View metadata, citation and similar papers at core.ac.uk

brought to you by CORE

provided by SJSU ScholarWorks

San Jose State University
SJSU ScholarWorks

Doctoral Projects

Master's Theses and Graduate Research

5-2019

Nurses' Perception of Discharging the Medically Complex Pediatric Patient

Stacie Camille Licon

Follow this and additional works at: https://scholarworks.sjsu.edu/etd_doctoral

Part of the Pediatric Nursing Commons

CALIFORNIA STATE UNIVERSITY, FRESNO

THE DIVISION OF GRADUATE STUDIES

DISSERTATION/THESIS OFFICE

ABSTRACT

NURSES' PERCEPTION OF DISCHARGING THE MEDICALLY COMPLEX PEDIATRIC PATIENT

The purpose of this study is to query the nurses for their perceptions of the barriers and facilitators of discharging medically complex pediatric patients from a free-standing children's hospital in central California. Using a mixed methods research design via an online survey, 90 nurses identified 3 distinct themes that act as barriers. Those barriers include: 1) knowing the plan of care, 2) time, and 3) disposition of the family. Several implications for improving the discharge process for medically complex patients and overcoming the identified barriers include strategies to improve multidisciplinary communication, implementation of a Family Learning Center, use of video interpreters when in-person interpreters are not available, and respect for discharge readiness. Recognizing and implementing the appropriate interventions based on nurses' feedback have the potential to improve quality and patient safety.

Stacie Camille Licon
May 2019

NURSES' PERCEPTION OF DISCHARGING THE MEDICALLY COMPLEX PEDIATRIC PATIENT

by

Stacie Camille Licon

A project

submitted in partial

fulfillment of the requirements for the degree of

Doctor of Nursing Practice

California State University, Northern Consortium

Doctor of Nursing Practice

May 2019

APPROVED

For the California State University, Northern Consortium
Doctor of Nursing Practice:

We, the undersigned, certify that the project of the following student meets the required standards of scholarship, format, and style of the university and the student's graduate degree program for the awarding of the Doctor of Nursing Practice degree.

Stacie Camille Licon
Project Author

Susan McNiesh

Susan McNiesh, PhD, MS, RNC-OB (Chair) Nursing

MJRobson

Mary-Ann Robson, MSN, RN Valley Children's Hospital

Jennifer Reyes

Jennifer Reyes, MSN, RN

AUTHORIZATION FOR REPRODUCTION

OF DOCTORAL PROJECT

_____ I grant permission for the reproduction of this project in part or in its entirety without further authorization from me, on the condition that the person or agency requesting reproduction absorbs the cost and provides proper acknowledgment of authorship.

__X__ Permission to reproduce this project in part or in its entirety must be obtained from me.

Signature of project author:

ACKNOWLEDGMENTS

I would like to express my sincere gratitude to Dr. Susan McNiesh for her continuous support in this DNP program. Her guidance has helped impress upon me the value that qualitative work provides to nursing practice. Our rich experiences as nurses need to be shared to improve the health of those we care for and to ensure the betterment of our profession.

I would also like to thank Mary-Ann Robson and Jennifer Reyes for supporting me through this process and allowing me to work with your teams. I really appreciated their professionalism in conducting this study. Your leadership was well reflected in their responses.

Rhanda Rylant and Christina Ashburner, you are the best! Thanks for helping make this a great experience. Your expertise in research was so valuable when I had to complete my IRB proposal and construct my survey. We just may have to do this again!

Finally, to my loving wife and family…thank you so much for standing with me through these long two years. Our evenings and weekends are back!

TABLE OF CONTENTS

Page

LIST OF TABLES vii

CHAPTER 1: INTRODUCTION 1

Background 2

Problem Statement 3

Purpose of Project 3

Theoretical Framework 4

CHAPTER 2: LITERATURE REVIEW 12

Phenomenon of Interest 12

Significance 12

Literature Review 13

Summary of Gaps 21

CHAPTER 3: METHODS 23

Design 23

Setting 24

Sample Characteristics 24

Ethical Considerations 24

Measures 26

Data Analysis 27

CHAPTER 4: RESULTS 28

Participant Characteristics 28

Survey Results 29

Quantitative Findings 29

Qualitative Findings 32

Page

CHAPTER 5: DISCUSSION....36
Limitations....36
Implications....37
Further Research....43
Conclusion....44
REFERENCES....45
APPENDICES....50
APPENDIX A: STUDY ADVERTISEMENT....52
APPENDIX B: SURVEY....54

LIST OF TABLES

Page

Table 1. Frequency of Nurses' Experiences with Discharge Processes 30

Table 2. Nurses' Satisfaction with Discharge 32

CHAPTER 1: INTRODUCTION

The discharge process is dynamic throughout the course of an inpatient visit. Intended to begin on admission, the discharge process has multiple essential components and depending on the severity of illness or condition a patient has, it can present as very complicated and can become overwhelming and difficult to follow for the healthcare team, the patient, and/or the family. For instance, imagine being the bedside nurse sending a family home for the first time after a gastrostomy feeding tube is surgically placed in their infant because they have a diagnosis of failure to thrive. In order to ensure a safe transition in care from hospital to home, the nurse must start education on the reasons for needing the feeding tube, but in addition, has the responsibility to instruct the caregiver on: 1) skin care at the insertion site, 2) tube changes, 3) bolus feeding with a syringe, 4) continuous pump feeding, 5) medication administration, 6) equipment management, and 7) emergency management. Consider the added peculiarity if the family/caregiver of the infant cannot read or speaks a different language.

Now imagine being a first-time parent taking your infant home and having to learn and perform all of these tasks to keep your infant healthy. This is a common scenario when discharging children with medical complexity and the ways in which the discharge plan and education is provided may affect patient outcomes post-discharge (Solan, et al., 2015).

Children with medical complexity are children that "may have a congenital or acquired multisystem disease, a severe neurologic condition with marked functional impairment, and/or technology dependence for activities of daily living" (Cohen et al., 2011, p. 529). The process of discharging the medically complex pediatric patient often

includes the patient and/or family and consists of the following: educating in a way that meets health literacy standards and includes written patient discharge instructions, assessing the understanding of the plan of care, scheduling follow-up appointments before discharge, organizing post-discharge services, confirming the medication plan, and reviewing with the patient and/or family what to do if a problem arises (Huber & Blanco, 2010; Wu et al., 2016). Acute care nurses are often tasked with completing these steps while taking care of multiple other patients. This project seeks to query the nurses' perceptions of the discharge process with an ultimate goal of seeking solutions to support the discharge process of this vulnerable population.

Background

Medical advancements in neonatal, pediatric, and surgical care have led to the survival of an estimated 11 million children in the United States with complex medical needs which require some sort of life-sustaining medical technology (Spratling, 2017). Common technologies include ventilators, tracheostomy tubes, pulse-oximeters, feeding pumps, feeding tubes and central lines (Spratling, 2017). Long-term hospitalization of medically complex children is no longer the preferred option of care. Instead, the goal is "to ensure that each child remains healthy, thrives, and obtains optimal medical home and developmental support that promotes ongoing care at home and minimizes recurrent hospitalization" (Elias & Murphy, 2012, p. 996). Medically complex children once they have met stability which includes no major changes to the plan of care, tolerating feedings, afebrile, and without respiratory distress are sent home to complete or continue interventions (Elias & Murphy, 2012). The ongoing medical interventions necessary for

continued care are then completed by either home care or, in many situations, by the family.

Problem Statement

Currently at the freestanding central California children's hospital where I am employed, education is provided at the bedside by the inpatient acute care or house resource pool nurse and is typically done by providing educational handouts and by explaining and demonstrating a task that a family will perform at home (i.e. providing a bolus feeding through a gastrostomy tube). The expectation is that learning is then evaluated by the nurse by observing return demonstration from the family; however, there are multiple observed barriers which may compromise the quality of education the family receives including inconsistent teaching strategies between nurses, a lack of time the nurse has to educate the family, unavailable equipment, and a lack of coordination between the providers and other ancillary services.

This awkward approach to discharge teaching of medically complex pediatric patients can lead to ineffective education leading families to emergency department revisits, medication errors, readmissions and a lack of confidence in family/caregivers in taking care of their child at home (Solan, et al., 2015). This experience leads to a poor transition from hospital to home (Solan, et al., 2015).

Purpose of the Project

This project evolved around creating solutions to ensure a fluid transition from hospital to home for medically complex pediatric patients. In order to better understand the current discharge process at the freestanding Central California children's hospital where I am employed, I queried both acute care and house resource pool nurses on their

discharge experiences. The purpose of this study was to evaluate the following three aim statements:

- Determine nurses' perceptions of how prepared caregivers of medically complex patients are for discharge
- Describe nurses' perceptions of potential barriers during the discharge process of medically complex patients
- Describe nurses' perceptions of potential facilitators during the discharge process of medically complex patients

Theoretical Framework

The health promotion model (HPM) is an excellent framework in which to prepare the family/caregiver so that they can adequately and safely assume care of their medically complex child at home upon discharge. The health promotion model first debuted in 1982 by Nola J. Pender. Its purpose was to assist nurses in understanding the major determinants of health behaviors as a basis for behavioral counseling to promote healthy lifestyles (Pender, 2011). After subsequent research, Pender produced a significantly revised version of the HPM and it was published in the third edition (1996) of the *Health Promotion in Nursing Practice* text (Sakraida, 2010).

