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2014

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An Evaluation of the Parent Education Discharge Instruction
Program for Care of Children After Cardiac Surgery in Southern
India

by

Sandra L. Staveski

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

Acknowledgements

My sincere thanks go to my dissertation chair Dr. Linda Franck for supporting me during my doctoral studies and for helping me to work persistently toward a dissertation I could be very proud of. Thank you for teaching me so much about research and about writing with precision. I appreciate your unwavering support, guidance, and encouragement and for always making time for me.

To Dr. Susan Kools my sincere appreciation for your never-ending encouragement, support, and expert guidance over the years. Thank you so much Susan for seeing me through my qualifying examinations. You and Linda have launched me on the next phase of my career, thank you so very much!

To Dr. Sara Day my sincere thanks for all your support and inspiration with performing international nursing research and for helping me to be able to show the power of nursing practice in developing countries. I grateful for all your support!

I would like to thank Children's HeartLink (CHL) for the wonderful partnership we have shared with the Parent Education Discharge Instruction (PEDI) program and for all your support over the years helping me to realize my dream of being a part of making congenital heart disease a treatable illness worldwide. I would like to express my sincere appreciation to the entire PEDI program development team including Estelle Brouwer, Lizzy DeVita, Justine Kidd, Jeff Paurus, Pam Sagan, Dr. Shanthi Sivanandam, our parent advisors, Dr. Sushma Reddy, and WiRED

International for making the PEDI program possible. My special thanks go to Bistra Zhelva for your partnership in making the PEDI program such a success globally. The studies included in this dissertation would not have been possible without the support of CHL partner sites and their visionary nurse leaders. My sincere thanks go to Sri Bala, V.P. Parveen, Dr. Rosalind Conway, and Reena Paul for making PEDI successful at Inova Heart Hospital and Amrita Institute of Medical Sciences, so many miles away from Oakland, California. I also want to express my gratitude to Dr. K.K. Kumar for his support of my work and for providing a platform to work from in India. Thank you.

To Drs. Hanley, Reddy, and Roth my sincere appreciation for your support over the years. Your support helped me to grow as a cardiovascular advanced practice nurse and to develop the tools to become a scientist. Special thanks goes to Mohan for inviting me to participate on a surgical visit with CHL so many years ago and for introducing me to working in India; it significantly changed my life's course for the better. I would like to express my sincere appreciation to Pam Wells and Dr. Martha Curley for their visionary nursing leadership and for their support and guidance; you helped me to move forward as a scientist even when it was hard. Thank you.

I would like to express my sincere appreciation to my Packard Children's Hospital study teammates because of your collaboration, support for nursing research, and efforts on our studies I was able to learn to be a principal investigator and be in a place to perform the PEDI investigations so far away. Thank you so very much Dr. Stephen Roth, Claire Abrajano, Dr. Josh Cisco, Tiffany Tesoro, May Wu, May Casazza, Chris Almgren, Froi Ascano, Dorothy Wong, Michelle Moore, Kristine Taylor, Karen Boulanger, Lee Erman, Emily Dong, Hanson

Quan, Amy Petty, Katy Felix, Ellen Bair, Dr. Brenda Golianu, Dr. Richard Shaw, Jen Bond, Maimi Ngyuen, Shannon Feehan, Liz Beken, Sealing Arounnarathi, Linda Merrit, Judy Ashford, Kristin Midura, Jana Norris, Meghan Beers, Chloe Journal, Gina Martin, Aihua Zhu, Sara Sherman-Levine, Karen Davis, Michelle Burns-James, and all the supporting nurses from the Cardiovascular ICU and 3 West.

To Mary Lynch I very much appreciate your support and mentorship with starting an academic career. I have learned so much from you. Thank you so very much.

Most importantly, I want to thank my family and friends who have given me unwavering support and who have had tremendous patience with my academic pursuits. Without you I would not have been able to cope with the stressors or fully appreciated the remarkable joy encountered on my journey thus far. Thank you so very much.

Abstract

The purpose of the Parent Education Discharge Instruction (PEDI) program is to teach nurses how to effectively impart home care information to parents in order to improve cardiac surgery outcomes for children in resource constrained environments. The PEDI program consists of a computer-based discharge education training program for nurses, individualized and group teaching sessions for parents, and standardized parent educational resources designed for both literate and low-literacy parents. The PEDI program is designed to enable 1) nurses to effectively convey knowledge and skills to parents (and other caregivers such as grandparents), and 2) parents to care for their children after discharge. Nurse and parent mastery of home care instructions are important precursors to optimal health and well-being of children with congenital heart disease (CHD) after palliation or corrective surgery.

This dissertation presents an evaluation of the PEDI program in two studies conducted in Southern India and findings are presented in three papers. The PEDI program was evaluated for feasibility at one location in Southern India and then, the effects of the PEDI program on nurse, parent, and child outcomes were examined at a different hospital in Southern India. The first paper, Pediatric Cardiac Surgery Parent Education Discharge Instruction (PEDI) Program: A Pilot Study, describes program development and critically appraises the PEDI program. The appraisal included: 1) evaluation of nurses' and parents' perspectives on the acceptability of Indian nurses conducting parent discharge education, 2) assessment of the utility of the PEDI program, 3) preliminarily testing of the effectiveness of the PEDI program on enhancing nurses' and parents' knowledge, 4) evaluation of adherence with discharge teaching documentation and oral and fingernail assessment documentation after PEDI program implementation, and 5) assessment of the PEDI program's sustainability.

The second paper, Parent Education Discharge Instruction Program for Care of Children at Home after Cardiac Surgery in Southern India, examines the PEDI program's effects on nurse and parent home care knowledge and the influence of knowledge on child outcomes (specifically surgical site infections, length of stay from cardiac procedure to discharge, and primary hospitalization and readmission costs). Finally, the third paper, An Analysis of Parent and Nurse Perceptions Associated with the Parent Education Discharge Instruction Program in Southern India, describes and compares nurses' and parents' perceptions before and after PEDI program implementation. The main findings of the two studies were that the PEDI structured nurse-led parent discharge program was feasible and perceived as useful by nurses and parents. In the second study, findings suggest that the program may improve at-home outcomes for children with CHD after cardiac surgery. The second study (third paper) findings also suggest that parent discharge teaching affects parent and nurse perceptions of parent uncertainty and readiness for discharge. Overall, the program shows promise, but further research is needed to examine direct relationships between nursing practice and clinical outcomes. Empowering nurses to perform parental discharge teaching by educating them on home care instructions and expanding their role to include autonomous teaching functions could have positive influences on child outcomes after cardiac surgery.

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Chapter 1

Introduction

Congenital heart disease (CHD) is a complex life-long illness typically requiring catheter and/or surgical intervention during childhood due to complicated, physiologic states (e.g., congestive heart failure, cyanosis) (Lincoln et al., 2014). Many times, children with CHD have significant co-existing conditions (e.g., pulmonary hypertension, genetic disorders) that further complicate their care and require special consideration in their ongoing treatment plans to minimize the risk of complications (Chatfield & Deardorff, 2014). For example, an infant with univentricular circulation has more inherent risk for complications after surgery, including (but not limited to) growth failure, shunt thrombosis, congestive heart failure, infectious endocarditis, and other infectious disease risk (e.g., sternal wound infections). As surgical interventions and medical treatment for CHD advance and become more available throughout the world, there will be more parents needing to learn how to appropriately manage their child's care at home and avoid complications after discharge.

Under the best of circumstances, parents of children with CHD have significant educational needs in order to understand this complex condition, its treatment, and how to manage their child's recovery and ongoing health care needs at home (Lerret, 2009; Sparacino et al., 1997). Parents may have difficulty understanding health information required to care for their children at home due to several important factors. These factors may include baseline low-literacy, inadequate health literacy, hurried and/or ineffectual parent teaching from health care providers, parental uncertainty or stress about the child's condition and transition to home, and a variety of socio-cultural influences (Cua & Kripalani, 2008; Dewalt & Hink, 2009; Franck, Mcquillan, Wray, Grocott, & Goldman, 2010). These challenges are magnified in resource

constrained environments such as India due to many parents living in remote rural villages, lack of transportation, prevalence of low-literacy, and/or lack of financial resources to obtain services. Consequently, parents require more in depth home care instruction to manage their children's care after hospital discharge to avoid complications (Lerret, 2009; Rao, 2007).

The consequences of parents being ill prepared for discharge are significant for the child after cardiac surgery and include the development of surgical site infections (SSIs), failure to thrive and growth retardation, inappropriate avoidance or participation in activities, development of vulnerable child syndrome, acquiring infectious endocarditis, hospital readmission, and even death (Tucker, Sullivan, Eichler, Williams, & Amato, 2012). Early, repeated discharge education is an important mechanism in preparing parents for managing their child's health and to avoid post-operative complications (Cua & Kripalani, 2008; Katz, Jacobson, Veledar, & Kripalani, 2007; Lerret, 2009). Nurses' consistent presence at the bedside places them in an excellent position to support parents during their discharge to home (Lerret, 2009). However, in general, nurses are rarely taught what to teach and how to teach parents and may be reluctant to provide parents with discharge education (Clare, 1985). In order to effectively teach parents home care information, nurses must have adequate knowledge of the child's condition and ongoing healthcare needs, understand the fundamentals of teaching parents, and possess good communication and evaluation skills (Lerret, 2009). A potential solution for improving child outcomes after cardiac surgery would be to educate, support, and empower nurses to lead a structured parent discharge program.

Currently in India, busy physicians will counsel patients at the time of discharge, impart a lot of information in a short time, may use medical jargon, may overestimate the parent's comprehension, and may not allow enough time for questions (Naidu, Rajavelu, & Rajagopalan,

2008). Moreover, nurses in India often rely only on the physician's written discharge summary to guide their teaching on the day of discharge. Although the discharge summary contains the facts of the child's hospital stay, it is likely to be written in technical medical jargon, and often omits important home care instructions (Naidu, et al., 2008). Empowering nurses to perform parental discharge teaching by educating them on home care instructions and providing them with support and guidance from senior nurse leaders could help facilitate a shift in their practice. A structured, comprehensive nurse-led parent discharge program could have positive influences on child outcomes after cardiac surgery.

The Parent Education Discharge Instruction (PEDI) program aims to support nurses in this important practice shift by teaching nurses how to effectively impart post-discharge home care information to parents in order to improve post-cardiac surgery outcomes for children in resource constrained environments. The PEDI program is designed to enable: 1) nurses to effectively convey knowledge and skills to parents (and other caregivers such as grandparents), and 2) parents to care for their children after discharge. The PEDI program consists of a computer-based discharge education training program for nurses, individual and group teaching sessions for parents, and standardized parent educational resources designed for both literate and low-literacy parents. Parent educational resources are available in English and six Indian dialects (Hindi, Bengali, Kannada, Malayalam, Tamil, and Telugu). Nursing educational resources are available in British English. The PEDI program has the potential to improve the lives of children with CHD after cardiac surgery through empowering nurses to become parent educators and coaches.

The conceptual framework for this dissertation is Meleis' Transitions Theory (Meleis, Sawyer, Im, Hilfinger, Messais, & Schumacher, 2000). Transitions involve a process of

movement or development and change or adaptation in fundamental life patterns (Meleis, 1975). Transitions cause changes in identities, roles, relationships, abilities, and patterns of behavior and are linked with situational and health-illness events, and processes that occur over time (Chick & Meleis, 1986; Weiss et al., 2007). Meleis (1991) defined transition as a change in health status, role relations, expectations or abilities, and it represents change in the needs of all human systems.

Transitions are complex and multidimensional and influencing factors can be either positive (facilitating) or negative (inhibiting) (Meleis, 1991). Personal, societal, and community conditions can also facilitate or hinder transitions. Personal conditions such as meaning of an experience, cultural beliefs, attitudes, socioeconomic status, preparation, literacy, and knowledge can all significantly impact patterns of response to a transition (Meleis, 1975).

Transitional experiences are characterized by their own uniqueness, diversity, and complexities (Meleis, 1975). The person experiencing a transition has patterns of responses that can be healthy or unhealthy. In healthy transitions, the person evolves to understanding of the diagnosis, treatment, recovery, and strategies for managing the transition and finally moves to mastery. Progress indicators that move clients toward positive outcomes include feeling connected, interacting, location and being situated, developing confidence, and coping. Outcome indicators that have emerged from transitions theory are mastery and fluid integrative identities, the behaviors needed to manage their new situation (Meleis et al., 2000). There is a reciprocal relationship with those who share knowledge; it empowers those who use it to educate and those who benefit from the knowledge. Our nursing therapeutics need to reflect this and be clarified, developed, tested, and evaluated. This dissertation focused on successful role supplementation of nurses and parents in order to minimize complications after pediatric cardiac surgery (e.g.,

surgical site infections), decrease parental uncertainty, and move toward closer alignment of nurses' and parents' perceptions of parental readiness for hospital discharge. Nursing and parental mastery of home care after cardiac surgery are fundamental constructs to enhance in order to achieve these outcomes.

The immediate outcomes from introduction of the PEDI program could include a reduction in complications such as surgical site infections, reduced length of stay for primary hospitalization and readmissions, reduced financial burden to parents (i.e., less than 5% of parents in India have health insurance), and a reduction in the parental perception of uncertainty and enhance their perception of readiness for discharge. Longer-term outcomes could include nurse empowerment, job satisfaction, and ultimately nursing retention.

