible and includes all people regardless of the presence or absence of disease (Newman, 1994). This is significant in heart transplant patients as several participants in this DNP study indicated that receiving a heart transplant for their child is often not associated with a cure, but trading one disease state for another. Newman's theory also suggests that the universal process of expanding consciousness is a part of every person in all situation, no matter how

unorganized or without hope it may seem (Newman, 1994). The process of expanding consciousness involves becoming more of oneself, of finding more meaningful relationships and moving beyond one's limitations (Newman, 1995 pg. 168). Expanding one's consciousness is similar to the process identified in this DNP project which includes: Transition from life as it was known, Adaptation to the new normal and Remodeling and building a new life.

Newman's theory is based on the identification of patterns with a focus on their meaning (Pharris, 2015). These patterns refer to information that depicts the whole and understanding of the meaning of all relationships at once (Endo, 2017). Newman indicates that patterns are always evolving and are time specific (Endo, 2017). The evolution and transformation of these patterns occur through the interaction between the patient and their environment (Endo, 2017). Patterns can be revealed retrospectively as sequential patterns over time (Endo, 2017). Sometimes a patient's life is orderly; other times, the patient goes through challenges and that time is chaotic (Pharris, 2015). Order and disorder are believed to be the times when expansion of consciousness occurs (Bateman, & Merryfeather, 2014). The development of the advanced heart failure/heart transplant model of care can help the multidisciplinary team to identify patterns that other families have experienced with a child who undergoes a heart transplant and facilitate appropriate interventions to support the patient and family. Patterns that have been recognized in other families in similar situations can be used with families to help them put structure around a time when things seem out of control and facilitate decision making and effective coping.

According to Newman's theory, nurses encounter patients when they are experiencing chaos, and together the nurse and patient can engage in pattern recognition (Endo, 2017). Pattern recognition can lead both the patient and nurse to know themselves more completely and gain a

better understanding of their situation which supports the evolution of their situation and ultimately to what Newman describes as a higher level of consciousness (Bateman & Merryfeather, 2014). Nursing interventions can be developed from pattern recognition; pattern recognition can provide insight into the meaning of the patterns for patients (Bateman & Merryfeather, 2014). Newman identified these interventions as the “caring partnership” in a patient-nurse relationship (Endo, 2017). It is essential that when nurses enter this caring partnership with transplant families that they are completely present and nonjudgmental in their approach and focus on those areas that the family identifies as most important at that time (Bateman & Merryfeather, 2014). A transforming presence can be established between the nurse and family in which the nurse becomes one with the family (Newman, 2008). This transforming presence goes beyond the recognition of patterns and demonstrates that a unitary transformation is occurring (Newman, 2008).

Nurses are often focused on finding solutions to problems and facilitating the restoration of health and in the HEC process nurses must be willing to be comfortable in periods of ambiguity, chaos, and unbalance as families move through the transplant process (Bateman & Merryfeather, 2014). Nurses are still able to support families in finding solutions and restoring health, however in using the HEC process the nurse would assist the family to gain a level of self-awareness and self-reliance so that at some point the family can maintain their wellness journey independent of the nurse (Bateman & Merryfeather, 2014). While families can move through the transplant process in similar patterns as identified by the themes uncovered in this DNP project it is important to ensure that each families’ journey is allowed to be their own. A nurse can engage a family in storytelling to understand what is meaningful; this can help nurses avoid approaching families with a preconceived idea, instead focusing on what is important to

the family during their experiences (Newman, 2008). The advanced heart failure/heart transplant model of care was developed to support families during the heart transplant process and was not meant to be implemented as a prescribed journey.