Theory Origin

Nola Pender's background in nursing, human development, psychology and education were instrumental in developing the HPM. Considered a middle-range theory, the HPM is a collage of three ideologies that integrate constructs from Martin Fishbein's expectancy-value theory (where individuals engage in actions to achieve goals that are perceived as possible and that result in valued outcomes), Albert Bandura's social

cognitive theory (where thoughts, behavior, and environment interact), and Jacqueline Fawcett's work on reciprocal interaction world view (in which humans are viewed holistically, but parts can be studied in the context of the whole) (Masters, 2018; Pender, 2011). HPM attempts to depict the multidimensional and holistic nature of persons interacting with their interpersonal and physical environments as they pursue health (Pender, Murdaugh, & Parsons, 2010).

Assumptions

There are seven major assumptions that illustrate the HPM and promote an active role of the person in shaping and maintaining healthy behaviors. They reflect both nursing and behavioral science perspectives:

1. "Persons seek to create conditions of living through which they can express their unique human potential.
2. Persons have the capacity for reflective self-awareness, including assessment of their own competence.
3. Persons value growth in directions viewed as positive and attempt to achieve a personally acceptable balance between change and stability.
4. Persons seek to actively regulate their own behavior.
5. Persons in all their biopsychosocial complexity interact with the environment, both progressively transforming the environment and being transformed over time.
6. Health professionals constitute a part of the interpersonal environment, which influences persons throughout their life span.

7. Self-initiated reconfiguration of person-environment interactive patterns is essential for behavior change". (Masters, 2018 p. 449)

Concepts of Theory and their Relationships

There are three major components of the revised HPM: 1) individual characteristics and experiences, 2) behavior-specific cognitions and affect, and 3) behavioral outcomes. The first component pertains to each person's unique personal characteristics (biological, psychological, and sociocultural) and experiences, which affect those individual's actions. Experiences that are reflected in the model pertain specifically to prior related behaviors because they will determine future health promoting behaviors (Masters, 2018). An example in practice would be a nurse identifying how family/caregivers like to learn best so an appropriate education plan could be established to teach families how to care for their medically complex child at home.

The second component of the HPM encompasses behavior-specific cognitions and affect that include: 1) perceived benefits of action, (positive or reinforcing consequences of undertaking a health behavior) 2) perceived barrier to actions (hurdles and personal costs of undertaking a health behavior), 3) perceived self-efficacy (judgment of personal capability to organize and execute a particular health behavior; self confidence in performing the health behavior successfully), and 4) activity-related affect (subjective emotions occurring prior to, during and following a specific health behavior) (Masters, 2018; Pender, 2011). In practice, if the family/caregiver was learning how to provide a bolus feeding to their infant, the nurse would encourage and provide positive reinforcement for correct return demonstration. The nurse would also provide

components of education to help the learner troubleshoot through problems. Once able to proficiently master the task of bolus feeding the family/caregiver would be competent and able to demonstrate self-efficacy. Self-efficacy plays a major role in creating a level of safety at transition from hospital to home.

The behavior-specific variables have motivational significance where nursing interventions can focus because they are amenable to change. Influences are also important in this second component of the HPM and include both interpersonal and situational circumstances. Interpersonal influences typically involve the family, peers, and providers and how they provide social support and role modeling in order to engage in specific health behaviors. Situational influences involve the options, demand characteristics, and perceptions of the compatibility of life context or the environment with engaging in a specific health behavior (Pender, 2011).

The third component of the HPM is the behavioral outcome. Commitment to a plan of action marks the beginning of a behavioral event. The commitment propels the person into a behavior including the identification of specific strategies. On the other hand, if there is an immediate competing demand an alternative behavior may preside as a possible course of action (Masters, 2018; Pender, 2011). As related to discharging the medically complex patient, the family/caregiver providing competent return demonstration of providing a bolus feeding to their infant without any prompting reflects a positive behavioral outcome. In addition, it provides that family/caregiver confidence.

In addition to the actual model, there are major concepts of the metaparadigm that Pender specifically identifies (person, environment, health and nursing). Pender's metaparadigm recognizes the "person" as the primary focus of the HPM and refers to the

person as an individual, family, or community (Masters, 2018). This project identifies "person" as the family/caregiver responsible for care. The "environment" is the physical, interpersonal, and economic condition that is needed for healthful living (Masters, 2018). For this project the "environment" reflects the home where the family/caregiver must be independent to provide care.

"Health" is the "persons" definition of health and "is more important than any general definition of health" (Sakraida, 2010, p. 436). Medically complex children do have a baseline level of health when they are not in the hospital. The maintenance of the plan of care at home by the family/caregiver is what establishes health. The role of the "nurse" is to raise consciousness related to health-promoting behaviors, promoting self-efficacy, enhancing the benefits of change, controlling the environment to support behavior change, and managing the barriers to change (Masters, 2018). The "nurse" component of the metaparadigm easily reflects the expectations of nursing when supporting families/caregivers through the discharge process of children with medical complexity.

Research

Studies on the HPM have been conducted over a period of 32 years. Initial revisions to the HPM of 1982 are a result of research and validity findings. Over the years, at least 13 instruments have been designed that measure the different HPM variables (Pender, 2011). The research to derive the model was based on adult samples that included male, female, young, old, well, and ill populations allowing the model to be generalized easily in the adult population (Masters, 2018). The HPM has been published in the literature extensively and is frequently used as a tool in research. There is

opportunity to use the HPM in nursing education where the emphasis is on illness care in acute care settings (Masters, 2018).

Theory Applicability

Children with medical complexities present a challenge after acute illnesses have resolved and continued care is required at home by the family. As noted earlier, an estimated 11 million children in the United States with complex medical needs require some sort of life-sustaining medical technology (Spratling, 2017). Additionally, "although children with medical complexity only comprise a small proportion of the pediatric population, they also account for 10% of hospital admissions, one-quarter of hospital days, and more than half of hospital readmissions" (Leyenaar, O'Brien, Leslie, Lindenauer, & Mangione-Smith, 2017, p.2). To ensure that parents are capable of taking care of their medically complex child at home, it is imperative to ensure that discharge teaching is optimal as it may affect patient outcomes post-discharge (Solan, et al., 2015).

The HPM is applicable to the setting and population that I work with because the focus is empowering the family to care for their medically complex child. My audience is adult focused and the HPM has been generalized easily within that population in many settings. The concepts and components within the HPM help support its relevance. By first reviewing Pender's metaparadigm, I can ascribe "person" to be the familial caregiver (primary focus). The "environment" in which the care takes place, which will likely be the home, but is not exclusive to it, as it may include the school or any general outing. "Health" in this circumstance refers to the child's most optimal health state regardless of his/her complex medical needs. "Nursing" is consistent with its general definition noted earlier.

The most defining use of the HPM with my population of interest is evident in the components itself. In the first component, individual characteristics and experiences, it would be important to evaluate the knowledge base and comfort level in which the family will be able to take care of their child. Important decisions will need to be considered if this is the child's first discharge home, and depending on the complexity of care, determine what education is important for the family. Success in a well-defined teaching plan will reflect successes at home. If the family is not able to successfully complete the education provided, the healthcare team will need to find other ways in which to support the family. Prior behaviors are important to determine discharge needs if the child with medical complexities has had multiple exacerbations and admissions. It could be that the family is not providing appropriate care and may need additional services at home or the education provided inpatient is not sufficient.

Behavior-specific actions (the second component of the HPM) is the hallmark goal to promote self-efficacy at home by the family and to minimize hospitalizations. Parent directed education via nursing interventions would spark benefit in action by having a family verbalize readiness for discharge based on their comfort of providing skills so that they can take care of their child. Barriers identified in being able to discharge a patient are often parental readiness because instruction at the bedside by the nurse might not be adequate.

Lastly, the third component that projects the behavioral outcome would be the successful completion and demonstration of skill needed by the family to care for their child and the verbalization that they are ready. Further evaluation of the education

interventions could be measured by reviewing any readmission criteria that might pertain to education provided.

Relevance to DNP project

I found the HPM most relevant to my DNP project because of the behaviors that would need to be acquired by families to care for their medically complex child at home. The focus is on education and learned behaviors so that family/caregivers will be successful. Self-efficacy is a major driver for parents' as they want to provide safe care at home and feel competent while doing it.

Although several other theories could have been selected, I chose the HPM primarily because of the flexibility that I found in Pender's metaparadigm and the focus on self-efficacy and social cognitive theory. The self-efficacy component in Pender's HPM also allows flexibility because it promotes personal health goals. Although these medically complex children require care outside of the hospital, there can still be "health" at their optimal state without illness with goals set and strategies set to prevent illness and acute exacerbations with resultant admission. Self-efficacy plays a central role in personal change and is the foundation of human motivation and action (Pender, 2011).