This dissertation presents an analysis of the PEDI program in Southern India through three papers. The PEDI program was formally evaluated at one location in Southern India and then, the effects of the PEDI program on nurse, parent, and child outcomes were examined at a different hospital in Southern India. The first paper, Pediatric Cardiac Surgery Parent Education Discharge Instruction (PEDI) Program: A Pilot Study, describes program development and critically appraises the PEDI program. The appraisal included: 1) evaluation of nurses' and parents' perspectives on the acceptability of Indian nurses conducting parent discharge education, 2) assessment of the utility of the PEDI program, 3) preliminarily testing of the effectiveness of the PEDI program to enhance nurses' and parents' knowledge, 4) evaluation of adherence with discharge teaching documentation and oral and fingernail assessment documentation after PEDI program implementation, and 5) assessment of the PEDI program's sustainability.

The second paper, Parent Education Discharge Instruction Program for Care of Children at Home after Cardiac Surgery in Southern India, examines the PEDI program's effects on nurse and parent home care knowledge and the influence of knowledge on child outcomes (specifically surgical site infections, length of stay from cardiac procedure to discharge, and primary hospitalization and readmission costs). Finally, the third paper, An Analysis of Parent and Nurse Perceptions Associated with the Parent Education Discharge Instruction Program in Southern India, describes and compares nurses' and parents' perceptions before and after PEDI program implementation. This dissertation concludes with a discussion chapter that reviews findings, describes the significance of the studies, and identifies research and clinical practice implications.

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Chapter 2

Pediatric Cardiac Surgery Parent Education Discharge Instruction (PEDI) Program: A Pilot Study

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Acknowledgements

We would like to acknowledge and thank the following individuals and organizations for their generous support in the development of the PEDI materials (in alphabetical order):

Estelle Brouwer, MPA

Children's HeartLink

Lizzy DeVita, illustrator and graphic designer

Justine Kidd, RN

Jeff Paurus, RN

Pam Sagan, RN

Shanthi Sivanandam, MD

WiRED International

Abstract

Background

In developing countries, more children with complex cardiac defects now receive treatment for their condition. For successful long-term outcomes, children also need skilled care at home after discharge. The Parent Education Discharge Instruction (PEDI) program was developed to educate nurses on the importance of discharge teaching and to provide them with a structured process for conducting parent teaching for home care of children after cardiac surgery. The aim of this pilot study was to generate preliminary data on the feasibility and acceptability of the nurse-led structured discharge program on an Indian pediatric cardiac surgery unit.

Methods

A pre/post design was used. Questionnaires were used to evaluate role acceptability, nurse and parent knowledge of discharge content, and utility of training materials with 40 nurses and 20 parents. Retrospective audits of 50 patient medical records (25 pre- and post-) were performed to evaluate discharge teaching documentation.

Results

Nurses' discharge knowledge increased from a mean of 81% to 96% ($p = 0.001$) after participation in the training. Nurses and parents reported high levels of satisfaction with the education materials (3.75-4 on 4.00 point scale). Evidence of discharge teaching documentation in patient medical records improved from 48% (12/25 medical records) to 96% (24/25 medical records) 6 months after implementation of the PEDI program.

Conclusion

The structured nurse-led parent discharge teaching program demonstrated feasibility, acceptability, utility, and sustainability in the cardiac surgery unit. Future studies are needed to examine nurse, parent, child, and organizational outcomes related to this expanded nursing role in resource constrained environments.

Introduction

In hospitals worldwide, nurses assist pediatric patients and families in the transition from hospital to home. Investigations in the developed world have found that children most at risk for poor outcomes after discharge include those with complicated medical or social situations and children with parents not proficient in caring for their child pre-operatively [1]. In developing countries, more children with complex cardiac defects are now receiving treatment for their condition, but for successful long-term outcomes they also need skilled care at home after discharge. As primary caregivers of children with congenital heart disease (CHD), parents want to give their children the best care possible. However, caring for a child with CHD requires understanding their child's physiology (e.g., cyanosis), implementing complicated feeding regimens, correctly administering medication, providing appropriate oral care, practicing infection prevention strategies, knowing when to seek medical attention, and facilitating activities appropriate to the child's level of recovery. Parents must gain knowledge and mastery of the child's post-operative home care for prevention and early detection of problems. Failure to do so can lead to complications and poor outcomes.

The purpose of the Parent Education Discharge Instruction (PEDI) program is to teach nurses how to effectively impart home care information to parents in order to improve post-cardiac surgery outcomes for children in resource constrained environments such as those found in Indian cardiac centers. The PEDI program consists of a computer-based discharge education training program for nurses, individualized and group teaching sessions for parents, and standardized parent educational resources designed for both literate and low-literacy parents. This article examines the development and pilot testing of the PEDI program in Southern India.

Traditionally, in India, physicians perform the majority of the discharge teaching for children with CHD and their families. Investigations in developed countries have revealed that ineffective physician-patient communication can be associated with medication mismanagement [2,3,4]. This may be due in part to a lack of formal training for physicians on patient education [2,3,4]. Typically, when busy physicians counsel patients at the time of discharge, they impart a lot of information in a short time, may use medical jargon, overestimate patients' comprehension, and do not allow enough time for questions [2,5]. As a consequence, patients can be discharged home without understanding key information (e.g., medication regimens) [2]. Inadequate understanding of home care information is an even greater problem for patients with limited literacy and health literacy [6].

While nurses routinely participate in or have responsibilities associated with patient discharges in both developed and developing countries they rarely have formal preparation for this role. Therefore, nurse-led parent discharge teaching, if performed at all, is based on what nurses believe parents need to know or what is written on the physician discharge summary [7]. Yet, a growing body of evidence supports the positive effect of nurses formally taking on the role of patient and family education and for example, one study found that nurse-delivered patient education to mothers in a developing country reduced newborn mortality [8]. Research in developed countries has found that nurses were instrumental to parents' understanding of their child's home care needs and facilitated successful transition from hospital to home through ongoing discharge education [9]. Studies have concluded that parent education by nurses is vital for adequately preparing families for hospital discharge and their transition from hospital to home [10,11]. Therefore, a structured nurse-led parent discharge education program, such as the PEDI program in Southern India, could improve home care for children after cardiac surgery.

The specific aims of this investigation were five-fold: 1) evaluating nurses' and parents' perspectives on the acceptability of Indian nurses conducting parent discharge education, 2) appraising the utility of the PEDI program, 3) testing the effectiveness of the PEDI program in enhancing nurses' and parents' knowledge, 4) evaluating adherence with discharge teaching documentation and oral and fingernail assessment documentation after PEDI program implementation, and 5) assessing the PEDI program's sustainability.

Methods

PEDI Program Development Team and Process. The Principal Investigator and Study Sponsor convened an expert panel to develop the PEDI intervention. The panel consisted of 12 international healthcare providers (physicians, nurses, advanced practice nurses) with extensive experience caring for children with CHD in resource constrained environments, three parents of children with CHD from developed and developing countries, learning experts, and the sponsoring non-governmental organization (NGO), Children's HeartLink.

The main PEDI development work was accomplished through a series of conference calls convened by the sponsoring NGO with the panel members. As the team developed a draft program, they further consulted with a wide range of stakeholders and potential end-users. Input from these consultations was discussed at subsequent conference calls, and consensus was reached by discussion on all major program components.

Phases of PEDI Program Development. The PEDI program developed in three phases over two years. (See Figure 1). Phase 1 was a needs assessment. The development team formulated a questionnaire for cardiac centers in India to examine the perceived need for a structured discharge education program, explore attitudes about the acceptability of a nurse-led parent education intervention, and elicit from the cardiac centers the specific discharge teaching

content that they believed important for parents to learn. The questionnaire was distributed to a convenience sample of nurses and physicians in leadership positions at six Indian pediatric cardiac centers via electronic survey or administered in an oral interview. The results of the needs assessment indicated: 1) perceived need for improved discharge teaching that could be filled by a structured nurse-led parent discharge program, 2) specific topics that should be covered in training materials, 3) the importance of educating parents with low-literacy, 4) a variety of tools e.g., handouts, posters, flipcharts that should be available to nurses charged with teaching pediatric post-cardiac surgery home care, and 5) a need for physician and hospital administration support for the PEDI program. The needs assessment findings, the panel's expertise, and stakeholder consultation combined to define the key content of the PEDI program.

The final PEDI program has two main goals: 1) to enable nurses to effectively convey discharge information and skills to parents (and other caregivers such as grandparents), and 2) to enable parents to provide appropriate home care for their children after discharge. In Phase 2, parent educational materials were developed for literate and low-literacy parents. In Phase 3, a computer-based course was designed to teach nurses how to conduct individual and group parent discharge education sessions using the appropriate literacy-level parent materials. The PEDI nurse and parent training materials are available at: <http://www.itnhealth.net/CHL/>. Parent educational resources are available in English and six Indian dialects (Hindi, Bengali, Kannada, Malayalam, Tamil, and Telugu). Nursing educational resources are available in British English. (See Figure 1).

PEDI Program Implementation. The PEDI implementation team consisted of members of the PEDI development team, the hospital nurse educator, two medical students, and an interpreter. Nurses on the cardiac surgery unit were educated using the computer-based PEDI

training program. Members of the project team demonstrated parent discharge teaching sessions on the cardiac surgery unit after 75% of the nursing staff received training. Nurses then performed the parent discharge teaching with coaching from team members. The final component of the implementation process was a team debriefing. (See Figure 2).

Research Design. This investigation used a pre/post quasi-experimental design. Research approval was obtained from the University of California San Francisco Committee on Human Research and from the hospital's Ethics Committee. Initial post-implementation data collection began one week after program implementation. (See Figure 2).

Setting. The study was conducted at a dedicated pediatric heart hospital with approximately 100 inpatient beds, serving an urban and rural population in Southern India. Approximately 800 cardiac surgeries are performed annually on children from newborn to age 19.

Sample. The investigation utilized a non-random, convenience sample from the heart hospital comprised of nurses caring for children with CHD after cardiac surgery and the children's parents. All participants either spoke English or communicated through an interpreter. In addition, 50 medical records of children who had cardiac surgery were reviewed. The children whose medical records were reviewed were unrelated to parent participants. Exclusion criteria were: 1) any nurse or parent who did not understand and speak English or did not wish to use an interpreter or 2) parent of a child receiving end-of-life care. All participants were assured that participation in the research component of the project was completely voluntary.

Measures. The project team developed all measures as no validated tools existed to measure the study outcomes. The outcome concepts were: acceptance-level of Indian nurses conducting parent discharge education, effectiveness of nurse-led discharge education program

for nurses and parents, utility of training materials, nursing discharge documentation practices, and program sustainability.

The Nurse Self Report (NSR). The NSR consisted of 25 forced-choice items on a 4-point positively weighted Likert scale and three narrative questions that were designed to elicit nurses' perceptions and attitudes related to the PEDI program. NSR subscales included usefulness, clarity, understandability, knowledge, cultural relevance, feasibility, effect on parental anxiety, and quality of the program.

The Parent Self Report (PSR). The PSR consisted of 16 forced-choice items on a 4-point positively weighted Likert scale and three narrative questions that were designed to elicit parent perceptions and attitudes related to the PEDI program. Nine subscales of the PSR included evaluation of quality, usefulness, clarity, understanding, knowledge, and ability to ask questions, cultural relevance, recommendations reasonability, and anxiety reduction.

Nursing Mastery Test (NMT): NMT is a 30-item questionnaire to assess nurses' knowledge of discharge content essential for parents to know prior to caring for their child after discharge. NMT questions were multiple choice or true/false. Total scores were calculated and then translated to 0-100 point scale. Scores were obtained prior to nurses viewing the computer-based training program to ascertain nurses' baseline knowledge levels and compared with scores immediately after viewing the training session to determine knowledge gained. (See Supplementary Materials Figure 3).

Parent Mastery Test (PMT): The PMT questionnaire measured parents' knowledge of their child's post-operative home care needs after a structured discharge education program performed by nurses. Four learning domains were assessed: 1) when to seek medical care, 2) signs of

infection, 3) oral care, and 4) fingernail care. Total scores were calculated and then converted to a 0-100 point scale. (See Supplementary Materials Figure 4).

Medical Record Review: Four members of the team reviewed 50 medical records of children after cardiac surgery for evidence of nurses' notation of performance of discharge teaching (Yes/No) and fingernail and oral assessment (Yes/No).

Group Teaching Sessions: Nursing staff maintained an audit trail of all group discharge teaching sessions to assist in the evaluation of program sustainability. The nurses documented educational topics reviewed and number of parent participants in the group teaching sessions.

Study Procedures. Nurses who consented to participate completed the NMT before and after viewing the computer-based training program. Once 75% of all nurses were educated, NSR and PSR questionnaires were completed by participants. The questionnaire responses were in either written format or interviews conducted with an interpreter and transcribed verbatim. The interpreter was master's prepared (non-medical) and fluent in several local Indian languages and English. Twenty-five medical records were reviewed prior to PEDI program implementation, and an additional 25 medical records were reviewed six months after PEDI program implementation. An audit trail for evidence of group teaching sessions was evaluated two years post-implementation of the PEDI program by the principal investigator.

Statistical Analysis.

All quantitative data were managed with SPSS software (SPSS version 22, Armonk, New York). Due to the fact that the self-report data may be skewed, descriptive data were initially analyzed by nonparametric methods. However, due to a ceiling effect the nonparametric testing provided little insight into the specific results of this investigation. Median and interquartile ranges were equal to 4.00 for each topic of the NSR and PSR. Therefore the means and standard

deviations provided more meaningful measures of central tendency. Assumptions for parametric statistics were met for the NMT. NMT scores were compared using paired Student's *t*-test. Presence of discharge documentation was evaluated using the Fisher Exact test. A *p* value less than 0.05 was considered significant.

