THE EFFECTIVENESS OF VIDEO DISCHARGE INSTRUCTIONS FOR THE NEWLY DIAGNOSED PEDIATRIC ONCOLOGY CAREGIVER

by

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ABSTRACT

DAWN MERGENTHALER. The Effectiveness of Video Discharge Instructions for the Newly
Diagnosed Pediatric Oncology Caregiver.
(Under the direction of DR. KATHLEEN JORDAN)

Effective discharge teaching for caregivers of newly diagnosed pediatric oncology patients can reduce unplanned medical utilization, health care costs, and incidence of relapse and treatment complications. Challenges to providing effective instruction for this population include reduced initial hospitalization time, caregiver receptiveness, and consistency of content. While there is little evidence-based best practice for related educational methodology, video delivery of patient education is increasingly popular. Two videos, linked to QR codes, were developed to accompany the standard discharge teaching tools for pediatric oncology patients. Intervention effectiveness was evaluated in three areas, each at a different timepoint: caregiver feedback, skill acquisition, and decision-making. Caregiver feedback, evaluated through QDTS scores, rated the quality of discharge teaching favorably (mean 8.46, SD 1.58). Following the education and hospital discharge, all caregivers demonstrated us of the appropriate skills/behaviors to be ready for the first outpatient clinic visit as assessed by the clinic readiness tool. The 30-day post-discharge survey revealed that all caregivers experienced an unexpected medical concern at home. Appropriate medical utilization decision making (emergency department, triage, clinic) was engaged to resolve the concerns. Further, high use of the QR codes outside of the hospital setting (52 times outside the initial teaching, with 37 from unique IP addresses) indicates the videos were referenced or shared with others who needed education to help care for the child. This is particularly noteworthy given post-pandemic visitor restrictions which hinders normal education pathways for extended caregivers. Overall results were positive, and further exploration of this innovative educational strategy is warranted.

Keywords: pediatric oncology, discharge education, videorecording

ACKNOWLEDGMENTS

The secret to quality is love.
~ Avedis Donabedian

Dr. Avedis Donabedian is known as the founder of the study of quality in health care and medical outcomes research. This quote caught my curiosity since love is not a very quantifiable term. I am not certain why the founder of such a data heavy science would choose an unquantifiable term to be the foundational descriptor of his work. My theory, though, is that to do this work, you need to start with passion. Passion for your profession, passion for excellence, passion for the patients you serve and the change you want to affect. I have been blessed to have been impacted along this journey by many passionate individuals.

My committee chair, Dr. Kathleen Jordan, inspires me to dream bigger, do more, and reach farther. Her infectious enthusiasm and never-ending fountain of patience with my learning process quelled my self-doubt whenever hurdles arose. Her unique ability to be teacher, mentor, and colleague at the same time raises the level of conversation and possibility with every encounter.

Dr. Kelly Powers challenged me throughout this process to consider equity as I bring technology into my project. Any solution I present is not really a solution if it cannot be available to all. This was a hard topic for me to wrestle with, but an important one to consider, as I move forward. I am grateful that she asks the ‘what if’ questions that challenge my assumptions and grow my project.

Dr. Meg Hunter had a tremendous influence in my project design. Initially, I leaned toward a ‘safer’ project design. She challenged me to design a project that could have more direct influence on patient metrics, even if it does not fit neatly in the typical project design parameters. I am thankful for her passion that, whatever we strive to do, design it in a way that it has the tightest connection to patient outcomes you can achieve.

Lastly, I am deeply thankful for my parents. Whenever I doubt, fail, or struggle, they pick me up, and whisper, “Yes, you can.”