Discussion

The use of Margaret Newman's theory of expanding consciousness (1994) can help to inform practice with families of pediatric heart transplant patients. This is accomplished by attending to what is meaningful to the family as their experience evolves and helping them recognize patterns commonly associated in each phase of transplant, and what other families have identified as beneficial while moving through similar experiences. The advanced heart failure/heart transplant model, in Table 3 incorporates the data received from the family interviews and can help in pattern recognition and meaningful remodeling with pediatric heart transplant families. The three themes identified from the interviews were Transition, Adaptation, and Remodeling. These three themes coincide with the phases of transplant care; pre-transplant/evaluation, transplant, and post-transplant. The first phase of pre-transplant/evaluation coincides with Transition in the advanced heart failure/heart transplant model of care. The time frame of the Transition phase begins at diagnosis and listing for a heart transplant and continues through heart transplantation. The Transition phase is associated with significant anxiety, stress, change, and hope for families. The Transition phase of the model of care focuses on providing families with comprehensive education around treatment options and providing support that facilitates the family's ability to make decisions. The education plan involves the entire family including the patient and siblings as appropriate. It is beneficial to engage a Child Life Specialist who assists in presenting developmentally appropriate information to pediatric patients and their siblings. Comprehensive transplant education is provided in multiple formats, including both

written and oral form, to ensure families have a reliable reference after the education has been completed. The education occurs over multiple sessions to allow for families to process the information and not become overwhelmed. For example, providing families with education on one phase of transplant at a time can be an appropriate way to divide the educational sessions. This education is mandatory and is completed before listing the patient for a heart transplant. Families are better able to master the challenges of a child's illness when clinicians help them to gain a better understanding of the illness (Rolland & Walsh, 2006). Families can also be better prepared for the challenges of the illness if they learn about the expected pattern of the illness and the emotional demands they can expect over the course of their child's illness (Rolland & Walsh, 2006).

A comprehensive psychosocial evaluation is also completed during the Transition phase of the model of care and is required before listing a patient for transplant. The goal of the psychosocial evaluation is to assess if there are appropriate social supports for the patient and family to manage the post-transplant care regimen to increase the chances for a successful outcome from transplant (Ryan & Chin, 2017). A Psychosocial assessment is an essential piece of the solid organ transplant evaluation process and has demonstrated a clear relationship between psychosocial factors and post-transplant outcomes; particularly around adherence to the post-transplant protocol (Fung & Shaw, 2008). The shortage of pediatric organ donors makes the psychosocial evaluation extremely important to ensure that the patient and family have the resources and skills necessary to adhere to a post-transplant regimen (Fisher, Storfer-Isser, Shaw, Bernard, Drury, Ularntinon & Horwitz, 2011). The psychosocial evaluation includes the completion of an assessment to evaluate the families' resources, support system, ability to provide post-transplant care for the patient and home environment (Ryan & Chin, 2017).

Additionally, a financial evaluation is completed by a transplant financial coordinator, and a palliative care consultation is provided (Ryan & Chin, 2017). The psychosocial evaluation helps to identify what resources and support the family has in place and from which resources the family could benefit.

Family communication is best supported during the Transition phase. This may require reevaluating and amending organizational policies and procedures, such as a strict visitation policy, which may not be conducive to communication between the family members. It is beneficial to provide families with realistic hope during the period of Transition being considerate of the patient's phase of care. For example, sharing a story of how other heart transplant patients are thriving post-transplant may not be as helpful in the pre-transplant phase as families often cannot foresee into the future when just having their child listed for heart transplant. A more appropriate discussion would be how other heart transplant families have coped during this initial pre-transplant/evaluation phase of care. There is significant research that demonstrates the strong psychological and physiological impact of a positive outlook in recovering from a medical crisis (Rolland & Walsh, 2006). Hope allows family members to be active participants in the illness and treatment process, it encourages initiative and perseverance and can optimize the quality of life, even if the illness progresses (Rolland & Walsh, 2006). Supporting families in decision making and problem-solving is extremely helpful in this phase of Transition when families are often overwhelmed and stressed and facing complex medical decisions and problems.

The second phase of care is the transplant phase of care; this is the Adaptation phase in the advanced heart failure/heart transplant model of care. The Adaption phase is the period from the heart transplant through the post-operative recovery period. This phase is associated with a

family's need for information, access to research and access to support and resources. During this period, the model of care focuses on ongoing education and providing medical updates regularly to families and is facilitated by including families on clinical rounds, providing access to the heart transplant and medical teams for questions, concerns, and clarification. A best practice is to include a regularly planned touch-point with families following rounds to ensure that they have a good understanding of the plan of care and have an opportunity to ask questions and seek clarification. Families need to learn about options when they are available and included in decision making.