Results

The final sample consisted of 38 nurses (NMT), 20 nurses' self-report surveys (NSR), 20 parents' self-report (PSR) and knowledge surveys, and 50 medical records of children after cardiac surgery. Findings are summarized in five categories: 1) acceptability of nurses providing discharge teaching, 2) utility of the PEDI program, 3) PEDI program effectiveness in enhancing nurses' and parents' home-care knowledge, 4) adherence with discharge documentation and oral and fingernail assessments, and 5) program sustainability over time.

Acceptability. Twenty nurses completed the NSR. Three participants did not respond to the open-ended NSR questions. Nurse participants described satisfaction with teaching parents about caring for their child after discharge ($M=3.95$, $SD=0.23$) and parent teaching made them "feel good" about the work they do ($M=4.00$). (See Table 1). All nurses' responses to open-ended questions were positive. Nurses reported enjoying the teaching role, and experiencing job satisfaction, confidence, and an increased sense of responsibility. One nurse remarked, "*I feel this role is very different from my previous role of being a nurse. I feel very comfortable with this booklet in my hand. I am confident that a lot of information can be given in a short span of time effectively.*" Another nurse commented "...*feeling good to know that our care is extended up to patient's home not only in hospital.*"

Twenty parents completed the PSR, one parent did not respond to the open-ended acceptability question on the PSR, and there were no negative comments on the acceptability of

nurses' teaching parents. Parents were generally supportive of nurses providing this education. One parent responded "*I will be happy and satisfied even with a nurse giving me discharge teaching.*" Whereas another parent stated "*Nurses should be given more training before they give us discharge teaching. I felt that explanation given by PEDI project team was better than that given by nurses.*"

Utility of the PEDI Program. Nurses evaluated the utility of the PEDI program and were supportive. NSR subscale scores ranged from 3.68 to 4.00. Of note nurses questioned the feasibility following the training program recommendations (M=3.68, SD=0.48) and whether there was increased depth of information given to parents (M=3.74, SD=0.653). (See Table 1 and 4 Supplementary Materials). One nurse commented that after PEDI program training she could "*....empower the parents to look after their child, thus quickening the healing process.*" Another nurse expressed that she was "*....capable of directing them (parents) for a faster recovery (of their child)....*" after implementation of the PEDI program.

Parents had a positive evaluation of the discharge teaching materials and were supportive of their use during the discharge process. (See Tables 2 and 4 Supplementary Materials). Overall, parents described the written materials as very good, informative, helpful, clear, understandable, and the pictographs in the low-literacy documents were self-explanatory. The parent handouts received only positive feedback. Parents felt the pictures and the content could help them better care for their child at home and decreased their apprehension with the transition from hospital to home. One parent expressed, "*I feel uncomfortable in asking little, little things to the doctor now. I am happy that with this booklet in hand I may not need to ask anyone.*" Another stated, "*I liked the booklet a lot. I understood very well how to take care of my child and I am glad that someone took so much pain in explaining me the discharge instructions.*"

When queried about additional items for improving the educational materials, several parents requested the inclusion of one-line statements to the low-literacy documents in appropriate dialects and their child's nutrition requirements to promote post-operative healing and weight gain. Additionally, parents identified "lifting their child" and "immunizations" as important content for inclusion in parent discharge education. These modifications were added to the next version of parent educational materials.

Pertinent educational content for parent materials was also explored via rank-order process by both parents and nurses. Nurses and parents ranked sternal wound care and infection control practices similarly as top priorities. Parents ranked nutrition (3), activities (4), and when to seek care (5), as priorities in their learning needs. In contrast, nurses ranked medications (3), follow-up care (4), and when to seek help (5), as the next priorities in parent education. (See Table 3 Supplementary Materials).

Effectiveness of the PEDI Program on Nurses' and Parents' Home Care Knowledge.

Forty of 53 nurses employed at the hospital (75.5%) completed the NMT. There were two participants with missing data, and these participants were excluded from the analysis; the final NMT sample was 38. Paired Student's *t*-test showed a statistically significant improvement in nurse knowledge scores (from 80.5 to 95.7, $p < 0.001$). The range of pre-test scores was 61.54 to 100% and post-test scores ranged from 76.92 to 100%.

Assessment for evidence of parental integration of knowledge was assessed using PMT. Eighty percent of parents (16/20) appropriately answered four open-ended questions about when to seek medical care, signs of infection, oral and fingernail care; the few parents who could not answer all four questions answered three questions correctly (4/20). All parents could recall medical conditions that require them to seek medical care and how to perform fingernail care.

There were two questions parents recalled less often: 1) two ways to care for their child's teeth and mouth and 2) two signs of infection. All parents stated brushing teeth; however, some could not recall the need for seeing a dentist. Additionally, parents could recall fever as one of the indications of infection, but some could not recall another symptom.

Adherence with Oral and Fingernail Assessments. Adherence with documentation requirements was evaluated through medical record review for oral and fingernail nursing assessments. Evidence of appropriate documentation in the medical record was evaluated (pre- and post-implementation). Prior to the PEDI program there was no evidence of oral and fingernail assessments in patient medical records. The post-implementation cohort showed 100% adherence with documentation of these assessments.

Program Sustainability. The core program sustainability elements measured were documentation of individualized nurse-parent discharge teaching (at six months) and group teaching sessions (at two years). Pre-implementation, 48% of the medical records (12/25 medical records) had evidence of discharge teaching documented, whereas, after implementation, discharge teaching was documented in 96% of the medical records (24/25 medical records; Fisher exact test, $p=0.0001$). An audit trail revealed evidence of 295 group teaching sessions from June 2010 to December 2012.

Discussion

Our investigation found that the PEDI program: 1) was acceptable to nurses and parents, 2) nurses' and parents' home care knowledge improved after program implementation, 3) training materials were useful for nurses and parents, 4) there was adherence with discharge documentation and oral and fingernail assessments, and 4) the program had short-term and long-term sustainability in the study site. Nurses had positive views about the PEDI program and

specifically stated that they enjoyed the teaching role. The intervention increased nurses' reported job satisfaction, confidence, and their sense of responsibility.

Nurses need to have a strong knowledge base of home care content, understand the fundamentals of teaching patients and their families, and have good communication and evaluation skills in order to adequately prepare parents for assuming responsibility for their child's home care duties [9]. Our investigation found that nurses and parents supported nurses providing discharge education. However, additional supports for nurses are needed in order for them to hone their skill with discharge teaching. Replication at an additional site in Southern India could strengthen the findings of this study.

Parent education has been shown to be a critical activity necessary to ensure parents are adequately prepared for their child's discharge and transition home in the developed world [10,11]. Despite relatively high baseline nursing knowledge scores, our investigation revealed a significant gain in discharge knowledge by nurses and parents alike, providing preliminary evidence that nurses in developing countries have mastery of important content required to assume the role of parent educators and that parents can also gain new knowledge from the PEDI program.

Short- and long-term program sustainability is a dynamic phenomenon [12]. Stirman and colleagues (2012) assert that a program's impact can be considered sustained if core elements remain at or above the level achieved during program implementation at a given point after implementation support has been withdrawn. Additionally, the new program must be delivered at a sufficient fidelity and adequate capacity for continuation [12]. In their systematic review of the literature on program sustainability, Stirman and colleagues (2012) indicated that a majority of investigations assessed sustainability during a two-year or greater period (and not a single

time-point) after support had been withdrawn. Our study revealed an extremely high level of sustained use of the PEDI program with individual nurse-parent teaching sessions documented in the medical record at six months and group teaching sessions were documented continuously over a greater than two-year period.

These findings should be considered in light of the study limitations. Our study data were collected from a nonrandom, small convenience sample at a single site and were exploratory in nature, using a pre-post design. Additionally there were no specific measures with demonstrated validity and reliability in this population and new measures were developed for this study. All these factors are sources of potential bias and limit generalizability. However, given the paucity of literature associated with structured, nurse-led parent discharge training programs in resource constrained environments, the findings from this exploratory pilot study can inform future research.

Conclusion

A structured nurse-led parent discharge teaching program demonstrated feasibility, acceptability, usefulness, effectiveness, and sustainability in our pilot study. Future studies are needed to examine nurse, child, parent, and organizational outcomes related to this expanded nursing role in resource constrained environments.

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Table 1 Nurse Self Report n=20

Subscale	Evaluation Method	Results
Quality	Overall quality of parent handouts	Mean = 3.9 SD = 0.31
Quality	Overall quality of nurse training	Mean = 3.9 SD = 0.3
Usefulness	Parent handouts	Mean = 3.85 SD = 0.36
Usefulness	Would use handout when performing teaching	Mean = 4 SD = 0
Usefulness	Would use documents again	Mean = 3.84 SD = 0.38
Usefulness	Training program	Mean = 3.9 SD = 0.31
Clarity	Recommendations in handouts presented in clear manner	Mean = 3.8 SD = 0.41
Clarity	Recommendations in training program presented in clear manner	Mean = 3.9 SD = 0.31
Understandability	Handout information presented in an understandable way	Mean = 3.85 SD = 0.37
Understandability	Training program is presented in an understandable manner	Mean = 3.9 SD = 0.37
Knowledge	Handouts informed parents	Mean = 3.75 SD = 0.44
Knowledge	Training informed nurses	Mean = 4 SD = 0
Knowledge	Training helped nurse remember discharge teaching	Mean = 4 SD = 0
Knowledge	Information given by nurses is more in depth since training	Mean = 3.74 SD = 0.65

Subscale	Evaluation Method	Results
Cultural relevance	Pictographs reflect typical ADLs in India	Mean = 3.8 SD = 0.41
Cultural relevance	Training program reflects ADLs in India	Mean = 3.75 SD = 0.44
Feasibility	Handout recommendations feasible for nurses to follow	Mean = 3.8 SD = 0.41
Feasibility	Training program recommendations feasible for nurses to follow	Mean = 3.68 SD = 0.48
Anxiety	Program reduces parental anxiety	Mean = 3.9 SD = 0.31
Satisfaction	With parent handouts	Mean = 3.89 SD = 0.32
Satisfaction	Parent teaching improves RN job satisfaction	Mean = 3.95 SD = 0.23
Satisfaction	With expanded role in discharge teaching	Mean = 3.89 SD = 0.32
Satisfaction	Makes nurses “feel good” about their work	Mean = 4 SD = 0

Table 2 Parent Self Report n=20

Subscale	Evaluation	Results
Quality	Overall quality of handouts	Mean = 3.95 SD = 0.23
Usefulness	Parent handouts useful in preparing me to go home	Mean = 3.9 SD = 0.31
Clarity	Recommendations in handouts presented in clear manner	Mean = 3.95 SD = 0.23
Understandability	Handouts helped me understand what was needed for home care	Mean = 3.85 SD = 0.37
Understandability	Handout information presented in understandable way	Mean = 3.95 SD = 0.23
Knowledge	Handouts informed you about your child's home care	Mean = 3.85 SD = 0.37
Knowledge	Helped me understand how to care for child's surgical wound	Mean = 3.8 SD = 0.523
Knowledge	Helped me understand when to seek help	Mean = 3.95 SD = 0.22
Knowledge	How to care for my child at home*	Mean = 3.9 SD = 0.22
Asking Questions	Nurses encouraged me to ask questions about home care	Mean = 3.8 SD = 0.41
Cultural relevance	Pictographs reflect typical ADL in India	Mean = 3.95 SD = 0.22
Recommendations	Handout recommendations reasonable to follow	Mean = 3.75 SD = 0.55
Anxiety	Decreased my anxiety	Mean = 3.85 SD = 0.49