DEDICATION

Many students honor the influence or support of their family and God during this momentous learning experience. While I am thankful for the enduring presence of both in my life, I am choosing instead to dedicate this work to the families I serve. In the midst of the most terrifying battle of their life, they supported my desire to learn, to improve, and to grow. Their gracious partnership, and the honest feedback, that grew this project cannot be overstated. In return, I hope to continue questioning, learning, and striving toward the day when a cure makes this work unnecessary and obsolete.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

CLABSI	central line associated blood stream infection
COG	Children’s Oncology Group
DNP	Doctor of Nursing Practice
ED	Emergency Department
IFSMT	Individual and Family Self-Management Theory
IP	Internet Protocol
IRB	Institutional Review Board
QCM	Quality Caring Model
QDTS	Quality of Discharge Teaching Scale
QR	Quick Response
SD	standard deviation

CHAPTER 1: Introduction

Effective discharge teaching for caregivers of newly diagnosed pediatric oncology patients has implications beyond knowledge acquisition. It has been linked to reducing incidence of relapse, treatment complications and unplanned medical utilization, thereby reducing health care costs (Bulut et al., 2019; Hamline et al., 2018; Hockenberry et al., 2021; Hoenk et al., 2021; Kaul et al., 2021; Stephens et al., 2017; Wilson Smith et al., 2018). Given the influence discharge teaching has on critical health care areas, ensuring effectiveness in the process should be a paramount part of patient care.

Remarkable advances in pediatric oncology over the last three decades have led to substantial gains in five-year survival rates. Overall five-year survival surpasses 84%, with some areas achieving over 90% survival rates (Howlader et al., 2020). Given this success, some aspects of research are focusing on the remaining 15% uncured or relapsed patients (Williams et al., 2021). While novel pharmacology is certainly one thrust of this research, other avenues of exploration focus on why the current treatment plan, successful in many patients, did not achieve more uniform results. Many researchers have evaluated how delays in treatment or dose reductions to accommodate side effects compromise treatment success. These situations have been linked with increased risk of cancer relapse (Bhatia et al., 2012, 2015, 2020; Leonard, 2012; Meeske et al., 2015).

Delays in treatment or dose alterations can occur for many reasons, such as infection, improper side effect control, or medication non-adherence, all of which could be influenced with proper caregiver preparation (Bhatia et al., 2020; Hockenberry et al, 2021). Given the trend toward shorter hospital stays and more treatment in the outpatient setting, caregivers of pediatric oncology patients are increasingly tasked with medication administration, symptom management and infection control. Poorly managed symptom control or infection prevention can lead to unplanned medical utilization, potential treatment delays, or treatment alterations, all of which can affect cure (Hockenberry et al., 2021; Landier et al., 2016). Effective discharge education lays crucial groundwork that prepares caregivers to safely monitor and care for these children at home, potentially decreasing the risk of treatment interruption or even relapse.

Unplanned healthcare utilization is emerging as a possible metric to gauge effective discharge education for pediatric chronic illnesses (Berry et al., 2014; Berry, Toomey et al., 2013; Berry, Ziniel et al., 2013) and supports the cost effectiveness of educational programs. A high percentage of pediatric hospital readmissions are preventable (Amin et al., 2016; Toomey et al., 2016) and the lack of effective caregiver education for home management is a major contributor to readmission (Lerret et al., 2015; Lerret & Weiss, 2011). While pediatric oncology is not technically a chronic condition, the length and breadth of treatment, coupled with the medical complexity and fragility of this patient subset certainly supports unplanned healthcare utilization as a method for measuring effective discharge education.

An oncology diagnosis in any setting induces stress and worry. The emotional responses are magnified in the setting of a pediatric setting. The understandable stress response has repercussions on a caregiver’s ability to absorb critical information (Feeg et al., 2018; Rogers et al., 2016). Over the last decade, the task of preparing the caregiver for discharge has collided with increasingly shorter hospital stay duration (Flury et al., 2011; Reilly, 2018), which condenses the teaching window. Expert industry consensus suggests a standardized educational timetable with specific topic progression (Landier et al., 2016; Rogers et al., 2018). However, evidence-based recommendations regarding methodology for ensuring effectiveness of the process remain elusive.