CHAPTER 2: LITERATURE REVIEW

Phenomenon of Interest

The objective for my doctoral project focused on appreciating the discharge process of medically complex pediatric patients as they transition from hospital to home. In order to better understand this phenomenon, I felt I needed to assess the barriers and facilitators that both acute care and house resource pool nurses in my organization face when discharging this vulnerable population and with an ultimate goal of sought solutions to support the process.

Significance

Medical advancements in neonatal, pediatric and surgical care have led to the survival of an estimated 11 million children in the United States with complex medical needs that require some sort of life-sustaining medical technology (Spratling, 2017). Common technologies include ventilators, tracheostomy tubes, pulse-oximeters, feeding pumps, feeding tubes and central lines (Spratling, 2017). Most children and youth with medical complexities are discharged to home after hospital admissions for acute exacerbations or conditions because long-term hospitalization of such children is no longer a preferred option (Elias & Murphy, 2012). Once stable, these medically complex children are discharged home with continued medical interventions for continued care, by either home care, or in many situations for the family to continue.

As the population grows, even though the medically complex patient only accounts for 10% of the hospital admissions, there is opportunity to ensure discharge processes are fluid because "the population does represent one-quarter of hospital days, and more than half of hospital readmissions" (Leyenaar, O'Brien, Leslie, Lindenauer, &

Mangione-Smith, 2017, p.2). Although reimbursement penalties are not as prevalent in Medicaid pediatric patients, penalties are being implemented in some states (Wu et al., 2016). By improving discharge processes of this population there is potential to improve readmission rates, decrease length of stays and improve patient/family satisfaction (Weiss et al., 2008; Weiss et al., 2016; Wu et al., 2016).

Literature Review

A quality improvement study utilizing sequential plan-do-study-act cycles was conducted in order to improve discharge efficiency to within 2 hours of meeting discharge goals from 50% to 80% of medically complex pediatric patient (Statile et al., 2016). Secondary measures included length of stay (LOS) and 30-day readmission rates. Sample characteristics included 227 medically complex children (54% male with a median age of 5.3 years). The majority were white and non-Hispanic with public primary insurance. Most common diagnoses were neuromuscular, gastrointestinal, and congenital. Overall, 80% of children were technology dependent. The study conducted at Cincinnati Children's Hospital Medical Center between July 2012 to May 2015 included several interventions to meet the primary goal that included implementation of a complex care: 1) inpatient multidisciplinary team, 2) order set, 3) multidisciplinary rounds, 4) needs assessment tool, and 5) medication pathway. Run charts were used to analyze the primary measure while the secondary measures of pre- and post- LOS were analyzed using Wilcoxon rank-sum test and 30-day readmission rates were compared using a chi-squared test. The results of the study showed an improvement from 50% - 88% of the primary measure over a 17-month period and was sustained for 6 months. Secondary measures showed no changes. Strengths of the study: 1) efficient discharges

for the medically complex population is possible but needs the proactive engagement of a multidisciplinary team in order to reach discharge goals, and 2) readmissions rate were not impacted by new process. Limitations of the study: 1) sampling did not include medically complex patients typical of a longer LOS such as those with a tracheostomy and ventilator (Statile et al., 2016).

Semi-structured interviews with families of children with medical complexity (CMC) and health care providers were conducted to ascertain families' priorities in hospital to home transitions (Leyenaar et al., 2017). Sampling for this study included parents of children with medical complexity, age >18 years, and English speaking. Health care provider participants included nurses, nurse practitioners, and nonresident physicians who work with CMC in inpatient and outpatient settings. The study was conducted at a tertiary care hospital from 2013 to 2014. Twenty-three interviews with parents of CMC and 16 interviews with healthcare providers were conducted. Analysis of the transcripts was done using an open coding approach and aligned with 7 domains related to families' priorities and goals for their hospital to home transitions. The 7 domains include: "1) family engagement, 2) respect for families' discharge readiness, 3) care coordination before discharge, 4) timely and efficient discharge processes, 5) pain and symptom control, 6) self-efficacy to support recovery and development, and 7) normalization and routines" (Leyenaar, O'Brien, Leslie, Lindenauer & Mangione-Smith, 2017, p. 3). These domains were then constructed to illustrate a conceptual framework that bridge the hospital and home setting. Strengths of the study included: 1) helped guide healthcare providers as to family priorities and preferences and could help direct the discharge process, and 2) consistent with transitional goals studied in adult

populations. Limitations of the study included: 1) it had only been conducted at one hospital so may not be generalizable, and 2) only included English speaking families. (Leyenaar et al., 2017).

A grounded theory study using semi-structured telephone interviews was conducted to determine needs and preferences of caregivers during hospital to home transitions of their medically complex children (Desai, Durkin, Jacob-Files, & Mangione-Smith, 2016). Eighteen caregivers, of patients aged 1 month to 18 years, completed the interviews; most were mothers, 35 years of age or older, who had a college degree, and spoke English. The study was conducted after patient discharges from the medical or surgical unit at Seattle Children's Hospital from September 2013 to January 2014. Interview transcriptions of general and open-ended questions "were analyzed using a combination of immersion and crystallization techniques and grounded theory methodology" (Desai et al., 2016, p.137).

Open coding was also used to assign different concepts and/or ideas, and axial coding was used to develop a theoretical framework of important needs and preferences identified by caregivers. The resulting multidimensional theoretical framework consisted of 3 overarching domains representative of caregiver needs and preferences for hospital to home transitions. These domains included: 1) caregiver self-efficacy for home care management, 2) adequate support and resources, and 3) comprehensive knowledge of the care plan. The first domain emerged as the center of the framework and was supported by the other two domains. The strength of this study is that it provides opportunities for quality improvement strategies. An additional strength is that it is consistent with the interventions and evidence demonstrated in adult populations. Weaknesses in the study

included: 1) only English-speaking caregivers, 2) telephone interviews only, 3) the sampling does not differentiate between newly diagnosed CMC versus an established chronic CMC, and 4) most were college educated (Desai et al., 2016).

An Internet-based discrete choice experiment (DCE), a quantitative technique, was used to rank the perception of the importance of 14 distinct discharge components for children (Blaine et al., 2018). Sampling characteristics for this study were inclusive of 704 participants from 46 different states and ran from March 17, 2014 until May 1, 2014. All participants were clinicians and included nurses, physicians, case managers, and social workers. Relative importance (RI) scores were used to determine the perception of most/least important discharge components as ranked by the clinicians. The two highest RI scores, indicating the most important discharge components, were: 1) "Educate the family and have them teach-back discharge plans and care", and 2) "Involve Care Team".

The two lowest RI scores, indicating the least important discharge components, were: 1) "Reconciliation", and 2) Delineate the roles and responsibilities for post-discharge care". Across the clinicians, the discharge components ranked highest and lowest according to the RI score were all the same. Strengths of this study included: 1) a decent sample size, 2) perceptions across four clinician types involved in discharge care, and 3) stability of results across clinicians. Weaknesses included: 1) might not be relevant to medically complex population, 2) the higher RI results are not strongly supportive with evidence of effectiveness; however, the lower scoring RI components do have a stronger body of evidence (i.e. much work has supported the admission/discharge process with "reconciliation" (Blaine et al., 2018).

Focus groups and individual interviews were conducted with caregivers of children discharged home from the hospital to determine a comprehensive understanding of the hospital to home transition and to identify commonly experienced barriers (Solan et al., 2015). Eligibility in the study required that a child had been discharged with a common, acute medical condition from the hospital medicine service, neurology, and/or neurosurgery services, and had to be English speaking. In addition, participants had to agree to attend a focus group within 30 days of discharge. The study was conducted at a free-standing, academic children's hospital with greater than 500 beds. Eleven focus groups and 4 individuals (61 parents/caregivers in total) were interviewed on the aspects of the inpatient experience, discharge processes, health system, and family factors thought to be most important.

An inductive, thematic approach was used to analyze the responses of the participants and resulted in major themes and associated subthemes. These themes were then structured and nested into 1 of 4 overarching concepts that created a conceptual model. The main concepts identified by families' experiences with hospital to home transitions included: 1) barriers to processing and acting on information, 2) desired information and suggestions for improvement, 3) discharge readiness, and 4) confidence with post-discharge care. Strengths of the study included identifying that the caregiver is the key to a successful transition; also, that the concepts could drive interventions that are supportive of family needs at transition. Weaknesses included: 1) single institution participation, 2) recall bias, 3) general pediatric population (Solan et al., 2015).

A quality improvement study utilizing Deming's plan-do-study-act cycles (IHI, 2019) was initiated as a collaborative amongst many pediatric hospitals in order to assess

change strategies that improved pediatric discharges (Wu et al., 2016). The primary measure of the study was to reduce discharge related care failures by half in a 12- month period. Care failures in this study were identified as any problem in the discharge process and could be a failure in comprehension of the diagnosis, failure in receiving of discharge instructions and education, non-compliance with discharge instructions, failure in receiving equipment, failure in providing pending lab results, scheduling of appointments, or needing an unplanned post-discharge readmission or emergent healthcare visit. Readiness for discharge and readmission rates were additional recommended measures but not required.