Figure 1 PEDI Program Development

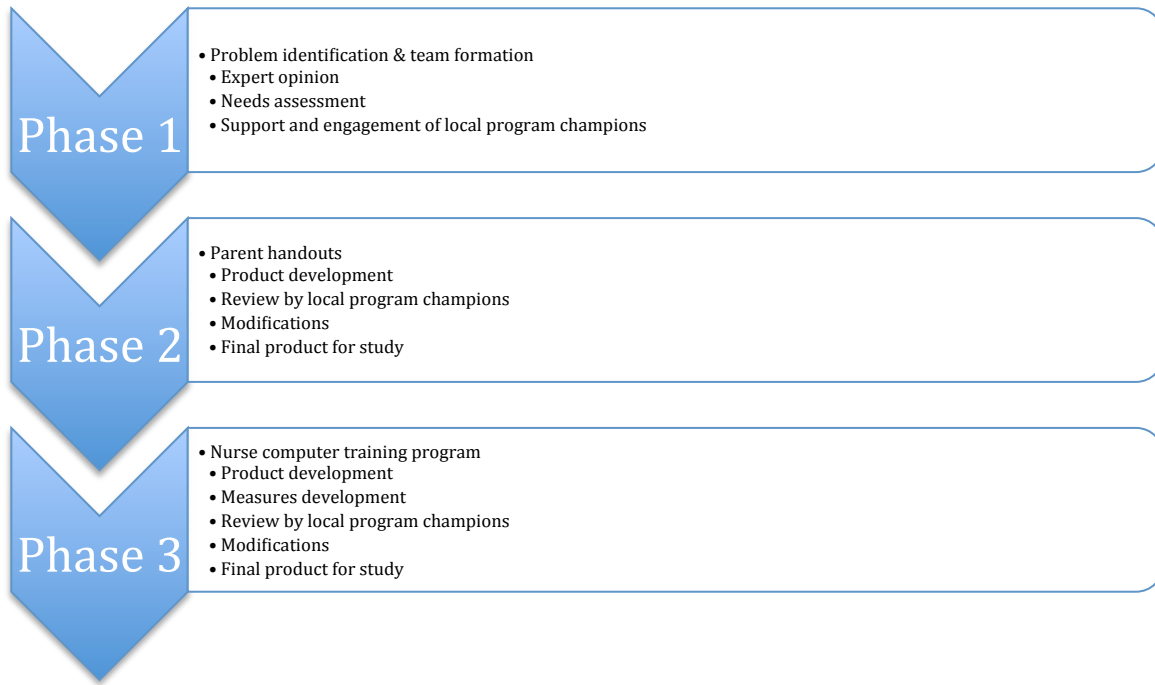
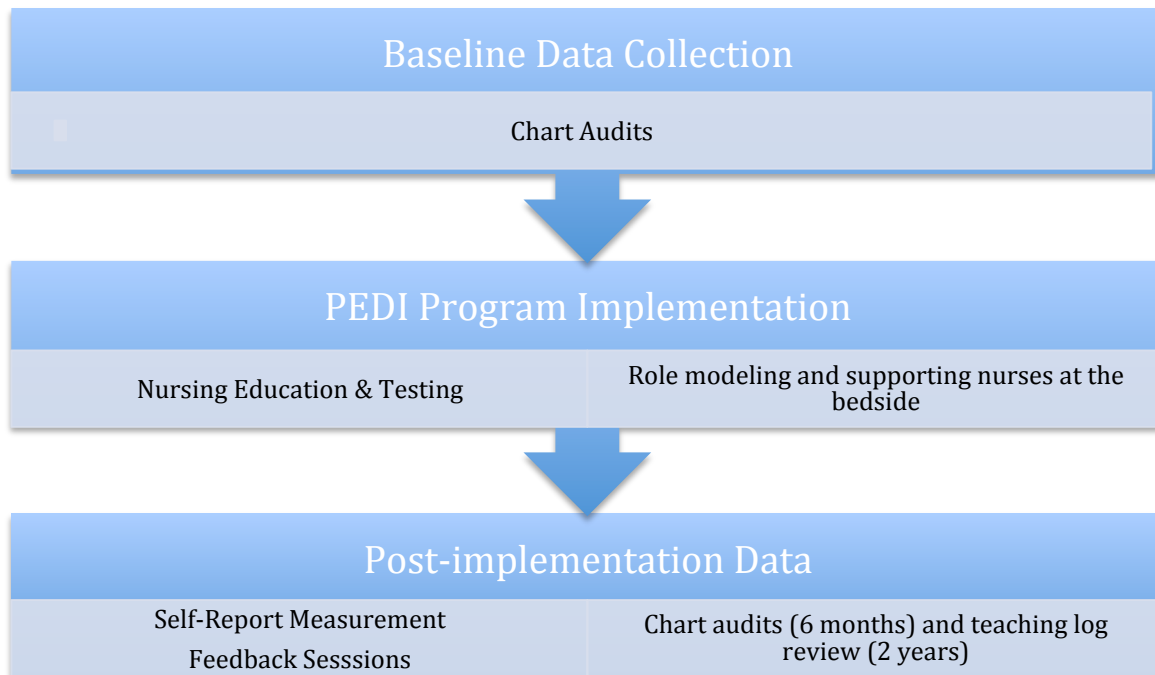


Figure 2 Study Design



Supplementary Materials

Table 3 Importance of Educational Content (Rank Order)

Topic	Nurse	Parent
Sternal wound care	1	1
Infection practices	2	2
Medications	3	7
Follow-up Care	4	9
When to seek help	5	5
Oral care/dental	6	10
Activities	7	4
Nutrition	8	3
Behaviors	9	8
School	10	11
Lifting (write-in)	-	6
Immunizations (write-in)	-	12

Table 4 Self-Report Tools

Domain	Nurse Self-Report Number of Questions	Parent Self-Report Number of Questions
Quality	2	1
Usefulness	4	1
Clarity	2	1
Understandability	2	2
Knowledge	4	4
Cultural relevance	2	1
Feasibility/Reasonability	2	1
Satisfaction	4	1
Anxiety	1	1
Parents ability to ask questions	0	1

Figure 3 Nurse Mastery Test

1. It is important for parents to learn in small, repetitive, incremental steps. **True**
2. Parents may expect to see changes in their child's behavior for a while after surgery. **True**
3. What are sternal precautions?
 - a. **No heavy lifting, no football, adequate rest**
 - b. No reading, soccer, and stay in bed
 - c. No heavy lifting, no soccer, and stay in bed
4. How long do children have to wait after surgery to resume normal activities?
 - a. 2 weeks
 - b. 4 weeks
 - c. **6 weeks**
 - d. 8 weeks
5. Protein in the child's diet is important for wound healing. **True**
6. Handwashing reduces infections. **True**
7. Short, clean fingernails are important. **True**
8. If a child vomits/spits out a medicine the parent should re-administer it. **False**
9. Parents need to follow-up with the physicians near their home? **True**
10. What type of water should be used to clean surgical wounds at the patients' home?
 - a. Sterile water
 - b. Bottle water
 - c. Boiled, cooled tap, pond, or river water
 - d. **All of the above**
11. What best describes a sternal wound infection?
 - a. **Warm, red, swollen, painful**
 - b. Pink, cool, and dry to touch
 - c. Darkened skin, cool and dry to touch
12. Brushing teeth at least twice a day is important? **True**
13. Parent should seek help if their child:
 - a. Is blue or grey
 - b. Has a swollen face
 - c. Has a fever
 - d. Has difficulty breathing
 - e. **All of the above**
14. Patient education is a part of the nursing process and should begin upon admission. **True**
15. Information given to parents about how to care for their children can improve their child's outcomes. **True**
16. What is the best way to teach parents?
 - a. Brief individualized, simple education session
 - b. Group teaching sessions
 - c. Handouts are enough
 - d. **Brief, repeated, individual, simple teaching sessions over a period of time, given handouts, and with the parents repeating back the information in their own words**
17. Nurses need to assess parents' readiness to learn, understanding, and competency in providing care. **True**
18. For 6 weeks after cardiac surgery what is too much weight for a small child to lift?
 - a. **Less than 5 kg**
 - b. Less than 10 kg
 - c. More than 10 kg
 - d. More than 5 kg
19. How is the best way to lift infants after cardiac surgery?
 - a. Under arms
 - b. By one arm
 - c. **Support head/neck with one hand and lower body and buttocks with another**
20. How long should steady pain last after surgery?
 - a. 3 days
 - b. **1 week**
 - c. 2 weeks
 - d. 4 weeks

21. When can children return to school?
 - a. 1 month
 - b. 2 months
 - c. 3 months
 - d. **1-2 weeks**
22. Should lotions, cream, sunscreen or oils be applied to the incision for the first 6 weeks? **No**
23. Itching is a normal sign of healing? **Yes**
24. A clean, cotton, shirt over the chest incision is important for reducing infections. **True**
25. Subacute bacterial endocarditis is an infection of your heart that might be avoided if appropriate antibiotics were taken before dental care. **True**
26. Medications need to be given on time. **True**
27. Discharge coordination includes:
 - a. Follow-up appointments
 - b. Medications
 - c. Educational handouts
 - d. Teaching sessions
 - e. None of the above
 - f. **All of the above**
 - g. B, C, and D
28. Discharge documentation includes:
 - a. Discharge content covered in the module
 - b. Readiness for learning, comprehension, understanding, competency through teach back
 - c. None of the above
 - d. **All of the above**
29. Oral and fingernail assessments and teaching are requirements. **True**
30. Nurses are important resources for children and parents. **True.**

Middle Quiz (ungraded)

1. Parents teaching back is appropriate at these times:
 - a. When the parents are first hearing the information.
 - b. After several repeated teaching sessions
 - c. Prior to discharge
 - d. A and B
 - e. **B and C**
2. Nursing documentation of discharge teaching is important. **True**
3. All ointments and creams on unhealed wounds can introduce bacteria that cause infection into the surgical wound. **True**
4. Proper dental care may avoid subacute bacterial endocarditis. **True**

Figure 4 Parent Mastery Test – Open-ended Questions

Question – Must answer all aspects to receive credit
1. Please state three changes in your child that you have been taught to return to the hospital or seek help from a doctor.
2. Please state two changes in your child's appearance that make you think they might have an infection.
3. Describe two ways to take care of your child's teeth and mouth.
4. Describe two ways to take good care of your child's hands and fingernails.

Chapter 3

Parent Education Discharge Instruction Program for Care of Children at Home after Cardiac Surgery in Southern India

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Acknowledgements

We would like to acknowledge and thank the following individuals and organizations for their generous support in the development of the PEDI materials (in alphabetical order):

Estelle Brouwer, MPA

Children's HeartLink

Lizzy DeVita, illustrator and graphic designer

Justine Kidd, RN

Jeff Paurus, RN

Pam Sagan, RN

Shanthi Sivanandam, MD

WiRED International

Bistra Zhelva MBA

Abstract

Objective: This investigation evaluated the effectiveness of a structured nurse-led parent discharge teaching program on nurse, parent, and child outcomes in India.

Methods: A pre-post design compared nurse and parent home care knowledge before and after the Parent Education Discharge Instruction (PEDI) program. Child surgical site infections and hospital costs were compared for six months prior to and after PEDI program implementation.

Results: Nurses (n=63) and parents (n=68) participated. Records of 195 children who had cardiac surgery were reviewed. Nurses had a high level baseline home care knowledge that increased 3 points (30 point scale) ($p < 0.005$) immediately after the PEDI program, but decreased to baseline four months after PEDI. Nurse teaching documentation increased 56% after PEDI. Parent knowledge scores increased 1.92 points (0-4 scale) after PEDI ($p < 0.005$). Surgical site infections decreased from 27% prior to 2% ($p > 0.05$) after PEDI implementation.

Conclusion: Nurse, parent, and child outcomes were improved after implementation of the structured nurse-led parent discharge program for parents in India. Further investigation of causality and influencing factors is warranted.

Practice Implications: Structured nurse-led parent discharge programs may help to prepare parents to provide better home care for their children after cardiac surgery.

1. Introduction

Children with congenital heart disease (CHD) in many developing countries are now receiving surgical repair or palliation for their complex medical condition. Consequently, parents require more in depth discharge education programs to enable them to recognize complications and manage their children's care after hospital discharge. Upon discharge, parents are required to adhere to specific discharge instructions such as proper medication administration, provision of sufficient nutrition to augment wound healing, maintenance of appropriate activity limitations to promote sternal ossification, and application of infection prevention practices at home to minimize the risk of surgical site infections (SSIs) [1].

Nurses are important agents in the transition from hospital to continued recovery at home through their discharge teaching. However, nurses often are not taught the fundamentals of patient/parent education or what discharge content is important to share with parents [2]. Therefore, nurse mastery of home care instructions and specific skills for discharge teaching are important precursor to effective parent discharge education. Nurses often rely only on the physician's written discharge summary to guide their teaching on the day of discharge. Although the discharge summary contains the facts of the child's hospital stay, it is likely to be written in technical medical jargon, and often omits important home care instructions [3,4]. Inadequate parent education results in a suboptimal transition from hospital to home, an increase in preventable post-operative complications, and ultimately hospital readmission [5].

We have previously reported preliminary findings suggesting that a structured nurse-led parent discharge education program was feasible, acceptable, useful, effective, and sustainable for educating parents of children after cardiac surgery in Southern India [6]. The Parent Education Discharge Instruction (PEDI) program consists of a computer-based discharge

education training program for nurses, individualized and group teaching sessions for parents, and standardized parent educational resources designed for both literate and low-literacy parents. Parent educational resources are available in English and six Indian dialects (Hindi, Bengali, Kannada, Malayalam, Tamil, and Telugu). The specific aims of this investigation were three-fold: 1) to compare nurses' home care knowledge and their medical record documentation before and after PEDI program implementation, 2) to compare the effect of the PEDI program on parental knowledge of home care requirements before and after PEDI program implementation, and 3) to compare child surgical outcomes (e.g., surgical site infections, length of stay from cardiac procedure to discharge, primary hospitalization and readmission costs) before and after PEDI program implementation. The primary outcome variable of this investigation was the presence of SSIs within thirty days of cardiac surgery before and after PEDI program implementation.

2. Methods

2.1. Design and Setting

A quasi-experimental design was used to compare nurse and parent home care knowledge, nursing documentation, and child outcomes before and after introduction of the PEDI program. Research approval was obtained from the Committee on Human Research at University of California San Francisco and from the Ethics Committee at the Amrita Institute of Medical Sciences (AIMS).

The investigation was performed in a pediatric cardiac center serving children from urban and rural regions in Southern India, the surrounding states, and from other countries.

Approximately 700 cardiac surgeries are performed annually at the center for children from

newborn to age 19 years. The cardiac surgery unit has approximately 45 inpatient cardiac surgery beds, in multi-bed rooms serving low- and middle-income families.

2.2. Participants and Procedures

2.2.1. Participants

The principal investigator and the supporting non-governmental organization (NGO), Children's HeartLink, engaged hospital leadership support for adopting the PEDI program as their standard of care based on previous pilot work at another facility in Southern India demonstrating its acceptability, feasibility, utility, and sustainability [6].

The investigation recruited non-random, convenience samples of: 1) nurses caring for children after cardiac surgery, 2) parents of children who had cardiac surgery, and 3) medical records of children who had cardiac surgery before and after implementation of the PEDI program. All nurse and parent participants either spoke English or communicated through an interpreter. Exclusion criteria were: 1) parents of a child nearing end-of-life, and/or 2) children and the families of children cared for in private rooms outside of the cardiac surgery unit.

Cohort 1 nurse participants completed a discharge education test at two time-points prior to (T1) and after training (T2), and a subset of Cohort 1 completed a discharge education test at four months after PEDI implementation (T3). Nurses in Cohort 2 consisted of cardiac surgery nurses hired after the initial study training. Therefore, Cohort 2 did not participate in T1 and T2, but they did receive PEDI training as part of their new-hire training on the cardiac surgery unit. Cohort 1 parent participants and consecutive child medical records (not matched) were accrued prior to implementation of the PEDI program. Parent participants in Cohort 2 and consecutive child medical records were accrued four months after PEDI program implementation.