The provision of emotional support during the Adaptation phase is important and can be achieved through support groups and individual psychological counseling. Many of the families interviewed identified that the stress of a child undergoing heart transplant resulted in psychological issues such as anxiety, depression, and Post Traumatic Stress Disorder (PTSD). This finding is consistent with a literature review of 31 studies that evaluated parents' quality of life and family functioning in pediatric organ transplantation where studies demonstrated that parents of children who underwent a solid organ transplant experienced a variety of psychological effects including PTSD, depression, and anxiety (Kikuchi & Kamibeppu, 2015). The transplant team can help facilitate psychological support for families by encouraging them to seek mental health resources through their medical benefits as well as facilitating access to any mental health resources the organization offers. By encouraging early psychological support, families can potentially avoid some of the longer term psychological effects identified by the study participants. This is significant as greater stress in families was shown to be associated with poorer adherence to post-transplant regimens in pediatric kidney transplant (Kikuchi & Kamibeppu, 2015). The International Society of Heart Lung Transplantation (ISHLT) has

recognized the psychological challenges of undergoing a heart transplant and recommends that studies be conducted to identify interventions that maximize psychological outcomes (Conway, Sheridan, Maddicks-Law, Fulbrook, Ski, Thompson et al., 2016).

Providing access to organizational resources is essential during the Adaptation phase of the model of care and can include access to housing near the hospital (e.g. Ronald McDonald House) food vouchers, parking vouchers, financial resources, and support groups. Families are especially in need of resources at this point in the transplant journey as they usually have had a child hospitalized for an extended period, can be far from home and are not able to work. Establishing routines during the Adaptation phase can be helpful to both the patients and families to organize the post-transplant care required after discharge. Finally, developing family-centered transplant policies to encourage families to be together is beneficial.

The third theme of Remodeling was identified from the family interviews and coincides with the post-transplant phase of care. This period occurs from the late post-operative care period through discharge. This phase is associated with a need for communication, trust, and relationships with the transplant team. The model of care focuses on establishing a clear communication plan between the patient and family and the transplant team. It is vital to ensure that the family has an understanding of who to contact after discharge. Families are provided with a detailed discharge plan outlining the schedule for follow-up to anticipate the regimen. The transplant team collaborates with pediatricians and outside cardiologists and offers a clear plan of who will be providing what care to the patient. The transplant team provides contact information to other healthcare providers to be easily reached for questions.

Comprehensive discharge education is required for the patient's primary caregiver and a backup caregiver. This education is followed up by the caregiver and back up caregiver

providing 24-hour care to demonstrate competency in providing discharge care to the patient under the supervision of the RN before discharge. It can be helpful in the initial transition from the inpatient setting to discharge to keep the transplant patient and family nearby the hospital. Keeping patients nearby allows the patient and family to attend the frequent follow-up appointments and to ensure that the transplant team is nearby if there are any complications after discharge.

The transplant team is to have regular contact with the family through follow up appointments, and phone calls in between the patients follow up appointments. Regular contact will help to ensure that the family has access to the team to ask questions, and can receive additional education and anticipatory guidance (Lerret, Johnson & Haglund, 2017). It also allows the transplant team to gauge the family's needs and provide an opportunity to intervene with any challenges. All follow-up appointments include the multidisciplinary team and a psychosocial evaluation by the transplant social worker. A multidisciplinary approach will help confirm that the family has access to any resources needed, is coping adequately and is being supported emotionally.

Lerret, Johnson, and Haglund (2017) explored parent experiences of transition from hospital to home after a solid organ transplant and suggested that attention should be paid to the critical role of family functioning during follow up appointments by the transplant social worker. Support groups for families after transplant in the outpatient setting should be established and encouraged. All families need to be assisted in seeking psychological support to ensure the ongoing success of heart transplant patients and their families. Families also benefit from engaging with other families who have undergone similar situations. While HIPPA rules prevent healthcare workers from sharing other patient information to connect families (U. S.

Department of Health and Human Services, 2015), many families are successful in finding other heart transplant families through support groups, word of mouth, and social media.