Ten hospitals participated, all of which were tertiary care freestanding children's hospitals in the United States and were members of Children's Hospital Association. The improvement study ran from November 2011 until October 2012. Populations of patients in the study were broad and were inclusive of children with specific disease processes, differing levels of clinical complexity, or with specific types of units. Change strategies were chosen amongst individual organizations including: 1) proactive discharge planning, 2) throughput improvement, 3) arrangement of post-discharge treatment, 4) communicate post-discharge plans to providers, 5) communicates post-discharge plan to patients/families, and 6) post-discharge support. Each change strategy had its own interventions. Phone calls at 2 to 7 days post discharge measured any care failures amongst the interventions. Run charts were used to analyze measures with baseline data pre-intervention and post-intervention using chi-squared testing. Interventions addressing discharge planning, quality of discharge instructions and providing post-discharge phone calls were undertaken by most sites and resulted with a decrease in call-

failures from 34% to 21%. Family perception of readiness improved from 85% to 91%. There was no improvement in 3-day readmission rates and slightly worse in 30-day readmission rates (from 4.5% to 6.3%). Strengths of this study included: improvement in lowering discharge related care failures and family readiness for discharge. Weaknesses included too many interventions and allowing each site to choose their own change strategy. This resulted in the inability to determine effectiveness of any one intervention (Wu et al., 2016).

A 3-study series using correlational design methodology was conducted to investigate relationships between predictors and outcomes of readiness for discharge (Weiss et a., 2008). One of the concurrent study populations included parents of hospitalized children. A total of 135 parents enrolled in the study at a children's hospital in the midwestern United States and whom had children with diseases across the spectrum. The study consisted of several tools/scales to assess parent, child and hospitalization characteristics, readiness for discharge, quality of discharge teaching, and care coordination perceived by parents. The Hollingshead four-factor index of social status, the Readiness for Hospital Discharge Scale (Cronbach's alpha reliability of .85), the Quality of Discharge Teaching Scale (Cronbach's alpha reliability of .89) and care coordination scale (Cronbach's alpha reliability of .58) were asked to be completed by parents within 4 hours of discharge. Then, at 3-weeks post-discharge, an additional 2 tools/scales were used to determine post-discharge coping and post-discharge utilization of support. The Post-discharge Coping Difficulty Scale (Cronbach's alpha reliability of .84) and utilization of support tool (yes/no format) were completed via a telephone interview. Using descriptive statistics to scale the instruments and logistic regression for

outcome variables, results indicated overall that the "skill" of the nurse in providing discharge teaching is important to promote feelings of readiness at discharge and how well parents were able to cope with transition to home determined their need for post-discharge support. Strengths of this study included a power-analysis to ensure appropriate sample size. Weaknesses included: 1) measurement of learning was not assessed, and 2) the care coordination scale only had a Cronbach's alpha of .58 making this an unreliable tool (Weiss et a., 2008).

A longitudinal correlational design was used to explore the sequential relationships of parent perceptions of the quality of their discharge teaching and nurse and parent perceptions of discharge readiness to post-discharge outcomes (Weiss et al., 2017). Convenience sampling consisted of 194 parents that were preparing for discharge to home with their child following a minimum two-day hospitalization, and were hospitalized on either the respiratory medical unit or a neurologic care unit in a pediatric academic medical center in the Midwestern United States. The study was conducted between 2012 and 2013. Data was collected on the day of discharge using a Quality of Discharge Teaching Scale (Cronbach's alpha from 0.88 to 0.92) and a Parent Readiness for Hospital Discharge Scale (Cronbach's alpha from 0.83 to 0.92). An RN-Readiness for Hospital Discharge Scale (same items as parent tool) was also scored at discharge by the nurse to rate parental readiness. At three weeks post-discharge parents were asked to complete a Post-Discharge Coping Difficulty Scale (Cronbach's alpha of 0.84) and report any occurrences of readmission and/or ED usage via telephone interview. from electronic records. Descriptive statistics were utilized in addition to equation modeling to analyze data. Overall results reflect that parent-reported quality of discharge teaching delivery,

was positively associated with parent perception and nurse assessment of discharge readiness. The amount of content was not positively associated and landed only at mid-scale. Parent perception of discharge readiness illustrated a negative association with post-discharge coping difficulty. The parent and nurse versions of the Readiness for Hospital Discharge Scale were weakly correlated. This study supported practice implications to provide high-quality delivery of discharge teaching. Weakness of the study included: 1) no identified patients with medical complexity and, 2) a small sample size in relation to the number of variables in use (Weiss et al., 2017).

Summary of Gaps

The literature review conducted revealed the challenges that the child with medical complexity presents in care coordination and discharge planning from hospital to home. Most of the qualitative studies based on structured interviews have determined themes around family engagement, discharge readiness, and self-efficacy. The quality improvement study found care coordination rounds with adequate planning to be instrumental in achieving reliable completion of tasks before discharge making it timely in nature and not impacting readmissions. Instruments on discharge teaching, and readiness for discharge were identified in a longitudinal correlational design noting that efforts to build nurses teaching skills can be used to increase discharge outcomes; however, time, high patient ratios, patient/family time constraints or lack of interest on the part of parents as noted in one of the studies creates barriers.

The discreet choice experiment conducted by Blaine et al. (2018) identified discharge education/teach-back as the most important component of the discharge process. To note, it is identified by a diverse group of pediatric clinicians that include

physicians, nurses, social workers and case managers. Identified in several studies as a best practice, but as a challenge to complete in others, teach-back methodology would be best implemented for parents of children with medical complexity. Further, how can discharge processes be better implemented to support the families of medically complex children to ensure competence and confidence when being discharged home? Noting that nurses are the clinicians most likely to complete the teaching, the literature is scarce on nursing perceptions of discharging medically complex pediatric patients.

CHAPTER 3: METHODS

This study assessed the perceptions of the barriers and facilitators nurses face when discharging medically complex children who require continued care at home and are medical technology dependent. The process of discharging medically complex patients can include many steps: “educating the patient and/or family, assessing the patient’s understanding of the plan of care, scheduling follow-up appointments, organizing post-discharge services, confirming the medication plan, and reviewing with the patient what to do if a problem arises" (Huber & Blanco, p. 67, 2010). Acute care nurses are often tasked with completing these steps for patients and/or the caregivers of these medically complex patients to facilitate discharge readiness. Thus, the specific aims of this study are to:

- Determine nurses' perceptions of how prepared caregivers of medically complex patients are for discharge
- Describe nurses’ perceptions of potential barriers during the discharge process of medically complex patients
- Describe nurses’ perceptions of potential facilitators during the discharge process of medically complex patients

Design

This study utilized a descriptive mixed methods research design via an online survey using SurveyMonkey. The survey was distributed by e-mail and available from October 1, 2018 until December 31, 2018 with monthly e-mail reminders to complete the survey. Fliers advertising the study were posted on the acute care units in highly visual areas, where nurses had the best opportunity to see them. Information from the fliers

were announced during unit huddles for a week at the beginning of each month to remind nurses about the survey (see Appendix A).

Setting

The study setting was a 358-bed freestanding children's hospital in Central California.

Sample Characteristics

The survey was sent to approximately 290 registered nurses in the acute care units which consist of 2 medical units, 1 surgical unit, a hematology/oncology unit, and rehabilitation unit. The survey was also sent to nurses working in the house resource pool since they are often staffed into one of these units. These nurses routinely care for and discharge patients with medical complexity from the hospital.

Registered nurses working in the NICU, PICU, and ambulatory division were excluded from this survey as registered nurse/patient ratios and resources differ drastically from the acute care units.

Recruitment and enrollment were secured via the nurses' password protected e-mail with a link to the survey. An information sheet was provided to participants in the recruitment email. The information sheet contained a description of the study, the purpose of this study, an explanation of risks and benefits, and information concerning participants' rights to withdraw from participation in the study at any time during the survey.

Ethical Considerations

The study was approved by the institutional review boards (IRB) of the participating hospital and university prior to participant recruitment. Consent by

participants was indicted by clicking “I agree” prior to the start of the survey via a study information page in the e-mail distributed for participant recruitment.

Risks

Although personal information was not collected, loss of confidentiality was a possible risk. This risk was mitigated by collecting the least amount of information necessary, storing information in a secure area, and subsequently destroying all data once the information had been quantified. All data (printed and electronic) was destroyed per hospital policy.

Participation was voluntary and all survey responses were set up through SurveyMonkey as strictly anonymous. Only demographic data was collected to maintain privacy/confidentiality of participant responses. Data collected was untraceable to any specific individual. All responses were password protected and was only accessible to the principal investigator and approved research staff. Participating in the survey will not affect the participant’s employment, position or any other opportunity.

Benefits

Although there would be no direct benefit to participants for participating in this study, a better understanding of the perceived barriers and facilitators to the discharge process of medically complex children requiring continued care at home may identify strategies to improve the discharge process. Improved processes could result in decreased readmissions for this patient population, and increased patient/family satisfaction scores related to safer transitions from hospital to home. In addition, the study has the potential to increase nursing satisfaction amongst nurses if strategies to assist with the discharge process are determined and measured with positive outcomes.