2.2.2. *Procedures*

The PEDI research team consisted of the principal investigator, hospital nurse educator, nursing director, and the cardiac surgery unit nurse manager and coordinated the implementation and evaluation of the PEDI program. Parents in Cohort 1 who consented to participate in the study completed the Parent Mastery Test (PMT) prior to PEDI program implementation [6]. Parents completed a paper copy of the questionnaire or were interviewed by the nurse educator, who transcribed their responses verbatim. The nurse educator has a master's degree and is fluent in several languages including local Indian dialects and English.

After 30 Cohort 1 parent questionnaires were completed, Cohort 1 nurses who consented to participate in the study were asked to complete the Nurse Mastery Test (NMT) before and after viewing the computer-based training program during a three-week period [6]. All nurses on the cardiac surgery unit, except two who were on leave, were educated using the PEDI program. After 90% of the nursing staff received training, members of the project team role-modeled 10 sessions of PEDI teaching on the cardiac surgery unit. Nurses then performed the PEDI teaching with coaching from the team. Concurrently, the principal investigator examined the medical records of 90 children for demographic and clinical characteristics, presence of SSIs and number of days from cardiac surgical procedure to discharge. Records from the International Quality Improvement Collaborative (IQIC) database were examined before and after PEDI program implementation in order to corroborate the medical record data and no discrepancies between data in the medical record and IQIC database were found. The AIMS infection control department was queried for monthly SSI rates for the hospital's pediatric cardiac surgery population and the proportion of SSIs within a six-month time period were calculated for

Cohorts 1 and 2. Primary hospitalization costs and readmission costs were accrued from a separate hospital database.

Each week the nurse manager examined nursing documentation for evidence of discharge teaching between T1 and T3. The nurse educator and nurse manager also incorporated the computer-based nurse PEDI discharge training into orientation for new nurses hired for the cardiac surgery unit.

Four months after the PEDI program implementation, a second sample of parents (Cohort 2) were recruited and they completed the Parent Mastery Test (PMT) [6]. Nurses in Cohort 1 were asked to complete the Nursing Mastery Testing (NMT) for a third time [6]. Newly employed nurses (Cohort 2) completed the NMT for the first time [6]. A second sample of 105 children's medical records (Cohort 2) was reviewed and verified with the IQIC database. A convenience subset of child medical records was evaluated for length of stay from cardiac procedure to discharge and the financial database re-queried for primary hospitalization costs and readmission costs for these children.

2.3. Measures

2.3.1. The Nursing Mastery Test (NMT)

NMT is a 30-item questionnaire to assess nurses' knowledge of discharge content essential for parents to know prior to caring for their child after discharge [6]. NMT questions were multiple choice or true/false. Total scores were calculated and based on 0-30 point scale. Learning domains included: 1) when to seek medical care, 2) signs of infection and infection prevention strategies, 3) oral care, 4) fingernail care, 5) medication administration, 6) surgical wound care, 7) behavioral changes after cardiac surgery, 8) appropriate activity restrictions and

school re-entry after cardiac surgery, 9) nutritional requirements after cardiac surgery, and 10) evidence-based home care teaching methods [6].

2.2.2. The Parent Mastery Test (PMT)

The PMT is a four-item questionnaire developed by the research team to measure parents' knowledge of important aspects of their child's post-operative care at home after pediatric cardiac surgery in India [6]. Learning domains included: 1) when to seek medical care, 2) signs of infection, 3) oral care, and 4) fingernail care. Total scores were calculated and based on 0-4 point scale and the proportion of individual correctly answered questions reported.

2.3.3. Nursing audit and documentation in medical record

Evidence of nurses' documentation of parent discharge teaching completion was reviewed each week on nursing audit forms (Yes/No) for this investigation during the first four months after PEDI program implementation. Additionally, medical records were evaluated for presence of parent discharge teaching in nursing notes (Yes/No) to corroborate the nursing discharge documentation on the study audit forms.

2.3.4. Child demographic and clinical characteristics

The medical records of children after cardiac surgery were examined for demographic and clinical characteristics. Five dichotomous (Yes/No) items were evaluated and include: 1) developmental delay, 2) presence of genetic syndrome, 3) other major medical illnesses, 4) presence of pulmonary hypertension, and 5) history of prematurity. In addition, two continuous variables were examined: 1) baseline oxygen saturation, and 2) baseline hematocrit. Finally, calculation of surgical risk using the Risk Adjusted Classification for Congenital Heart Surgery (RACHS-1) was evaluated [7]. All data were corroborated with the IQIC database.

2.3.5. *Surgical Site Infections*

Children's medical records were examined for presence of SSIs during hospitalization and verified by the IQIC database. The managers of the IQIC database perform 30-day follow-up calls to assess for development of SSIs after hospital discharge and these data were included in the analysis. Data collection occurred during summer and monsoon months, because those are historically the months with the highest rates of SSIs.

2.3.6. *Other child surgical outcomes*

Four variables were evaluated in child medical records and the financial database included: 1) length of time from surgical procedure to discharge, 2) primary hospitalization costs, 3) occurrence of re-hospitalization after pediatric cardiac surgery, and 4) readmission costs for nursing care and bed utilization.

2.3. *Analysis*

Data were entered into SPSS (IBM SPSS Statistics Version 22.0; Armonk, New York). All data were expressed in means and standard deviation units for consistency. However, examination of statistical significance was based on meeting the assumptions for parametric or nonparametric statistics. Independent samples Student's *t*-tests were performed on continuous variables such as days from cardiac procedure to discharge, oxygen saturation, hematocrit, and primary hospitalization and readmission costs. Mann-Whitney U tests were performed on PMT scores, Cohort 1 and Cohort 2 NMT scores at T3, and RACHS-1 scores. Wilcoxon Signed Rank test was used to examine Cohort 1 NMT scores at T1 and T2. A subset of Cohort 1 with NMT scores at T1, T2, and T3 were evaluated with the Friedman test. The Fisher exact test was utilized to examine the proportion of children with SSIs in Cohort 1 and 2, the proportion of medical records with appropriate discharge documentation in nursing notes, and the proportion

of parents who correctly answered questions in the PMT. A p value less than 0.05 was considered significant.

3. Results

3.1. Nurses – sample characteristics

There were 63 nurse participants in this study (Cohort 1 = 45, Cohort 2 = 18). Each cohort included 90% of nurses working on the cardiac surgery unit at the time point; the remaining 10% were on leave. No nurses declined participation. However, there was attrition and this was reflected in the smaller Cohort 1 sample size at time-point three ($n = 10$).

3.1.1. Nurse discharge knowledge

Initial testing of mean nursing knowledge scores (0-30 scale) between T1 and T2 showed an improvement from 24.4 (SD = 2.89) to 27.4 (SD = 1.55) (Wilcoxon Signed Rank test, $p < 0.005$). However, the scores essentially returned to baseline when evaluated four months after program implementation in the subset of nurses that were still actively employed at the hospital. This subset had mean knowledge score at T1 of 23.4 (SD = 2.41), 28.1 (SD = 1.37) at T2, and 23.8 (SD = 3.4) at T3. Additionally, there were 18 newly-hired nurses (who received PEDI training as part of their orientation) who had a mean score of 23.4 (SD = 3.33). There was no significant difference between the NMT scores for nurses in Cohort 1 and Cohort 2 at T3 (Mann-Whitney U test, $p=0.865$). (See Table 1).

3.1.2. Nursing discharge documentation

The proportion of documented discharge teaching for Cohort 1 prior to PEDI program implementation was 53% (23/43). This increased to 95% in Cohort 2 (52/55, Fisher exact test, $p < 0.005$). There were 46 discharge audits performed by the nurse manager on a weekly basis during the four-month period after PEDI implementation that revealed 100% adherence with the

discharge teaching documentation standards. These audit results were independently confirmed by the principal investigator during medical record examination and were found to have 100% adherence with documentation in nursing notes of participant medical records.

3.2. Parents' sample characteristics

There were 68 parent participants (Cohort 1= 30, Cohort 2= 38). Two parents declined to participate in the study. Two parents in Cohort 1 later declined to complete the PMT.

3.2.1. Parent knowledge

Baseline mean PMT scores were 1.76 (SD = 1.4; 0-4 scale) for Cohort 1 and 3.68 (SD = 0.852) for Cohort 2 after PEDI program implementation (Mann-Whitney U test, $p < 0.005$). The proportion of parents correctly answering individual questions improved after PEDI program implementation (Q1: 50% vs. 97%, Q2: 62% vs. 97%, Q3: 24% vs. 84%, Q4: 41% vs. 89%; Fisher exact test, all $p < 0.005$).

3.3. Child - sample characteristics

The medical records of 195 children in Cohorts 1 and 2 were examined for baseline characteristics and presence of SSIs (Cohort 1=90; Cohort 2 =105). There were no differences in baseline demographic and clinical characteristics between Cohorts 1 and 2. (See Table 2). A subset of Cohort 1 and Cohort 2 were evaluated for length of stay from cardiac surgical procedure to discharge, cost of primary hospitalization, and readmission (Cohort 1= 61; Cohort 2=68).

3.3.1. Surgical site infections

The overall percentage of children with SSIs in Cohort 1 was 26.7% and the percentage of children in the post-implementation cohort (Cohort 2) with SSIs was 1.9% (Fisher exact test, $p < 0.005$). Further analysis was performed comparing SSI rates for the same months June to

December in 2011 and 2012 there was a significant reduction in SSIs between the two matched periods (20 SSIs out of 390 procedures in June to December 2011 versus five SSIs out of 400 procedures in June to December 2012; Fisher exact test $p = 0.002$). (See Table 3).

3.3.2. Length of stay, hospitalization costs, and readmission costs

There was no significant difference in the length of hospitalization from cardiac procedure to discharge between cohorts (Cohort 1 M= 12.3 days, SD = 7.62; Cohort 2 M= 12.9 days, SD = 9.19; $p = 0.342$) or in the cost of primary hospitalization (pre-PEDI M= US \$3252, SD = 1726; post-PEDI M= US \$3524, SD = 1393, $p = 0.571$). There were three readmissions for children in Cohort 1 with a mean readmission cost of US \$4420 (SD = 6752). There were five readmissions for children in Cohort 2 with a mean readmission cost of US \$600 (SD = 1140).

4. Discussion and conclusion

4.1. Discussion

This investigation evaluated relationships between nurse, parent, and child outcomes before and after implementation of the PEDI program at a hospital in Southern India. We found that nurses had a high level of baseline discharge knowledge and that their knowledge scores increased immediately after participating in the PEDI program instruction, returning to baseline four months after program implementation. There was a significant and sustained increase in nursing discharge documentation after implementation of the PEDI program with almost all parents receiving discharge teaching four months after program implementation. Additionally, there was a significant increase in parent knowledge scores in Cohort 2. Finally, our findings indicate that children in Cohort 2 had fewer SSIs than those in Cohort 1 and a trend in lower readmission costs, but no difference in length of stay between cardiac procedure and discharge or primary hospitalization costs.

4.1.1. Nurse discharge knowledge

The PEDI program taught nurses discharge content and evidence-based methods of discharge teaching. Nursing mastery of important discharge content and teaching methods are central to parents' ability to learn discharge content [5]. Yet, little is known about what constitutes nursing mastery of discharge content or how to enhance use of effective teaching methods by nurses in developed or developing countries. Our findings suggest that nurses in one hospital in a developing country have reasonable knowledge about home care for children with CHD after cardiac surgery, that knowledge can be increased with instruction, but is not sustained without further intervention. Further research is needed to develop better strategies for sustaining the knowledge gained in educational sessions and to better understand the relationships between knowledge and skillfully communicating that knowledge in effective discharge teaching.

4.1.2. Nurse documentation

This investigation found a substantial and sustained increase in nursing documentation of discharge teaching to parents. Reviewing patient records for evidence of discharge teaching and for the robustness of the documentation provides insight into a nurse's clinical practice. The use of documentation audits may have enhanced acceptance of this new care standard by nurses because the audits served as a reminder of the practice change and were closely monitored by their direct supervisor. This was one of the strategies described by Wang and associates (2011) in their systematic review of 77 papers on the quality of nursing documentation and interventions to enhance documentation [8]. Currently, regulatory compliance expectations are increasing in India, and as a consequence there is a growing effort to enhance the quality of nursing documentation, which may have contributed to the increase in nursing discharge documentation

practices during the study period [9]. Further research is warranted to better understand the relationship between the quality of discharge documentation and the quality of discharge teaching performed.

4.1.3. Parent knowledge

This investigation found a significant improvement in parent knowledge about home care after implementation of the PEDI program. In her systematic review, Lerret (2009) described parent education as essential for parents to comprehend their child's home care needs, as well as to ensure their adherence to discharge recommendations [5]. Our study findings suggest that the PEDI program developed specifically for parents in resource constrained environments may have provided parents with improved knowledge to care for their child at home. Further research is needed to determine if greater parent knowledge is associated with fewer preventable complications for children such as SSIs.

4.1.4. Child outcomes

4.1.5. Surgical site infections

SSI following surgical intervention for children with CHD has been cited as major source of morbidity, mortality, and financial cost in a number of studies [10,11]. SSIs represent a spectrum of disease ranging from superficial infections to deep sternal wound infections known as mediastinitis, and is a major cause of increased hospital days [10]. There are no studies documenting increased length of stay or the costs of SSIs in Indian hospitals. However, given that less than five percent of Indian children have medical insurance that covers CHD, such complications may have a significant impact on families' financial status [12]. Reducing preventable complications is a valuable contribution to the lives of children with CHD. Additionally, the negative impact of prolonged hospitalization or readmission on throughput

within pediatric cardiac centers and the ability to provide surgical interventions for children with CHD is a significant consideration [13]. Our findings suggest that SSI prevention education provided to parents through the PEDI program could be associated with a reduction in SSIs and deserve further study in a multi-site trial.