Table 3
Advanced Heart Failure/Heart Transplant Model of Care

Transition	Adaptation	Remodeling
Mandatory transplant education session for patient/family (required before listing) <ul style="list-style-type: none"> • Transplant specific education by phases of care • Provide education in multiple forms (oral and written) in multiple languages • Provide opportunity for entire family to participate; include child life for younger patients/siblings • Provide education over multiple sessions to allow for reinforcement & questions 	Provide transplant education and ongoing medical information regularly <ul style="list-style-type: none"> • Provide frequent access to the transplant team to clarify information, ask questions and discuss the plan of care • Encourage family participation in daily rounds • Transplant team member to follow up after daily rounds • Explain options for treatment, & medical information with family 	Establish a clear communication plan with the transplant team <ul style="list-style-type: none"> • How to contact team with questions? • When to call transplant team • Provide follow up schedule/testing requirements for transplant • Collaborate with primary Cardiologist, Pediatrician & other subspecialists
Mandatory Psychosocial evaluation of family (required before listing) <ul style="list-style-type: none"> • Complete family resilience assessment • Evaluate family resources • Evaluate family support system • Evaluate family ability to provide post-transplant care • Financial evaluation • Identify types of family support and help facilitate resource needed • Palliative care consultation 	Communicate available resources and options for accessing them to families <ul style="list-style-type: none"> • Housing • Food • Parking • Child Care • Financial resources • Support groups 	Discharge Education <ul style="list-style-type: none"> • Provide comprehensive discharge education • 24-hour care before discharge by the primary caregiver and back up caregiver • Consider proximity to hospital before discharge; provide housing close to the hospital for a specified time
Facilitate family communication <ul style="list-style-type: none"> • Evaluate need for flexibility with hospital policy and protocols (visitation) 	Establish support groups for parents and caregivers to provide emotional support <ul style="list-style-type: none"> • Other psychological resources available based on insurance coverage 	Schedule regular check-in with families <ul style="list-style-type: none"> • Scheduled calls to transplant families after discharge & between follow up appointments • Provide follow up and testing schedule to families
Provide realistic hope to families <ul style="list-style-type: none"> • Success stories of patients in the same phase of care 	Establish routines for patients and families <ul style="list-style-type: none"> • School • Child Life • PT/OT 	Develop outpatient transplant support group for caregivers of transplant patients
Support decision making and problem-solving	Establish family-centered policies for transplant patients that encourage families to be together	Other transplant families <ul style="list-style-type: none"> • Success stories • Organizational skills Provide multidisciplinary follow-up care that includes Social work, psychological support as needed & support groups

The advanced heart failure/heart transplant model of care allows families to expand their consciousness and find meaning and previously unforeseen ways of moving through their situation. However, the model of care may develop further or change over time as the pediatric advanced heart failure/heart transplant program is implemented and nurses continue to assist families in expanding their consciousness through pattern recognition, become fully present with families of children undergoing heart transplant and learning what is most meaningful to them.

Recommendations

Having a child undergo a heart transplant has a significant impact on families. This project identified common themes of families who had a child undergo a heart transplant. These themes can be considered when developing interventions for families whose child is on the journey to heart transplantation. Including these themes in interventions supports a family-centered practice which has been the hallmark of pediatric care. A significant organizational commitment is required to implement this family-centered pediatric advanced heart failure/heart transplant model of care. The commitment from organizational leadership requires a philosophical belief that providing family-centered care to patients is valuable and that the organization needs to invest in a family-centered pediatric heart failure/heart transplant program's model of care. The model of care will require education for the clinical staff caring for heart transplant patients and hiring a dedicated multidisciplinary transplant team. Additionally, this model of care will require hospital leadership to consider any changes needed to organizational policies and procedures to promote family support, bonding, communication, problem-solving and decision making. Finally, access to hospital resources will be needed to support transplant families.

Significance & Contribution to Literature

The development a family-centered pediatric advanced heart failure/heart transplant model of care makes a significant contribution to the pediatric Advanced Heart Failure/Heart Transplant Program at Children's MN. The literature has indicated that family centered care is the hallmark of pediatric health care in the U. S. (Shields et al., 2012) and the organizations mission strives to improve children's health by providing the highest-quality, family-centered care, advanced through research and education (Children's Minnesota, 2017). By implementing this model of care the organization is demonstrating its commitment to family-centered care.