Measures

The survey was designed to better understand the barriers and facilitators perceived by acute care nurses when discharging medically complex children that require continued care at home and whom will have at least one of the following technologies on discharge: tracheostomy, ventilators, feeding tubes, and/or central lines. The questions developed for the survey were based on studies identifying best practices for discharge and, in addition, included study reviews of families' perspectives on the discharge process. Once drafted, the questions were then reviewed and edited by a team of colleagues familiar with the project including one with experience in survey design.

There were 24 survey questions in total; 15 questions were related to the nurses' perception of the discharge process and were rated on a 6-point Likert scale from "Never" to "Always". Three questions were related to nurses' satisfaction with the discharge process in which they were able to provide and were rated on a 5-point Likert scale from "Very Dissatisfied" to "Very Satisfied". Eight of the questions included an open-ended response requesting narrative comments relative to the questions' topic, as well as how the participant perceived the process could be facilitated. An "Additional Comments" section at the end of the survey was available for any open-ended comments. Finally, six questions were related to subject demographics (See Appendix B).

The expectation was that nurses could complete this survey while on shift so questions were kept concise yet descriptive so that understanding was clear. A practice trial in time was completed by colleagues excluded from the study and average timing to complete the survey took 10 to 12 minutes. The survey was then advertised to take no longer than 15 minutes to complete.

Data Analysis

Quantitative data was analyzed using simple descriptive statistics. Responses were tabulated and expressed using numeric values and percentages. Microsoft Excel was used to organize the data, calculate the percentages and display the information in tables and graphs.

Qualitative data was analyzed using content analysis. Content analysis is a flexible and subjective interpretation of text content that is meticulously reviewed identifying themes and patterns (Hsieh & Shannon, 2005). Credibility for themes was established through prolonged engagement with the text in addition to debriefing with my project chair.

CHAPTER 4: RESULTS

A total of 283 pediatric nurses working in the acute care departments and house resource pool were included in this study to assess their perceptions of the barriers and facilitators they face when discharging medically complex children. The electronic survey was available from October 1, 2018 until December 31, 2018 with monthly e-mail reminders sent to staff to complete the survey. The survey was encouraged to be completed while on shift and resulted in 90 nurses completing the survey (a 32% response rate). Time limitations or perceived insignificance may have contributed to some questions not being completed.

Participant Characteristics

The majority of participants were female (n=83; 92%) and worked in acute care as their primary department (n=74; 83%) while the rest worked in the House Resource Pool (n=15; 17%). The majority had a baccalaureate degree or higher (n=67; 74%) and worked the day shift (n=62, 69%). The types of patients within the acute care units that the participants cared for included medical (n=38; 43%), surgical (n=17; 19%), oncology (n=14; 16%), and rehabilitation (n=8; 9%). Thirteen percent of respondents (n= 12) noted that they might work with other populations in acute care or a combination of these types of patients because they are in the house resource pool. Experience amongst the participants ranged from less than 1 year to greater than 20 years: less than 1 year (n=2; 2%), 1 to 5 years (n=33; 37%), 6 to 10 years (n=13; 14%), 11 to 15 years (n=15; 17%), 16 to 20 years (n=15; 13%), and greater than 20 years (n=15; 17%).

Survey Results

Discharging the medically complex pediatric patient to home is a complicated task that many acute care nurses are bound to face. In order to better understand what this process consists of it is important to learn from frontline nurses about what helps and what hinders their ability to complete this very important intervention. The nurses' perspective is important to understand before solutions can be evaluated.

The survey consisted of 15 questions related to the frequency of nurses' experiences with discharge processes and were rated by the nurses on a 6-point Likert scale from "Never" to "Always". Three questions were related to satisfaction with the discharge process and were rated on a 5-point Likert scale from "Very Dissatisfied" to "Very Satisfied". Selective questions gave the nurses the opportunity for open comment, with a final "Additional Comments" section at the end of the entire survey where narrative comments were also welcomed. One question was removed at analysis as there was a noted transcription error that must have occurred when uploading the survey in SurveyMonkey. The resultant question was confusing and obtained the least amount of responses.

Quantitative Findings

Using simple descriptive statistics, quantitative data obtained from the survey were reviewed, summarized, tabulated, and expressed in numeric values and as percentages. In conducting the data analysis, Microsoft Excel was used to organize the data, calculate the percentages, and display the information in tables and graphs.

The most favorable findings where both "very frequently" and "always" were selected are demonstrated in the following four questions regarding the discharge process

of medically complex children. "How often do you find that discharge plans and goals are discussed during handoff communication between nurses from shift to shift" was rated to happen at least 62% of the time. The surveyed team identified at least 64% of the time that "educational materials (handouts, videos, etc.) were provided to families in the appropriate language". Seventy-eight percent of the surveyed respondents perceived that "medically complex pediatric patients are discharged when parents are ready to assume care at home". Additionally, 78% of respondents identified that "medication regimens were reviewed with patients/caregivers of medically complex patients prior to discharge". (see Table 1).

Table 1

Frequency of Nurses' Experiences with Discharge Processes

Questions How often do you find that:	TOTAL (n)	Never (%)	Very Rarely (%)	Rarely (%)	Occasionally (%)	Very Frequently (%)	Always (%)	TOTAL
1. Discharge goals are reviewed and discussed between nurses and providers?	**90**	1%	3%	9%	39%	43%	4%	**100%**
2. The electronic medical record provides a clear understanding of discharge coordination between the physician, nurse, case manager, social work, etc?	**90**	0%	17%	13%	37%	32%	1%	**100%**
3. Discharge plans and goals are discussed during handoff communication between nurses from shift to shift?	**90**	0%	1%	3%	33%	58%	4%	**100%**
4. Discharge teaching is initiated on admission?	**90**	2%	13%	19%	33%	26%	7%	**100%**
5. "Teach-back" (where parents state in their own words information you have provided) and/or "show-me" (where parents demonstrate skills that you have taught) methods are used with patients/caregivers to ensure understanding of instructions provided?	**90**	1%	4%	4%	37%	42%	11%	**100%**
6. Educational materials (handouts, videos, etc.) are readily available?	**86**	1%	2%	10%	28%	44%	14%	**100%**
7. Educational materials (handouts, videos, etc.) are provided to families in the appropriate language?	**86**	0%	5%	6%	26%	57%	7%	**100%**
8. Interpretive services (via person, telephone, or video) are available and easily accessible for discharge teaching for medically complex patients?	**86**	0%	7%	14%	42%	26%	12%	**100%**
9. Resource nurses, when assigned to a unit, provide assistance with the discharge process of medically complex patients?	**86**	7%	6%	8%	29%	34%	16%	**100%**
10. Parents/caregivers of medically complex pediatric patients verbalize they are not prepared or confident to take care of their child at home?	**86**	3%	5%	23%	49%	19%	1%	**100%**
12. In your perception, medically complex pediatric patients are discharged when parents are ready to assume care at home?	**82**	0%	2%	1%	18%	65%	13%	**100%**
13. Medications for medically complex patients are filled prior to discharge?	**82**	1%	5%	7%	34%	37%	16%	**100%**
14. Medication regimens are reviewed with patients/caregivers of medically complex patients prior to discharge?	**82**	0%	2%	5%	15%	48%	30%	**100%**
15. Medical equipment that will be used in the home is available for patients/caregivers to demonstrate and troubleshoot prior to discharge?	**81**	2%	7%	9%	28%	46%	7%	**100%**

Nurses responding to the survey where both "very frequently" and "always" were selected at the 50th percentile include: "reviewing and discussing discharge goals between nurses and providers" (47%), utilizing "teach-back and/or show-me methods to ensure

the understanding of instructions provided" (53%), and having "educational materials (handouts, videos, etc.) readily available" (58%). Resource nurses were found to be favorably assistive with the discharge process 50% of the time. Other moderately occurring findings include "medications being filled prior to discharge" (53%), and "medical equipment that will be used in the home is available in the hospital so patients/caregivers can demonstrate and troubleshoot problems prior to discharge" (53%).

Less frequently performed or available processes occurring during the discharge of medically complex patients included "using the electronic medical record as a means of communication during discharge coordination" (33%), "beginning discharge teaching on admission" (33%), and using "interpretive services (via person, telephone, or video) when discharging medically complex patients" (38%). Participants identified that the question "How often do you find that the parent/caregiver of a medically complex pediatric patient verbalizes that they are not prepared or confident to take care of their child at home" happened the least frequently at (20%).