4.1.6. Readmissions

Hurried teaching, ineffective learning, complicated home care needs, and caregiver stress can lead to hospital readmissions [14]. While there were a small number of readmissions to the cardiac surgery unit, there was a trend toward lower readmission costs after PEDI implementation. Further research is warranted to determine if providing parents with SSI prevention education influences adherence with specific home care instruction and reduces readmission costs.

4.1.7. Limitations

The findings from this study should be considered in light of its limitations. Our study collected data from a non-random, convenience sample from a single site and was exploratory in nature, using a pre-post comparison design. Contextual factors may have influenced the results, such as an SSI quality improvement project that was completed two months prior to initiation of this study. Further limitations associated with the evaluation of readmissions included incomplete data due to parents seeking care at a hospital closer to home or financial considerations. All these factors are sources of potential bias and limit the generalizability. Nonetheless, given the paucity of literature on structured nurse-led parent discharge training programs in resource constrained environments, this exploratory study provides insight to inform future research.

4.2. Conclusion

A structured nurse-led parent discharge program in a resource constrained environment may have a positive influence on nurse, parent, and child outcomes. Further investigation is warranted for examining direct relationships and causality.

4.3. Practice Implications

A structured nurse-led parent discharge program may be useful in preparing parents for home care. If shown to have proven positive effects, this program could be more broadly applied to other children with complex illnesses in resource constrained environments.

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Table 1

Comparison Pre- and Post-PEDI Program Implementation,
Nurse and Parent Total Knowledge Scores

Time Point	Cohort 1			Cohort 2	
	Nurse n=45	Subset n=10	Parent n=29	Nurse n=18	Parent n=37
1	24.4 (2.9)	23.4 (2.4)	1.76 (1.4)	--	--
2	27.4 (1.5)	28.1 (1.4)	--	--	--
3	--	23.8 (3.4)	--	23.39 (3.3)	3.68 (0.9)
<i>p</i> -value	<0.001	0.753		0.865	<0.001

Reported values are in Mean (SD) units.

Wilcoxon Cohort 1 Time points 1 & 2

Friedman Cohort 1 Time points 1, 2, & 3

Mann-Whitney U Cohort 2 nurses and parents

P value significant = 0.05

Table 2

Child Characteristics n=195

Characteristics	Cohort 1 n=90	Cohort 2 n=105	p-value
RACHS-1	2.46 (+/-0.942)	2.51 (+/-0.989)	0.714
Pre-operative Hct	39.2 (+/-8.536)	41.1 (+/-8.686)	0.728
Adm Sat	88.5 (+/-13.206)	87.19 (+/-16.029)	0.196
DTDFP	12.26 (+/-7.262)	12.94 (+/-9.19)	0.342
Sex (male)	43 (48%)	59 (56%)	0.242
Prematurity	3 (3%)	4 (4%)	0.859
Genetic Syndrome	9 (12%)	11 (12%)	0.912
Non-cardiac illness	4 (5%)	3 (3%)	0.563
PAH	24 (26%)	23 (25%)	0.439
Developmental Delay	7 (8%)	4 (4%)	0.238

RACHS-1 – Complexity Score (1-6, increasing complexity.) Mann-Whitney U

Pre-operative Hct – Pre-operative Hematocrit, independent sample t-test

Adm Sat – Admission Oxygen Saturation, independent sample t-test

DTDFP – Days to discharge from procedure, independent sample t-test

PAH – Pulmonary Arterial Hypertension (and other dichotomous variables) Mann-Whitney U

Table 3

Surgical Site Infection Rates 2011 and 2012

Month	2011			2012		
	Number of cases	SSI per 100 cases	SSI rate	Number of cases	SSI per 100 cases	SSI rate
January	46	5	10.86	64	1	1.56
February	47	5	10.64	50	1	2.00
March	45	1	2.22	58	0	0
April	71	4	5.63	70	2	2.85
May	56	3	5.63	61	1	1.63
June	56	6	10.71	50	1	2.00
July	50	3	6.00	64	2	3.12
August	45	1	2.22	52	0	0
September	57	8	14.03	52	0	0
October	61	1	1.64	63	0	0
November	61	0	0	67	1	1.49
December	60	1	1.67	52	1	1.92

Pre-implementation data collection April 2012

Post-implementation data collection September 2012

Chapter 4

An Analysis of Nurse and Parent Perceptions Associated with the Parent Education Discharge Instruction Program in Southern India

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Acknowledgements

We would like to acknowledge and thank the following individuals and organizations for their generous support in the development of the PEDI materials (in alphabetical order):

Estelle Brouwer, MPA

Children's HeartLink

Lizzy DeVita, illustrator and graphic designer

Justine Kidd, RN

Jeff Paurus, RN

Pam Sagan, RN

Shanthi Sivanandam, MD

WiRED International

Bistra Zhelva MBA

Abstract

Objective: To describe and compare parent and nurse perceptions of a structured nurse-led parent discharge teaching program in India.

Methods: A pre-post design was used to compare parent and nurse perceptions of parental uncertainty and readiness for hospital discharge before and after introduction of the Parent Education Discharge Instruction (PEDI) program in a pediatric cardiac surgery unit.

Results: Parents (n=68) and nurses (n=63) participated. After PEDI program implementation parents had less uncertainty and ambiguity about their child's illness. However, they rated themselves as being less able to cope with the transition to home and as having less support at home than needed. Parents' and nurses' perception of parental readiness for hospital discharge were more closely aligned after implementation of the PEDI program.

Conclusion: Results suggest that the PEDI program had positive and negative effects on parental perceptions of uncertainty and readiness for discharge. Further examination is warranted to delineate these influences and to design methods for supporting parents during the transition to home care.

Practical Implications: Nurses should assess parental uncertainty and readiness for discharge and provide necessary supports to improve the transition to home care.

1. Introduction

Nurses care for children with congenital heart disease (CHD) and their families through many transitions in care and have the opportunity to improve children's physical and mental health by educating and supporting parents [1,2]. Under the best of circumstances, parents of children with CHD have significant educational needs in order to understand this complex condition, its treatment, and how to manage their child's illness at home [1]. These challenges are magnified in resource constrained environments due to the prevalence of low-literacy, financial stressors, and a general lack of resources available to the parents [3,4,5]. In the context of these challenges and the complex, long-term nature of CHD, parents express feelings of stress, uncertainty, and not being adequately prepared for hospital discharge and ongoing home care [1,5].

Discharge teaching provides nurses the opportunity to partner with, educate, and support parents during the transition from hospital to home care. Parents and nurses have the opportunity to create a mutually enhancing, significant relationship where they work as a team to promote the child's health and reduce parental uncertainty [6]. Mutuality is especially important when considering discharge from the hospital to home for children with complex home care needs. Mutuality drives parents and nurses to work together toward reaching a common goal of safe discharge through achievement of parental mastery of home care content, and helps parents have greater confidence when caring for their child at home [6].

This investigation describes parents' and nurses' perceptions of parental uncertainty and readiness for hospital discharge before and after implementation of the Parent Education Discharge Instruction (PEDI) program in a resource constrained environment. The PEDI program consists of a computer-based discharge education training program for nurses,

individualized and group teaching sessions for parents, and standardized parent educational materials designed for both literate and low-literacy parents [7]. Parent educational resources are available in English and six Indian dialects (Hindi, Bengali, Kannada, Malayalam, Tamil, and Telugu). The specific aims of this investigation were four-fold: 1) to describe parental readiness for hospital discharge and uncertainty during illness before and after PEDI program implementation, 2) to evaluate the association between parental discharge knowledge and their perceptions of uncertainty and readiness for hospital discharge before and after PEDI program implementation, 3) to describe nurses' perception of parent's readiness for hospital discharge before and after PEDI program implementation, and 4) to compare the differences between parents' and nurses' perception of parental readiness for hospital discharge before and after PEDI program implementation.

2. Methods

2.1. Design and Setting

A pre/post quasi-experimental design was used to measure parents' and nurses' perceptions of parental uncertainty and readiness for hospital discharge before and after introduction of the PEDI program. Research approval was obtained from the Committee on Human Research (CHR) at University of California San Francisco and from Amrita Institute of Medical Sciences' Ethics Committee.

The setting was a hospital with approximately 45 inpatient cardiac surgery beds, serving children from urban and rural regions in Southern India, the surrounding states, and from other countries. Approximately 700 pediatric cardiac surgeries are performed annually at the hospital. All parents in this study had children cared for on the cardiac surgery unit. The cardiac surgery

unit has multiple open rooms with six beds in each room and serves low- and middle-income families.

2.2. Participants and Procedures

Data collection occurred prior to (Cohort 1) and four months after implementation (Cohort 2) of the PEDI program. A non-random, convenience sample was recruited, including: 1) parents of children who had cardiac surgery and 2) nurses caring for children after cardiac surgery. Exclusion criteria were: 1) parents of a child nearing end-of-life, 2) children and their families cared for in private rooms outside of the cardiac surgery unit and 3) any nurse or parent who did not understand and speak English, or who did not wish to use an interpreter. Parent and nurse participants in Cohort 1 did not receive PEDI training whereas Cohort 2 did receive PEDI training.

This investigation was embedded in the PEDI Study, a pilot study measuring parent and nurse home care knowledge, nursing documentation, and child outcomes before and after introduction of the PEDI program. Details of the investigation's methods are described elsewhere [7]. Salient to this investigation, parent participants completed the Parent Mastery Test (PMT), the Parent Perception of Uncertainty in Illness Scale (PPUS), and the Readiness for Hospital Discharge Scale (RHDS-parent) before (Cohort 1) and after implementation of the PEDI program (Cohort 2) [7,8,9]. Nurses completed the Readiness for Hospital Discharge Scale (RHDS-nurse) before (Cohort 1) and after implementation of the PEDI program (Cohort 2).

2.2. Measures

2.2.1. The Parent Mastery Test (PMT)

The PMT measures parental knowledge of important aspects of their child's home care after pediatric cardiac surgery in India. The PMT is a four-item questionnaire developed by the

research team to measure parents' knowledge of important aspects of their child's post-operative care at home after pediatric cardiac surgery in India [7]. Learning domains included: 1) when to seek medical care, 2) signs of infection, 3) oral care, and 4) fingernail care. Total scores were calculated and based on a 0-4 point scale and the proportion of correctly answered questions was reported.

2.2.2. Readiness for Hospital Discharge Scale for parents of hospitalized children (RHDS-parent)

The RHDS-parent was developed and validated in the United States (US) to measure parents' perceptions, confidence, knowledge, and skills related to transition from hospital to home [9]. The RHDS-parent has 29 items positively weighted, Likert-format questions (0-10 scale) and is expressed in a total scale and four subscales with an overall Cronbach's alpha of 0.85 [9]. The subscales reliability ranged from $r=0.70$ to 0.86) [9]. The RHDS-parent has been used in studies of parents of children after solid organ transplant and was evaluated in hospitalized neonates and children with acute and chronic conditions [9,10].

2.2.3. Readiness for Hospital Discharge Scale for parents of hospitalized children (RHDS-nurse)

Because parent and nurse perceptions may be different from each other the RHDS-parent and RHDS-nurse pose the same questions, asking parents and nurses to assess their perception of parental readiness for discharge to home care. [9]. RHDS-nurse is comprised of 29 positively weighted Likert-format (0-10 scale), the same as the RHDS-parent, but from the nurses' viewpoint, and has four subscales. The subscales include parent status, parent knowledge, parent coping ability, and expected parental support subscales. Psychometric properties for the RHDS-nurse had not been published at the time of this study.

2.2.4. *Parent Perception of Uncertainty Scale (PPUS)*

The PPUS is a 31-item Likert-format self-report scale with a standardized alpha of 0.91 [8]. The PPUS is a measure of how well a person copes and is able to resolve the uncertainty in a stressful situation related to their child's illness and medical treatment. The PPUS has a reliability coefficient of 0.89 and has four dimensions: 1) ambiguity concerning state of illness, 2) unpredictability concerning hospital course and prognosis, 3) lack of information about illness, its treatment, and the system of care, and 4) lack of clarity in what information is available [8,11,12]. The total PPUS scores range from 31-155, with higher scores indicating greater uncertainty. Inter-rater reliability for the dimensions ranges from 0.72 to 0.87 [8]. The PPUS has been used in investigations in the US and Taiwan to examine parents' of children diagnosed with cancer perceptions of uncertainty with their child's illness [13,14].

2.3. *Analysis*

Data were analyzed using SPSS (IBM SPSS Statistics Version 22; Armonk, New York). PPUS, RHDS-parent, and RHDS-nurse total scores and subscales, were generated as long as 80% of survey questions were answered. PPUS and RHDS-parent mean score differences between cohorts were evaluated using independent samples Student's *t*-tests. RHDS-parent and RHDS-nurse scores before and after PEDI program implementation were compared using a matched pair Student's *t*-test and Pearson's product-moment correlation. Pearson's product-moment correlation were used to describe the association between PPUS and RHDS-parent scores. Spearman's rank-order correlation were used to describe the association between total PMT scores and PPUS and RHDS-parent scores. Mean PMT scores were compared using the by Fisher exact test. A *p* value less than 0.05 was considered significant.

3. Results

3.1.1. Parents- sample characteristics

Sixty-eight parents participated in this study (Cohort 1=30, Cohort 2 =38) and two declined. There was no attrition.