The family centered advanced heart failure/heart transplant model of care will make a contribution to both family-centered care and pediatric transplant literature.

Significance & Contribution to the Nursing Profession

The advanced heart failure/heart transplant model of care can make a significant contribution to the nursing practice at Children's MN as it helps to facilitate the care of a new patient population. Caring for a new patient population can be intimidating as a nurse, however providing some structure to the approach through a model of care can be beneficial to the patient, family, and the nursing staff. This model of care can also be advantageous to nurses in other pediatric heart transplant centers in supporting families as they journey through transplant.

Limitations

There were several limitations to this project. The first limitation is that it utilized a convenience sample of pediatric heart transplant families and results cannot be generalized. Second, the majority of the participants were mothers of children who had undergone a heart transplant; there was one father who participated. Third, the majority of the participants had children who received a heart transplant for a diagnosis of cardiomyopathy rather than congenital heart disease (Table 4). Diagnosis can impact their experiences, as well as the return on investment of the advanced heart failure/heart transplant model of care for the organization as children with cardiomyopathy often present suddenly and in general tend not to wait as long for a heart transplant as those who have congenital heart disease.

Future Implications

The implications of this study on a new pediatric heart transplant program include providing a model of care that is family-centered and evidence-based. This can facilitate the

multidisciplinary care team in providing care for pediatric heart transplant patients and their families. This model of care can impact the success of the heart transplant by supporting families; this support increases the likelihood of the transplant's success. The model of care can help to decrease the risk of patients and families experiencing long-term psychological distress and help them to better cope with the experience of having a child undergo a heart transplant. Similar research in the future could be considered for families with children undergoing other solid organ transplants. Additionally, research with families of children experiencing life-threatening, critical, or chronic illnesses could be studied to evaluate whether their lived experiences are similar to those of heart transplant families. If additional research demonstrates similar lived experiences in other solid organ transplants or serious illnesses, the model of could be beneficial to a broader group of families.