Study participants were queried concerning their satisfaction with selected discharge processes involving the medically complex pediatric patient. According to their responses, 61% were "satisfied" to "very satisfied" when it comes to "the education and information provided with transition from hospital to home by the multidisciplinary team" and with "the education they are able to provide at the bedside to patients and/or parents of children with medical complexities". Forty-four percent of participants surveyed identified that they were "Very dissatisfied" to "Dissatisfied" with "the amount of time they are able to spend to provide discharge education to patient/caregivers of medically complex patients" (see Table 2)

Table 2

Nurses' Satisfaction with Discharge

Questions	TOTAL (n)	Very Dissatisfied (%)	Dissatisfied (%)	Neither (%)	Satisfied (%)	Very Satisfied (%)	TOTAL
16. How satisfied are you with the education and information provided with transition from hospital to home of medically complex patients by the multidisciplinary team (case management, home care, and vendors)?	**79**	1%	18%	20%	56%	5%	**100%**
17. How satisfied are you with the discharge education you are able to provide at the bedside to patients and/or parents of children with medical complexities?	**79**	1%	10%	28%	56%	5%	**100%**
18. How satisfied are you with the amount of time you are able to spend to provide discharge education to patient/caregivers of medically complex patients?	**79**	5%	39%	25%	28%	3%	**100%**

Qualitative Findings

Eight of the survey questions allowed an opportunity for open comment by the participants in order for the researchers to further understand the barriers and facilitators that exist when nurses are discharging medically complex children to their homes. These eight questions resulted in 465 written comments. Content analysis was used to interpret this qualitative data by identifying themes within key thoughts and concepts (Hsieh & Shannon, 2005). Overall, three themes emerged as barriers to discharging the medically complex patient. They were: 1) knowing the plan of care, 2) time, and 3) disposition of the family.

Plan of Care

Being able to begin the discharge process at admission or at any time in the stay allows for proactive discharge planning (Wu et al., 2016); however, the nurses describe the discharge date and goal as a moving target making it difficult to plan. As one nurse shares the difficulty in planning, she states the "patient may or may not be going home with a PICC [peripherally inserted central catheter]. The patient may or may not be going home on NG [naso-gastric] tube feedings".

A shared theme amongst the nurses is that lack of communication creates a lot of "uncertainty of how long the actual admission will be. Uncertain of exactly what the patient will need when they do go home". Another writes:

> Everything is trying to get done at the last minute and if you are the nurse who gets to send them [patient] home, you are dreading it because you know you will be running around trying to tie all the loose ends.

Time

Qualitative data reflects many comments surrounding time and the difficulty in performing education, especially "teach-back" and "show-me" education. Time is the underlying barrier as noted by one of the nurse's comments "There is not enough time. Ever. If you have 4 patients, it's nearly impossible to find time to do teaching adequately". Another nurse describes:

> There are some days you have the time to sit with your families and educate well. However, some days the turn over [of patients] and push from the Throughput Manager and charge nurses is so much that you don't have the time you need to really give the attention to your patients that they need and deserve.

The nurses express being torn by "needing more time (and identifying that) there is not enough staff to monitor their other patients while being stuck in a patient room educating parents". Another nurse states:

> Having a team with a patient with complex medical issues can be very challenging. It is especially hard to prepare a family for discharge on a busy team because you can only spend 15 minutes at a time with family for teaching, if even that….in the past we didn't have so many complex patients and so it was easier to

> coordinate time but now kids have many issues and a lot of coordination is required and with so much charting and monitoring it makes it difficult

Family Disposition

Family disposition was the third largest theme identified amongst nurses. Barriers identified were related to the families' language and/or emotional demeanor. Open ended questions provided a general sense of what participants face during their shift when needing an interpreter. They describe language barriers as being unable to "get an interpreter when you need them without waiting an hour…and by the time they arrive you [the nurse] are tied up with another task". Another nurse also notes:

> Interpreters are available, but not always at the moment that you need them, and then when they do get to the unit, often times you have become busy with something else and they are unable to wait for an extended period of time.

In attempts to bridge the language barrier with technology assistance, nurses identified that the "interpreter phone service is inadequate because the interpreters are often hard to hear or there is echoing". They also describe that the cordless phones are simply undependable and do not work resulting in phones at the nurse's station having to be utilized and the difficulty in ensuring that the conversations are kept private. Video phones are identified as "better technology" but are not available on all units or "staff don't know how to use the device".

The emotional readiness to learn by parents/caregivers was noted as complicated and at times a barrier to discharge teaching. When attempting to address discharge planning at admission, nurses describe:

> Many times, it isn't done due to the family being sleepy by the time they come to an acute care floor…plus many times information is overwhelming to families because they are getting admission education and medical education along with being with their sick child.

A night shift nurses discuss the timing of admission and states "during my shift, if a patient comes in late, like at 0200 or 0300 for example, the parents have been with their child in the ED for a long time and are tired and not mentally prepared for learning".

On occasion, nurses also identified that some parents perceived to not be ready for discharge are those that "find lots of excuses or obligations prior to discharge to avoid going home". They may be "unable to teach back" or need "repeated prompting and reteaching". In these instances, "they [parents/caregivers] can become dependent on nursing staff". The responding nurses identified that in situations like these an assessment is made and they "will try in any way possible to teach them so they understand, perhaps in a different way, so they feel confident and ready to go home". They suggest that maybe the parent is just "nervous but competent" and need the additional time for education.

CHAPTER 5: DISCUSSION

The following statement by a survey participant reflects the state of affairs that nurses experience when attempting to provide discharge education to parents/caregivers of medically complex patients:

> I don't feel that I do a good job providing education for complex patients due to lack of time and resources. It is difficult to find materials to provide education in every way that parents like to learn. I have very few parents who prefer written materials and am often interrupted when attempting hands-on education. Education is generally very time consuming. It is difficult to leave the other patients for an extended period of time and also difficult to interrupt education to check on the other patients.

Based off of survey responses, there are steps that can be taken to improve this process and to impart high quality discharge teaching.

Limitations

This study has a few limitations. The first is the sample size in which only a 31% response rate was obtained during the three-month study duration. Initially looking like ninety participants, as the survey progressed, response rates dropped to 79 participants by the end of the survey. Losing those participants could have been a result of the survey being completed during work hours and being interrupted by the necessity to do other tasks? It may have also seemed redundant to some participants as some questions seemed similar to one another and they lost interest. Some responses indicated that participants "had already answered that question".

A second limitation to the study was a concurrent Lean project management plan involving the discharge process at the hospital where this study was conducted. An electronic survey was also used and included seven similarly written questions compared to this study. The studies did not overlap in time but were two weeks apart. This concurring project could have impacted the response rate for this study and/or could have led to confusion in the patient population since the concurring project was related to all discharges and not just the medically complex.

Implications

The emerging themes from this study identify several implications for improving the discharge process for medically complex patients. The first is in relation to the plan of care. When the plan of care is not communicated or is not clear staff express the difficulty in successfully planning for discharge. Instead, staff reflect an ever-moving target resulting in a barrier to true discharge planning. Wu et al. (2016) confirm a historical practice of fragmented discharge processes. This type of practice is noted in adult studies to result in as many as 49% of at least one or more medications errors at discharge or a 10% to 20% adverse event after discharge; all of which are deemed to be preventable Wu et al.

Successful, efficient, discharge planning of the medically complex pediatric patient can be done. As noted in the Statile et al. study, interventions that focused on proactive planning involved frequent communication amongst a multidisciplinary team, weekly rounds, an order set with defined goals (i.e. baseline oxygen requirement for 12 hours), a needs assessment tool that defined education requirements for discharge, financial needs, and a medication pathway. With these interventions in place the study

showed an efficiency goal of discharging medically complex pediatric patients within 2 hours of goals being met from 50% to 88% (2016). The study also did not increase readmission rates during this time period which could have been a result of trying to meet efficiency and was a balancing measure pre- and post-intervention (Statile et al.).

A concurrent Lean project happening in my organization during the time of my study and focusing on the discharge process for all populations in acute care identified several of the same interventions to undertake, paying close attention to multidisciplinary communication. Strategies underway include: 1) care board rounding with the provider to update anticipated discharge dates/goals and needed education, 2) improvements to discharge education documentation to clearly identify what has occurred and what still needs to be taught, and 3) daily Celebration Rounds (discharge huddles) held by the charge nurse, case manager and social worker to discuss anticipated discharge needs (medications, durable medical equipment and transportation) and completion of tasks within 24 hours prior to discharge followed by supportive documentation.

Daily goals for discharge orders are to be written by 10:00 am with an actual discharge to occur at 1200 followed with a celebration of small tokens for the patients and a festive escort to their vehicle by volunteer services. This project is being led with a strong emphasis on multidisciplinary communication. At the time of this writing, metrics of success are not available on this quality improvement plan.

The second theme emphasizes time and the difficulty in completing "everything" including teach-back and show-me education. Implications for practice include specific resources to support this initiative. Teach-Back is recognized as an evidence-based practice and is not one that should be overlooked because it can bridge gaps in discharge

teaching of all patients and/or caregivers regardless of health literacy and has been recognized as a strategy to reduce hospital readmissions in the pediatric population (Klingbeil & Gibson, 2018; CHSPS, 2016). Discharge Education/Teach-back is also considered the most important discharge component amongst clinicians (Blaine et al., 2018).