3.1.2. Parent knowledge

Mean PMT scores were 44% correct for Cohort 1 and increased to 92% correct in Cohort 2 after PEDI program implementation (Fisher exact test, $p < 0.005$). The proportion of parents correctly answering individual questions improved after PEDI program implementation from 24% in Cohort 1 (for oral care practices) to 97% in Cohort 2 (for signs of infection).

3.1.3. Parent perceptions

Parents in Cohort 1 ($n=29$) had higher mean total RHDS-parent scores ($M=224$, $SD=32.2$) than Cohort 2 ($M=202.5$, $SD=12.5$; $p < 0.05$). Parent readiness for hospital discharge subscale analysis revealed statistically significant lower mean scores in all domains (paired Student's t -test, all $p=0.001$). (See Table 1). Parents in Cohort 2 had lower mean total PPUS scores ($M=83.6$, $SD=4.9$) than parents in Cohort 1 ($M=93.3$, $SD=10.7$) (paired Student's t -test, $p < 0.05$). Subscale analysis showed lower ambiguity scores in cohort 2 ($M=33.4$, $SD=3.7$) than cohort 1 ($M=40.8$, $SD=10.7$; $p < 0.005$).

There was no significant relationship between the total PPUS scores and RHDS-parent scores ($r=0.31$, $p=0.12$) in parent Cohort 1 whereas in Cohort 2, there was a moderate positive correlation between total PPUS scores and parent perception of readiness for hospital discharge ($r=0.41$). Subscale analysis revealed moderate positive correlation for expected support ($r=0.47$) and coping ability ($r=0.59$; all $p < 0.05$). (See Table 3).

Cohort 1 showed no significant correlation between total PMT and PPUS scores ($\rho = 0.059, p = 0.78$). However, Cohort 2 had a strong inverse correlation between total PMT and total PPUS scores ($\rho = -0.45, p = 0.005$) and had a moderate inverse correlation in two subscales (ambiguity $\rho = -0.45$ and unpredictability $\rho = -0.325, p < 0.05$). There was no significant correlation between clarity or information subscales. (See Table 2).

There were no significant correlations between total PMT and RHDS-parent scores in Cohort 1 whereas, for Cohort 2, there was a moderate inverse correlation between total knowledge and total RHDS scores ($\rho = -0.45, p = 0.005$). Subscale analysis revealed a moderate inverse correlation with expected support and total PMT scores ($\rho = -0.49$), and coping and total PMT scores ($\rho = -0.48$) in parents after receiving the PEDI program (all $p < 0.005$). There was a weak inverse correlation in parent status and total PMT scores ($\rho = -0.37, p = 0.023$). Finally, there was no significant correlation in the information subscale and total PMT scores or child personal status and total PMT scores. (See Table 2).

3.2.1 Nurse - sample characteristics

Fifty-eight nurses participated (Cohort 1=25, Cohort 2=33) and ten nurses did not complete the RHDS-nurse survey due to staffing constraints and workload (Cohort 1=5, Cohort 2=5).

3.2.2. Nurses' perceptions of parental readiness for hospital discharge

Total RHDS-nurse scores were higher in Cohort 1 ($M=225.5, SD=27.7$) than Cohort 2 ($M=201, SD=9.4, p < 0.05$). Similarly subscale analysis revealed higher scores in all subscales in Cohort 1, compared with Cohort 2. (See Table 3).

3.3.1. Parent and nurses matched RHDS comparison- sample characteristics

There were 56 matched parent and nurse participants in this study (Cohort 1 = 23, Cohort 2 =33). Cohort 1 had two nurse participants fail to complete the RHDS-nurse and the matched pairs were excluded from the sample.

3.3.2. Parent and nurse matched RHDS comparison

There was no significant difference in mean total RHDS between nurses and parents in Cohort 1 and 2. However, subscale analysis in Cohort 2 revealed nurses perceived parents to have higher mean knowledge scores ($M = 67.0$, $SD = 6.0$ vs. $M = 64.9$, $SD = 6.2$, $p = 0.021$) and lower mean coping ability scores ($M = 22.3$, $SD = 1.5$ vs. $M = 22.9$, $SD = 2.1$, $p = 0.029$). Additionally, there was a strong positive correlation between parents' and nurses' perception of parental readiness for hospital discharge ($r = 0.81$, $p = 0.001$) in Cohort 2. (See Table 4).

4. Discussion

4.1. Parents

Parents of children with CHD require home care knowledge in order to ensure their child's health and safety, but there has been no research on how to achieve this in a resource constrained environment. One study in India examined awareness, attitudes, and knowledge of parents of children with CHD and found that parents had a poor understanding of the importance of oral hygiene [15]. If lack of knowledge contributes to poor oral hygiene practices in children with CHD, children would be at higher risk for infectious endocarditis and other complications that could lead to rehospitalization or even death. Previous research has documented parental desire for more information and education to assist in understanding their child's illness and care at home [16,17].

Standardized parental discharge teaching has been associated with increased knowledge, confidence, parental perception of readiness for discharge, and better coping in both developed and developing countries [9,18]. Our findings provide the first evidence that a nurse-led structured discharge teaching program can increase parent knowledge in a low resource setting. Moreover, the increase in knowledge was associated with parents experiencing less overall uncertainty about their child's illness and parents had greater knowledge about oral hygiene practices to reduce the risk of infectious endocarditis. Further research is needed to determine if improved knowledge leads to better oral hygiene practices or reduced infection rates.

Research has shown that families of children with CHD who lack social supports have high stress levels [5,19]. The use of education strategies to reduce parental stress, uncertainty, and anxiety has been explored in the literature. For example, Fincher and colleagues (2012) described a reduction in parental anxiety with pre-operative parent education compared to no intervention in same day surgery patients [20]. Moreover, parental anxiety has been associated with a lower likelihood to follow pre-operative requirements for these patients and increased the likelihood of procedural cancellation [21]. While the parents in our study may have perceived themselves as being less prepared for discharge after home care instruction, they did have less uncertainty and ambiguity about their child's condition. These findings are suggestive of a linkage between parental uncertainty and discharge readiness and warrants further investigation into potential mechanisms to improve parental perception of readiness for hospital discharge.

In an integrative review of discharge literature, Lerret (2009) found that meaningful interactions with staff and confidence building for parents ensured successful transitions from hospital to home care [1]. Others found that standardized teaching and community follow-up increased mothers' understanding of CHD and their comfort level in caring for their child

[22,23]. Our investigation found parents had less ambiguity and perceived their child's hospital course and prognosis to be more predictable after implementation of the PEDI program.

However, parents in our study felt less ready for discharge, had the perception of receiving less support at home than needed, and felt less able to cope with the transition home after receiving home care instructions. Further research is warranted to explicate key aspects associated with successful transition to home care. For example, examination of the importance of relationships and confidence building for parents as the key component for a successful transition compared to standardized education and follow-up.

4.2. Parent and nurse comparisons of readiness for hospital discharge

Weiss and colleagues (2014) found nursing assessment of poor discharge readiness was associated with a significant increase in post-discharge health care resource utilization. In contrast adult medical patients' assessment of their discharge readiness had no association with health care resource utilization [24]. While there was a low correlation between parents' and nurses' perceptions of parental readiness for hospital discharge before the introduction of the PEDI intervention, parents' and nurses' perception of readiness for discharge were more closely aligned after PEDI program implementation. The closer alignment may be due to mutuality and the subsequent development of a nurse-parent discharge dyad [6]. Nurses in the pre-implementation phase may not have fully appreciated the knowledge and skills parents needed to care for their children at home. The standardized teaching program may have heightened nurses' awareness of the importance of follow-up care for children's continued recovery and during the more formal discharge teaching, they were better able to assess parents' learning needs more accurately. Further research is needed to test interventions that enhance the mutuality between parents and nurses during home care instruction and foster further development of a nurse-parent

dyad. Research is also needed to improve assessment of children's risk after discharge from hospital, and to develop interventions to mitigate those risks.

4.4. *Limitations*

These findings should be considered in light of the study limitations. Our study collected data from a non-random, convenience sample from a single site and used a pre-post design. Additionally, we utilized several tools that have not been validated in the Indian context. There was nurse attrition over the course of the study due to staffing constraints and workload. All these factors are sources of potential bias and limit the generalizability of the findings. However, given the paucity of literature related to structured nurse-led parent discharge training programs in resource constrained environments, this exploratory study provides insight to inform future research.

4.5. *Conclusion*

The results of our study suggest that the PEDI home care instruction program performed by nurses had positive influences on parental perceptions that included a reduction in parental uncertainty and closer alignment in parents' and nurses' perceptions of parental readiness for hospital discharge. However, we also found negative effects such as a reduction in parental perception of readiness for hospital discharge after receiving more in depth discharge instructions. Further explication of these influences could lead to development of better interventions to educate and support parents during the transition from hospital to home care and may ultimately lead to healthier lives for children with CHD.

4.6. *Practice Implications*

Nurses should assess parental uncertainty and readiness for discharge and provide necessary supports to improve the transition to home care.

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Figure 1 – Study Design

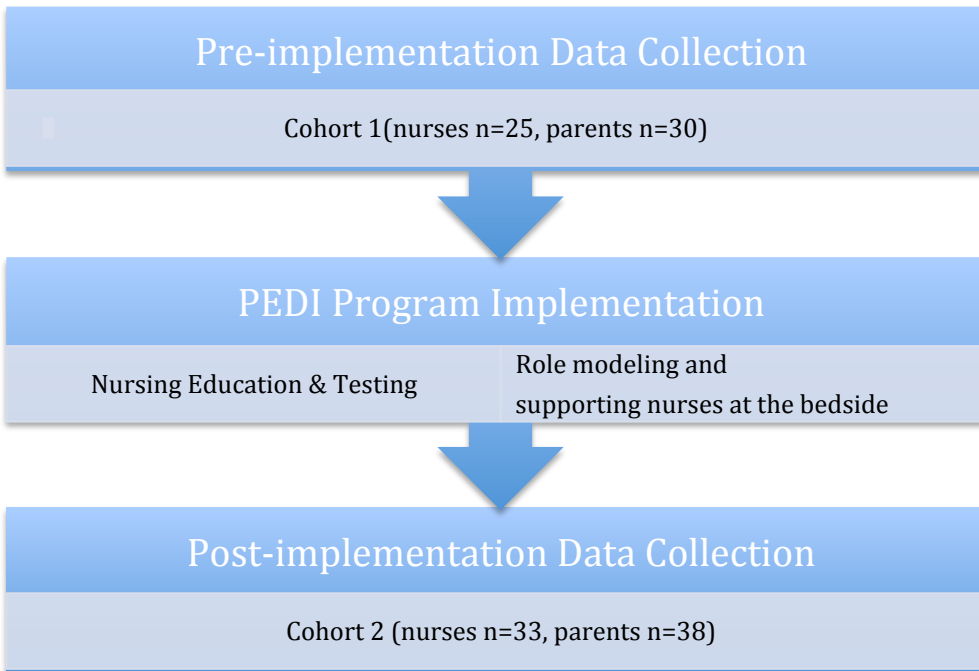


Table 1 Comparison of Parent and Nurse Perceptions in Cohort 1 and Cohort 2

	Cohort 1		Cohort 2		<i>p</i> value
	Mean	(SD)	Mean	(SD)	
Total PPUS	93.3	(10.7)	83.6	(4.9)	0.001
<i>Ambiguity</i>	40.8	(6.8)	33.4	(3.7)	0.001
<i>Lack of Clarity</i>	24.7	(2.9)	24.4	(2.0)	0.11
<i>Information</i>	15.1	(2.0)	14.1	(1.4)	0.09
<i>Unpredictability</i>	10.0	(2.1)	9.5	(2.0)	0.87
Total RHDS-parent	224.0	(32.3)	202.5	(12.5)	0.001
<i>Parent Status</i>	59.5	(12.8)	50.3	(4.4)	0.001
<i>Child Status</i>	37.7	(7.5)	33.1	(3.7)	0.001
<i>Knowledge</i>	70.3	(13.0)	65.1	(6.2)	0.001
<i>Coping</i>	24.3	(4.1)	23.1	(2.2)	0.001
<i>Expected Support</i>	31.5	(9.9)	30.9	(3.2)	0.001
Total RHDS-nurse	225.5	(27.7)	201.0	(9.3)	0.001
<i>Parent Status</i>	59.0	(9.1)	49.5	(3.9)	0.001
<i>Child Status</i>	37.1	(8.0)	32.0	(1.9)	0.001
<i>Knowledge</i>	73.0	(8.4)	67.0	(6.0)	0.007
<i>Coping</i>	24.3	(3.6)	22.3	(1.5)	0.001
<i>Expected Support</i>	32.1	(4.5)	30.3	(2.4)	0.006

Parent (Cohort 1 n=30; Cohort 2 n=37)

Nurse (Cohort 1 n=25; Cohort 2 n=33)

Independent samples t-test

p<0.05 significant

Table 2. Parent Correlations Between Total Parent Mastery Test Scores and Parent Perceptions of Uncertainty and Readiness for Hospital Discharge

	Cohort 1 (<i>rho</i>)	<i>p</i> -value	Cohort 2 (<i>rho</i>)	<i>p</i> -value
Total RHDS	0.059	0.78	-0.45	0.005
<i>Parent Status</i>	0.074	0.71	-0.37	0.023
<i>Child Status</i>	0.065	0.75	-0.23	0.181
<i>Knowledge</i>	0.181	0.39	0.075	0.657
<i>Coping</i>	-0.055	0.78	-0.48	0.003
<i>Expected Support</i>	-0.206	0.31	-0.49	0.002
Total PPUS	-0.023	0.79	-0.43	0.008
<i>Ambiguity</i>	0.070	0.88	-0.45	0.005
<i>Lack of Clarity</i>	0.025	0.98	0.31	0.059
<i>Information</i>	-0.037	0.95	-0.14	0.427
<i>Unpredictability</i>	-0.163	0.41	-0.33	0.05