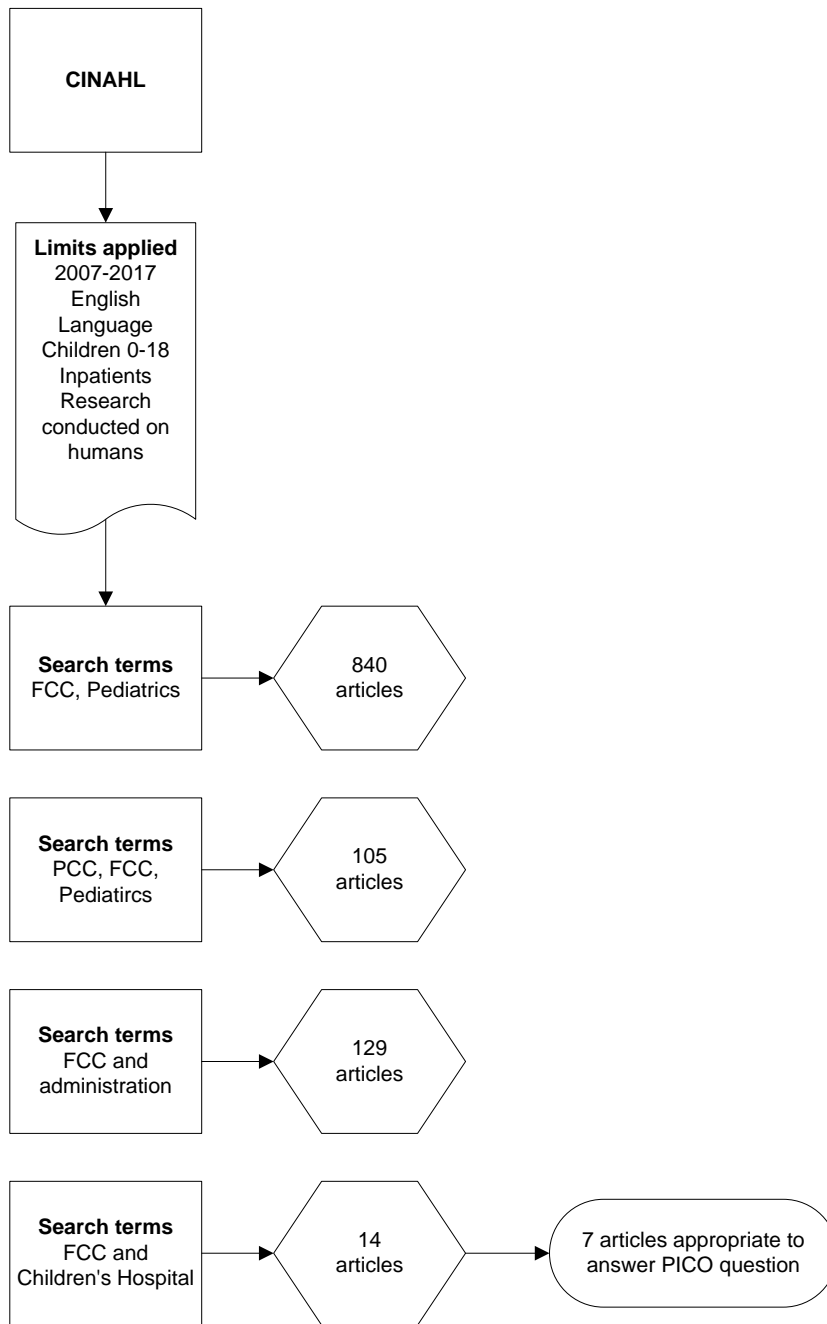
Appendix A

Interview Questions

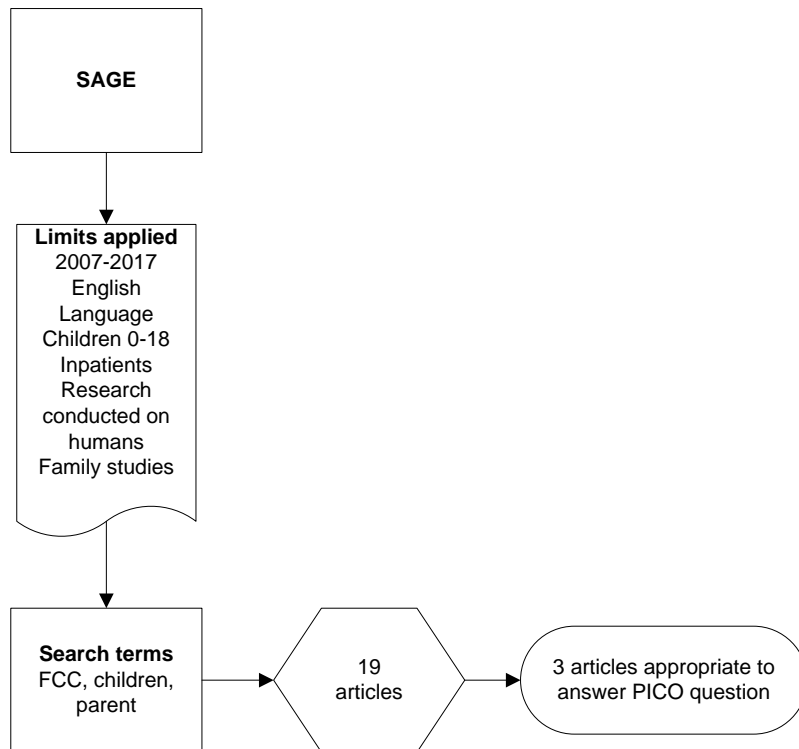
I am interested in learning more about family's experiences of having their child undergo a heart transplant. I'd like to hear your family's story and appreciate you sharing it with me and providing the details to help me understand fully what that experience was like for your family.

- In thinking back to the period of time when your child was referred and listed for transplant, can you describe for me in detail what that experience was like for you and your family?
- Can you share with me your experience when you learned that there was a heart available for your child?
- How did your child undergoing a heart transplant impact your family?
- Tell me about a typical day for you and your family while your child was hospitalized waiting for transplant/after receiving transplant?
- What things were helpful to you and your family when your child was hospitalized before/after his/her transplant? Why?
- What things were difficult for you and your family when your child was hospitalized before/after his/her transplant? Why?
- What else would you like to share with me about you and your family experience having a child undergo a heart transplant?