An option that should be considered as a solution for the discharge of medically complex children is the development of a Family Learning Center. In this model, a family learning center would provide a setting such as a classroom or learning lab dedicated entirely to parent and/or family education. The learning center would have educational materials including low/high fidelity manikins, medical equipment, computers and tablets, and nursing staff available to facilitate standard, consistent, and competent learning modalities for families. This learning environment would allow private and individualized training where the family can learn how to care for their child safely at home. Instruction and training in the Family Learning Center could be arranged by the child's healthcare team based on learning needs and scheduled as referrals to the center. The center could also prove useful for families needing refresher courses or for those requiring education prior to same day surgeries.

There are children's hospitals in the United States that have such a center and report positive findings that indicate "88% of families feeling confident and prepared to care for their child at home for nasogastric tube insertion and enteral feeding" (Relias Media, 2003, para. 13). In addition, they recognized a 62% reduction in time spent by home care nurses when discharge teaching was started in the learning center (Relias Media, 2003, para. 13).

A family learning center could prove beneficial and meet the constructs of the 7 domains (engagement with care team, respect for readiness, care coordination, efficient discharge, symptom control, self-efficacy, and normalization) as noted in the Leyenaar et al. (2017) study. The family learning center would include family engagement, provide a mechanism to assess discharge readiness, and coupled with careful discharge planning of a multidisciplinary team, create an efficient discharge process. Family learning through the center would support self-efficacy and allow parents/caregivers the opportunity to practice home care skills that are noted as being priorities (Leyenaar et al.; (Desai, Durkin, Jacob-Files & Mangione-Smith, 2016).

The last theme identified as a barrier to discharging the medically complex patient deals with the family disposition. Language was the most identified barrier. Implications for practice to supplement in-person interpreters is to consider the use of video interpreters and to ensure ease of availability and adequate training to support everyday usage including during the discharge process. Although there are limited studies regarding the best delivery of information through language medias, early findings suggest that newer technologies may prove desirable. According to a systematic review conducted by Joseph, Garruba, & Melder (2018), patients prefer visual communication whether it is in-person or via video. In addition, if having to choose between a long wait time for an in-person interpreter or a video interpreter, the video interpreter was more desirable. Anttila, Rappaport, Tijerino, Zaman, & Sharif (2017), also report a higher satisfaction with face to face interpretation; again, regardless if the interpreter is in-person or via video. In order to ensure safe transitions from hospital to home of

medically complex patients, the utilization of video interpretation has the potential to build the gap identified in the current study.

Another component of family disposition that can affect the discharge process is related to the emotional distress that families experience when having a hospitalized child. A gamut of emotions could be experienced by families ranging from avoidance to learn skills so the patient can be discharged to home to wanting to learn but not finding the confidence in themselves to perform the skill. In trying to start the discharge process on admission, barriers can come from families being exhausted because they have been in the emergency department all night or in unfortunate circumstances where unexpected traumatic events have occurred, and a state of overwhelming disbelief and shock can create barriers to education. In these situations, it is crucial to initiate the appropriate services as soon as possible but most importantly "respect families' discharge readiness" as identified in families' priorities regarding hospital to home transitions by Leyenaar et al. (2016). A Family Learning Center could prove beneficial for these families, too, since the center would allow a time and place with less stress.

Nurses' perceptions of potential facilitators during the discharge process of medically complex patients include three modalities: a resource nurse, 24 - 48 hour care, and care conferences. Resource nurses were determined to be of value in that they can help with teaching families and assessing competence. They have the ability to coordinate information between preferred pharmacies, MDs, case managers, social workers, etc., which can be extremely time consuming for complex discharges. As noted by a survey participant, "a resource nurse allows the assigned RN to appropriately care for the other patients on his/her team". Likewise, another nurse writes:

> It is my observation and opinion that medically complex patients are most efficiently and safely discharged by the bedside nurse who know their care best, having cared for them for one or more days. The bedside nurse is more equipped to explain goals/at home procedures and answer caregiver questions appropriately. The resource nurse will give the bedside nurse the opportunity to spend quality time with parents by watching the rest of his or her team during the discharge instructions and coordination.

Whether the family educator or care team provider for the rest of the team, the resource nurse was identified as a facilitator of the discharge process.

The current practice of 24 – 48 hour inpatient care was described as a facilitator of the discharge process by both acute care and house resource pool nurses that completed the survey. Expectations are that the parent/caregiver is able to independently care for their child under the supervision of the nurse for 24 to 48 hours prior to discharge. This type of care is usually required for parents/caregivers of children who have newly placed feeding tubes and/or are requiring parenteral nutrition and lipids. This period of time allows the nurse to evaluate care provided by the parent/caregiver and determine if additional education is needed or if the parent/caregiver can provide care safely to their medically complex child and be discharged home. As a determinant of parental readiness to assume care at home, a nurse describes, “we try to give them [parents] as many tools and help as we can, it just takes them doing it on their own. I think the most helpful thing is the 24 to 48 hour rooming in process. This way they have an opportunity to do it all on their own and can ask questions”.

The last item identified to assist in facilitating the discharge process of medically complex patients involves conducting care conferences. Care conferences are multidisciplinary meetings that involve the parent/caregiver of the medically complex patient and all stakeholders in the patient's care. The meeting provides an opportunity to meet and discuss a multitude of topics including a prolonged hospital stay, a confusing diagnosis, prognosis or major medical decision. Preparation for discharge is another reason for a care conference (Fox, Brittan, & Stille, 2014). The goal is shared decision making as a result of effective communication (Fox, Brittan, & Stille, 2014). Although a current practice in the hospital it is not consistently done with all medically complex patients. As addressed by one of the nurses, "we need to have more care conferences so that everyone is on the same page and knows the plan for discharge and what is needed for the families prior to going home".

Further Research

An interesting comment returned in the survey was a request for an "in-service on how to get parents to teach-back". Based on this response, the findings of this study and findings from an evidence-based practice implementation by Klingbeil and Gibson (2018), it was identified that staff do not routinely use teach-back while communicating with parents/caregivers. Reasons are identified as the time requirement to complete the teach-back strategy; however, there is potential that staff might not recognize the appropriate skills of teach-back and using open-ended questions to draw responses or demonstration from families. There is potential that teach-back utilization is even lower if staff do not know how to perform the skill as noted in a pre-intervention survey conducted by Klingbeil and Gibson (2018) that found that staff used closed ended

questions. After an educational session on teach back and health literacy the utilization of closed-ended questions decreased. Next steps in my current project should be to more closely assess the utilization of teach-back by staff by either replicating the Klingbeil and Gibson's study or developing a measurement tool to utilize while observing practice through simulation exercises or direct practice. A Family Learning Center could also prove beneficial for improving teach-back. Although not intended to replace all teach-back at the hospital, the Family Learning Center could be a place where nurses could be assessed or taught through the process.

Conclusion

Discharging the medically complex pediatric patient is a complicated process; however, there are interventions that can assist in ensuring a fluid transition from hospital to home. As the coordinator of care, nurses' perceptions of barriers and facilitators of the discharge process for this vulnerable population can provide a baseline on current practice happening at the point of care. Recognizing and implementing the appropriate interventions based on their feedback have the potential to improve quality and patient safety.

REFERENCES

REFERENCES

Anttila, A., Rappaport, D., Tijerino, J., Zaman, N., & Sharif, I. (2017). Interpretation modalities used on family-centered rounds: Perspectives of Spanish-speaking families. *Hospital Pediatrics, 7,* 492-498.

Blaine, K., Rogers, J., O'Neill, M., McBride, S., Faerber, J., Feudtner, C., & Berry, J. (2018). Clinician perceptions of the importance of hospital discharge components for children. *Journal for Healthcare Quality, 40*(2), 79-88.

Children's Hospitals' Solutions for Patient Safety. (2016). *SPS prevention bundles: Readmissions.* Retrieved from https://www. solutionsforpatientsafety.org/wp-content/uploads/SPS-Prevention-Bundles.pdf

Cohen, E., Kuo, D. Z., Agrawal, R., Berry, J. G., Bhagat, S. M., Simon, T. D., & Srivastava, R. (2011). Children with medical complexity: An emerging population for clinical and research initiatives. *Pediatrics*, *127*(3), 529-538.

Desai, A. D., Durkin, L. K., Jacob-Files, E. A., & Mangione-Smith, R. (2016). Caregiver perceptions of hospital to home transitions according to medical complexity: A qualitative study. *Academic Pediatrics, 16*(2), 136-144.

Elias, E. R., & Murphy, N. A. (2012). Home care of children and youth with complex health care needs and technology dependencies. *American Academy of Pediatrics, 129*, 996-1005.

Fox, D., Brittan, M., & Stille, C. (2014). The pediatric inpatient family care conference: A proposed structure toward shared decision-making. *Hospital Pediatrics, 4*(5), 305-310. doi: 10.1542/hpeds.2014-0017

Hsieh, H., & Shannon, S. (2005). Three approaches to qualitative content analysis. *Qualitative Health, 15*(9), 1277-1288.

Huber, C., & Blanco, M. (2010). Cleaning up the discharge process: A number of components and personnel are crucial to success. *The American Journal of Nursing, 110*(9), 66-69.