RHDS – Readiness for Hospital Discharge Score (Total Score)

PPUS—Parental Perception of Uncertainty (Total Score)

Spearman’s rank-order correlation

p<0.05 significant

Table 3. Parent Perceptions - Correlations Between PPUS and RHDS-parent in Cohort 1 and Cohort 2

	Cohort 1 (<i>r</i>)	<i>p</i> -value	Cohort 2 (<i>r</i>)	<i>p</i> -value
Total PPUS	0.31	0.12	0.41	0.012
<i>Ambiguity</i>	0.34	0.08	0.45	0.006
<i>Lack of Clarity</i>	0.07	0.73	-0.16	0.34
<i>Information</i>	0.26	0.20	0.09	0.59
<i>Unpredictability</i>	-0.09	0.66	0.16	0.34
Total RHDS-Parent	0.31	0.12	0.41	0.012
<i>Parent Status</i>	0.09	0.66	0.37	0.024
<i>Child Status</i>	-0.01	0.99	0.36	0.031
<i>Knowledge</i>	0.30	0.13	-0.09	0.60
<i>Coping</i>	0.32	0.09	0.59	0.0001
<i>Expected Support</i>	0.11	0.59	0.47	0.003

RHDS – Readiness for Hospital Discharge Score (Total Score)

PPUS—Parental Perception of Uncertainty (Total Score)

Pearson product-moment correlation

p<0.05 significant

Table 4. Comparison Between RHDS-parent and RHDS-nurse Before and After PEDI Program Implementation n=33

Paired Sample Correlation	Cohort 1		Cohort 2	
	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>
Total RHDS	0.25	0.28	0.81	0.001
Parent Personal Status	0.30	0.16	0.33	0.06
Child Personal Status	-0.02	0.91	-0.25	0.17
Knowledge	0.24	0.29	0.71	0.001
Coping	0.41	0.052	0.60	0.001
Expected Support	0.11	0.64	0.78	0.001

*Readiness for Hospital Discharge
Paired Samples Correlations
p<0.05 significant*

Chapter 5

Discussion

Children with congenital heart disease (CHD) in many developing countries now have more access to cardiac surgical interventions. Children who have undergone cardiac surgery have complex ongoing health care needs, such as (but not limited to) the need for complicated medication regimes for palliated circulations and appropriate oral care to avoid infective endocarditis. Parents need more in depth home care education to manage their child's health after hospital discharge in order to optimize their child's health. For successful transitions from hospital to home care parents, must understand important health care information and nurses' consistent presence at the bedside places them in an excellent position to support parental learning. Nurses can enable children with CHD to successfully continue their recovery at home after hospitalization by performing early, repeated discharge education. The purpose of this chapter is to review the findings of three papers (two studies) exploring a nurse-led parent discharge education program, describe the significance of the findings, and identify research and clinical practice implications. The three papers provide preliminary evidence that a structured nurse-led parent discharge program was useful for nurses, children with CHD after cardiac surgery, their parents, and for hospitals.

The first investigation in this series found that the Parent Education Discharge Instruction (PEDI) intervention: 1) was acceptable to nurses and parents, 2) nurses' and parents' home care knowledge improved after program implementation, 3) discharge documentation improved after PEDI program implementation, 4) training materials were useful for nurses and parents, and 5) the program was sustained over time. In general, nurses' comments were positive about all aspects of the PEDI intervention. They specifically stated that they gained enjoyment from the

teaching role. Nurses' reported that the intervention improved job satisfaction, confidence, and their sense of responsibility. Parent participants were supportive of nurses providing home care teaching. The PEDI program was found to have utility, to be beneficial for nurses and parents alike, and could be sustained over time.

This study adds to a growing body of evidence that supports nurses shifting their practice to include an autonomous coaching role in the low resource settings (Chomba et al., 2008; Tengir & Cetinkaya, 2010). For example, Chomba and colleagues (2008) found a reduction in early neonatal mortality (6.2/1000 live births versus 11.2/1000 live births) when African mothers were taught newborn home care by their midwife. Specifically for parents of children with CHD, Yang and associates (2010) found that parents who received an educational intervention delivered by nurses had greater knowledge and decreased stress measured at one week and at one month time period post-discharge. In general, parent education by nurses has been shown to be an effective mechanism to prepare patients and their families for discharge and their transition home (Titler & Pettit, 1995; Weiss et al., 2008). Our findings support the existing literature and show interesting insight into the positive affect the coaching role has on nurse job satisfaction. Additionally, we have shown preliminary evidence about the sustainability of a structured nurse-led discharge program. Nurses enhancing parental home care knowledge has the potential to be an important component for improving children's health in resource constrained environments and deserves further evaluation (Pleasant & Kurvilla, 2008).

The second investigation in this series evaluated the effectiveness of a structured, nurse-led parent discharge teaching program on nurse, parent, and child outcomes. We found nurses had a high level of baseline discharge knowledge and that their knowledge scores increased immediately after participating in the PEDI program, returning to baseline four months after

program implementation. Our findings indicated that there was a significant and sustained increase in nursing discharge documentation after implementation of the PEDI program. Additionally, there was a significant increase in parent knowledge scores after implementation. Finally, our findings revealed that after PEDI program implementation, children had fewer surgical site infections (SSIs) and a trend toward lower readmission costs than prior to program implementation. A structured nurse-led parent discharge program may be useful in preparing parents for the transition to home and for their adherence with home care recommendations. If the investigation is successfully replicated in other locations it could be more broadly applied in other resource constrained environments.

The literature describes parents of children with CHD having significant knowledge deficits about their child's health care requirements and supports the need for more in depth parent education programs (Arya, Glickstein, Levasseur, & Williams, 2012; Cheuk, Wong, Choi, Chau, & Cheing, 2004; Stinson & McKeever, 1995; Williams et al., 2008; Wray & Maynard, 2006). In addition, investigators have described parents demanding more information and welcoming support and communication from the healthcare team (Kendall, Parsons, Sloper, & Lewin, 2007; Upham & Medoff-Cooper, 2005). Our investigation found parents prior to implementation of the PEDI program had important knowledge deficits and that parents wanted more home care instruction. Additionally, parents welcomed the support provided by nurses during the transition to home care. Our study extends the current literature to examine the effect of nurse-led parent discharge education on clinical outcomes and shows promising trends in the reduction of SSIs and readmission costs.

The PEDI intervention was designed to empower parents to be prepared to manage home care and the ongoing health care needs of their child. Sparacino and colleagues (1997) examined

parents of children with CHD and found several important findings including 1) parents had dilemmas associated with illness, disclosure, and normality, 2) uncertainty about their child's disease was challenging, 3) parents struggled with social integration versus social isolation and the impact of illness on their family, and 4) parents had coping dilemmas that they struggled with throughout their child's life. Rempell and Harrison (2007) described parents viewing their child's life as normal helped to ward off worry. However, they knew that their child's life was different and would continue to be different from the lives of others in some way. Parents of children with CHD experience uncertainty and distress associated with real or perceived knowledge deficits. A better understanding of parental perceptions associated with the transition to home care is an essential step in creating interventions to reduce the stress of having a child with CHD for parents. The third investigation in this series examines nurses' and parents' perceptions of parental preparedness for hospital discharge and is the first time parental perception of uncertainty and readiness for hospital discharge scales have been used in combination to evaluate a structured parent discharge education program.

The final investigation in this series described and compared nurses' and parents' perceptions of the PEDI program. Our findings indicate after the PEDI intervention, parents had less uncertainty about their child's illness. They perceived their hospital course and prognosis to be more predictable. However, parent participants expressed a sense of being less able to cope with the transition to home and perceived they would have less support than they needed after the PEDI intervention. Our investigation found that prior to PEDI program implementation, nurses may not have fully appreciated the scope of the challenges faced by parents during the transition to home care. Parents' and nurses' perception of parental readiness for hospital discharge were more closely aligned after PEDI implementation. The PEDI program was found

to be useful in preparing nurses for assuming the role of parent teacher and that they supported parents' mastery of home care content. Expansion of nurses' role to include independent parent teaching was received positively by parents and ultimately led to nurses and parents perceptions being more closely aligned on a parent's readiness for hospital discharge and requirements for successful transition to home care.

Parental preparedness for discharge is a complex, multidimensional phenomenon (Anthony & Hudson-Barr, 2004; Steele & Sterling, 1992). Parents have expressed anxiety about their educational needs and expectations (Smith & Daughtrey, 2000) and the child's life course (Firth, Grimes, Poppleton, Hall & Richold, 2000). For example, parents have expressed an increase in doubts about their caregiving skills (up to 61%) in the post-discharge period (Beeri, Haramati, Rein, & Nir, 2001; Pinelli, 1981). Parental distress, anxiety, or uncertainty may affect their coping which in turn may hinder their abilities to provide for their child's health care needs at home. Decreasing parental feelings of ambiguity by knowing what to expect and reducing overall parental uncertainty through education could be important for parents during their transition from hospital to home. Further research is warranted to develop supportive interventions for reducing parental uncertainty.

Social support has been found to be essential to parents of hospitalized children feeling ready for transition to home care (Affleck, Teenen, Rowe, Roscher, & Walker, 1989; Snowdon & Kane, 1995). Investigations have found that support must be available to both the child and caregiver/parent throughout their experience for successful transition to home care (Snowdon & Kane, 1995). Building parental confidence and coping skills and connecting them with community resources have also been identified as important for successful transition to home care (Boonmee & Pickler, 2005; Melnyk, 1994; Worthington, 1995). Our study found parent

discharge education had both negative and positive effects on parental perceptions of uncertainty and readiness for hospital discharge, challenges the current literature, and deserves further explication to better understand how nurses can assist parents with the transition to home care.

During the discharge process, nurses have the opportunity to create meaningful, mutual relationships with parents that in turn may reduce parental distress and enhance their mastery of home care instructions (Curley, 1997; Lerret, 2009). Our investigation expands the current literature by providing preliminary evidence that nurses and parents perceptions can be more closely aligned when evaluating parental preparedness for hospital discharge through implementation of a structured nurse-parent discharge education program. This alignment may help foster parental home care preparedness by adherence with home care recommendations. However, our data revealed increased knowledge did not increase parental confidence in their readiness for discharge and their perception of coping abilities which challenges findings of other investigations. Further research is required to better understand the relationship of education and parental support and to explicate methods to enhance parental confidence and coping after discharge.

A lack of parental coping abilities has been associated with increased post-discharge resource utilization (Weiss et al., 2008). Specific interventions targeting pre- and post-discharge support have been found to be useful during the transition to home care, especially in socially and economically disadvantaged populations (Franck, Mcquillan, Wray, Grocott, & Goldman, 2010). The studies in this dissertation support the hypothesis that nurses in low resource settings are capable of supporting parents during the transition to home care. Through the PEDI program, nurses became coaches in order to support parents during their transition from hospital to home. This shift in practice and transition to an autonomous coaching role could have

significant implications, not only for their job satisfaction, but on parental mastery of important home care instructions. Further research is warranted.

In resource constrained environments such as India, the negative impact of prolonged hospitalization or readmission on throughput within overtaxed pediatric Indian cardiac centers and the ability to provide surgical interventions for more children with CHD are significant impetuses for further research. For example, currently India has 14 centers that provide care to children with CHD. According to the American College of Cardiology guidelines, there should be a center for every five million people and by these standards; India would require 200 centers (Saxena, 2005). There are 10-12 pediatric cardiac surgeons and 25 pediatric cardiologists in India caring for the approximate 6500 surgical cases performed yearly which comprises less than two percent of the total number of children with CHD estimated to require heart surgery (Saxena, 2005). The remainder of the children will not receive care and many will die. Expedited throughput and prevention of readmissions could ease some of the burden of CHD in India.

Further research is required to examine direct effects of the PEDI program on clinical outcomes and further delineation of specific parental supports required both pre- and post-discharge to reduce complications. Direct examination of causality through a multicenter randomized controlled trial (RCT) comparing centers using their standard of care with the PEDI program using cluster randomization could provide clear evidence of the effect of the program on clinical outcomes. I believe that the PEDI program structure lends itself readily to parental mastery of home care instruction and may lead to improved health of children with CHD globally. On a personal note, the most valuable aspect of this research for me has been its impact on female roles (e.g., nurses, mothers) in a hierarchical society and their empowerment to be in a better position to affect positive change for children with CHD.

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Appendix

Parent Education Discharge Instruction Program for Pediatric Cardiac Surgery
(Hospitals utilizing PEDI program)

Innova Children's Heart Hospital
Secunderabad, India 800 cases/year

Amrita Institute of Medical Sciences and Research Centre (AIMS)
Kochi, India 700 cases/year

First Hospital of Lanzhou University,
Lanzhou, China 200 cases/year

Institut Jantung Negara (IJN)/ National Heart Institute
Kuala Lumpur, Malaysia 900 cases/year

Narayana Hrudayalaya Hospital
Bangalore, India 3000 cases/year

Nhi Dong 1 (Children's Hospital #1)
Ho Chi Minh City, Vietnam 300 cases/year

The West China Hospital #1/Sichuan University
Chengdu, Sichuan 600 cases/year

Shanghai Children's Medical Center
Shanghai, China 2500 cases/year

Hospital do Crianca e Maternidade/Hospital de Base
São José do Rio Preto, Brazil 120 cases/year

270 visits to our open access PEDI webpage
30 requests for documents

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