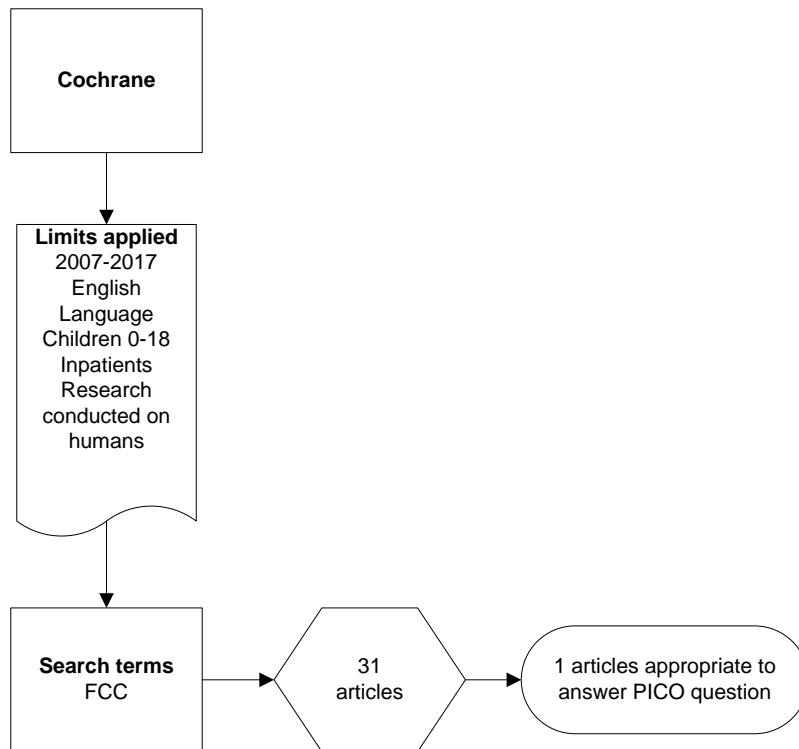
Appendix B
Literature Search Flowcharts



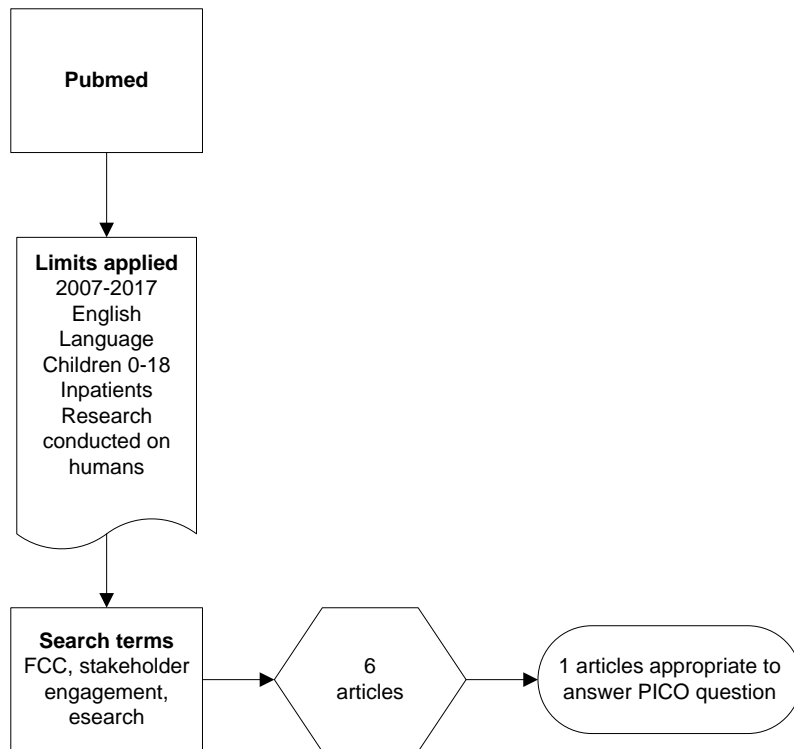
FCC=Family Centered Care
PCC=Patient Centered Care



FCC=Family Centered Care
PCC=Patient Centered Care



FCC=Family Centered Care
PCC=Patient Centered Care



FCC=Family Centered Care
PCC=Patient Centered Care

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