Institute for Healthcare Improvement. (2019). *Science of improvement: How to improve.* Retrieved fromhttp://www.ihi.org/resources/Pages/HowtoImprove/ScienceofImprovementHowtoImprove.aspx

Joesph, C., Garruba, M., & Melder, A. (2018). Patient satisfaction of telephone or video interpreter services compared with in-person services: A systematic review. *Australian Health Review, 42,* 168-177. doi: 10.1071/AH16195

Klingbeil, C., & Gibson, C. (2018). The teach back project: A system-wide evidence-based practice implementation. *Journal of Pediatric Nursing, 42,* 81-85.

Leyenaar, J. K., & O'Brien, E. R., Leslie, L. K., Lindenauer, P. K., & Mangione-Smith, R. M. (2017). Families' priorities regarding hospital-to-home transitions for children with medical complexity. *Pediatrics*, *139*(1), 33. doi:10.1542/peds.2016-1581.

Masters, K. (2018). Models and theories focused on nursing goals and functions. In J. B. Butts & K. L. Rich (Eds.), *Philosophies and theories for advanced nursing practice* (3rd ed., pp. 425-454). Burlington, MA: Jones & Bartlett Learning.

Pender, N. J. (2011). *The health promotion model manual.* Retrieved from https://deepblue.lib.umich.edu/bitstream/handle/2027.42/85350/HEALTH_PROMOTION_MANUAL_Rev_5-2011.pdf

Pender, N., Murdaugh, C., & Parsons, M. (2011). *Health promotion in nursing practice.* Upper Saddle River, NJ: Pearson Education, Inc.

Relias Media. (2003). *Focus on pediatrics: Practice makes perfect with NG tube insertion.* Retrieved from https://www.reliasmedia.com/articles/26137-focus-on-pediatrics-practice-makes-perfect-with-ng-tube-insertion

Sakraida, T. J. (2010). Health promotion model. In M. R. Alligood & A. M. Tomey (Eds.), *Nursing theorists and their work* (7th ed., pp 434-453). Maryland Heights, MO: Mosby Elsevier.

Solan, L. G., Beck, A. F., Brunswick, S. A., Sauers, H. S., Wade-Murphy, S., Simmons, J. M., … & Sherman, S. N. (2015). The family perspective on hospital to home transitions: A qualitative study. *Pediatrics, 136*(6), 1539-1549.

Spratling, R. (2017). Understanding the health care utilization of children who require medical technology: A descriptive study of children who require tracheostomies. *Applied Nursing Research, 34*, 62-65.

Statile, A. M., Schondelmeyer, A. C., Thomson, J. E., Brower, L. H., Davis, B., Redel, J., & Hausfeld, J. (2016). Improving discharge efficiency in medically complex pediatric patients. *Pediatrics*, *138*(2), e1-e10. doi:10.1542/peds.2015-3832.

Weiss, M. E., Johnson, N. L., Malin, S., Jerofke, T., Lang, C., & Sherburne, E. (2008). Readiness for discharge in parents of hospitalized children. *Journal of Pediatric Nursing, 23*(4), 282-295.

Weiss, M. E., Sawin, K. J., Gralton, K., Johnson, N., Klingbeil, C., Lerret, S., ….Schiffman, R. (2017). Discharge teaching, readiness for discharge, and post-

discharge outcomes in parents of hospitalized children. *Journal of Pediatric Nursing, 34*, 58-64.

Wu, S., Tyler, A., Logsdon, T., Holmes, N., Balkian, A., Brittan, M., ….Saysana, M. (2016). A quality improvement collaborative to improve the discharge process for hospitalized children. *Pediatrics, 138*(2), e1-e9. doi: 10.1542/peds.2014-3604

APPENDICES

APPENDIX A: STUDY ADVERTISEMENT

CALLING ALL ACUTE CARE & HRP NURSES

OCTOBER 1, 2018
TO
DECEMBER 31, 2018

TAKE THE SURVEY

NURSING RESEARCH

A nursing research study is being conducted to better understand the barriers and facilitators of the discharge process you encounter when discharging the medically complex child home.

SURVEYS WILL BE SENT VIA E-MAIL WITH A LINK TO SURVEYMONKEY STARTING OCTOBER 1, 2018

ALL SURVEYS ARE CONFIDENTIAL

Study being conducted by Stacie Licon, RN, MSN, CNS, ACCNS-P, CPN
Contact Stacie at 353-7102 or e-mail for any questions

APPENDIX B: SURVEY

This survey was designed to better understand the barriers and facilitators perceived by acute care nurses when discharging medically complex children that require continued care at home and whom will have at least one of the following technologies on discharge: tracheostomy, ventilators, feeding tubes, and/or central lines. Please answer the following questions related to the discharge process of the medically complex child using the following scale.

Never	Very Rarely	Rarely	Occasionally	Very Frequently	Always

From "Never" to "Always," how often do you find that:

1. **Discharge goals are reviewed and discussed between nurses and providers.**

   Never Very Rarely Rarely Occasionally Very Frequently Always

2. **The electronic medical record provides a clear understanding of discharge coordination between the physician, nurse, case manager, social services, etc.**

   Never Very Rarely Rarely Occasionally Very Frequently Always

3. **Discharge plans and goals are discussed during hand off communication between nurses from shift to shift.**

   Never Very Rarely Rarely Occasionally Very Frequently Always

4. **Discharge teaching is initiated on admission.**

   Never Very Rarely Rarely Occasionally Very Frequently Always

   If discharge teaching is not initiated on admission, what are barriers and what in your opinion might help? Please be as specific as possible.

5. **"Teach-back" (where parents state in their own words information you have provided) and/or "show-me" (where parents demonstrate skills that you have taught) methods are used with patients/caregivers to ensure understanding of instructions provided.**

   Never Very Rarely Rarely Occasionally Very Frequently Always

If "Teach-back" and Show-me" methods are not routinely used, what are barriers, and what in your opinion might help? Please be as specific as possible.

6. **Educational materials (handouts, videos, etc.) are readily available.**

Never	Very Rarely	Rarely	Occasionally	Very Frequently	Always

7. **Educational materials (handouts, videos, etc.) are provided to families in the appropriate language.**

Never	Very Rarely	Rarely	Occasionally	Very Frequently	Always

8. **Interpretive services (via person, telephone, or video) are available and easily accessible for discharge teaching for medically complex patients.**

Never	Very Rarely	Rarely	Occasionally	Very Frequently	Always

If interpretive services are not routinely available, what are barriers, and what in your opinion might help? Please be as specific as possible.

9. **Resource nurses, when assigned to a unit, provide assistance with the discharge process of medically complex patients.**

Never	Very Rarely	Rarely	Occasionally	Very Frequently	Always

If resources nurses are available, do you find their assistance helpful? Please be as specific as possible.

10. Parents/caregivers of medically complex pediatric patients verbalize they are not prepared or feel confident to take care of their child at home.

Never Very Rarely Rarely Occasionally Very Frequently Always

11. Discharge instructions provided to caregi... ...lex patients contain a plan on potential probl...

Removed from analysis

Never ... Very Frequently Always

12. In your perception, medically complex pediatric patients are discharged when parents are ready to assume care at home.

Never Very Rarely Rarely Occasionally Very Frequently Always

If you have perceived that parents are not ready, what has given you that impression? Please be as specific as possible.

13. Medications for medically complex patients are filled prior to discharge.

Never Very Rarely Rarely Occasionally Very Frequently Always

14. Medication regimens are reviewed with patients/caregivers of medically complex patients prior to discharge.

Never Very Rarely Rarely Occasionally Very Frequently Always

15. Medical equipment that will be used in the home is available for patients/caregivers to demonstrate and troubleshoot prior to discharge.

Never Very Rarely Rarely Occasionally Very Frequently Always

Please answer the following questions related to your satisfaction of the discharge process for medically complex children using the following scale.

Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied

16. How satisfied are you with the education and information provided with transition from hospital to home of medically complex patients by the multidisciplinary team (case management, home care, and vendors)?

Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

If you are dissatisfied, what are barriers? Please be as specific as possible.

17. How satisfied are you with the discharge education you are able to provide at the bedside to patients and/or parents of children with medical complexities?

Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

If you are dissatisfied, what are barriers? Please be as specific as possible.

18. How satisfied are you with the amount of time you are able to spend to provide discharge education to patient/caregivers of medically complex patients?

Very Dissatisfied Dissatisfied Neither Satisfied Very Satisfied

If you are dissatisfied, what are barriers? Please be as specific as possible.

Additional Comments:

Demographic Questions

19. How many years of nursing experience do you have?

- 0-1 years
- 2-5 years
- 6-10 years
- 11-20 years
- 21-25 years
- >25 years

20. What types of patients do you typically care for?

- Medical
- Surgical
- Oncology
- Rehabilitation

21. What shift do you typically work on?

- Nights
- Days

22. Gender?

- Male
- Female

23. Highest nursing degree?

- Diploma
- Associate Degree
- Baccalaureate degree
- Master's Degree
- Doctorate degree

24. Are you an acute care nurse or house resource pool nurse?

- Acute Care
- House Resource Pool