1.1 Problem Statement

The combination of rapid growth in the pediatric oncology program, with shortened initial hospitalization time, has created educational challenges in preparing caregivers for discharge. The pediatric inpatient unit, strengthened with experienced nurses, houses a general population which makes pediatric oncology patients a high-risk/low volume subset. Providers, who normally facilitate layered, comprehensive education with caregivers and patients, are challenged by time constraints and high patient volume, increasing the importance of adopting a standardized discharge plan to ensure adequate caregiver preparation.

While educational topic guidance exists to support the wide range of diagnoses within pediatric oncology, there is a lack of evidence-based best practice for methodology to ensure effective foundational caregiver education prior to discharge from the inpatient setting. Current practice includes written material reinforced with face-to-face discussion with the medical team and the immediate caregivers (usually the parents). The bulk of education occurs during the day, in the patient's hospital room. Given the nature of shift work, it is not unusual for education to be started by one provider and continued by another. This fragmentation challenges the ability for the education to be consistent and complete.

Institutional educational practices at the implementation site have begun to utilize video as a mode of delivery for patient education, given its ability to standardize information in a multimodal format available for topic reinforcement through re-viewing. Current interventional site initiatives include educational iPad availability for patients, integrated electronic medical record ability to assign educational video content for viewing, and the ability to push the video content to the patient care apps in the outpatient world. However, there exists no institutional inventory of video topic selection for the pediatric oncology patient. This gap in institutional resources and their effectiveness in such a high-risk patient population should be explored.

1.2 Purpose/Clinical Question

The purpose of this DNP scholarly project was to explore the use of a video summary of two specific discharge education components for caregivers of newly diagnosed pediatric patients. This project was conducted to evaluate how the use of video summaries can enhance the usual discharge education platform. Evaluative areas explored by this project included caregiver perception, skill acquisition and caregiver decision making.

Given the purposes described, this PICO question guided the DNP scholarly project: Among caregivers of newly diagnosed pediatric oncology patients, does the addition of a video education program, combined with the standard discharge education method, enhance quality of discharge teaching scores, readiness for the first outpatient clinic visit, and clinical home care management decisions?

1.3 Project Objectives

Evidence supports education modalities that are consistent, family centered, multimodal and which are fulfilled with a video platform. The intervention site supports video education technology for other diagnoses but lacks content for the pediatric oncology patient. The DNP project leader created two supplementary educational videos to enhance usual discharge education processes. One video focused on fever care. Another video provided guidance about preparing for outpatient clinic visits (inclusive of general central line home care). The topic choices are supported by best practice literature (Rogers et al., 2018) and have broad usefulness across all types of pediatric oncology diagnoses. In piloting this type of education, this DNP project explored the effect of this education modality on quality of discharge teaching scores, readiness for clinic appointment, and caregiver decision-making processes.

CHAPTER 2: Literature Review

To guide intervention development and implementation, two comprehensive literature reviews were conducted. A total of fifty-three articles were selected for inclusion.

Two searches were performed using PubMed and CINAHL databases. The first search utilized the following search terms: *pediatric oncology* OR *pediatric cancer* OR *childhood cancer* OR *children with cancer* AND *unplanned medical utilization* OR *emergency department* OR *emergency room* OR *admission*. The search was limited to studies in academic journals, in the English language, and between 2016-2022. The reference lists of identified studies were also reviewed and examined for possible inclusion even if outside of the search date range. Titles and abstracts were screened using inclusion criteria of pediatric oncology focus and unplanned medical utilization. Studies describing unit specific process improvement outside of discharge education, pediatric oncology patients not on active therapy, adult patients, or pediatric patients without an oncology diagnosis were excluded (see Appendix A). Thirty articles were identified for inclusion in the review. Utilizing Polit and Beck's (2019) level of evidence guide, twenty-seven articles were level IV, one article was level V and two were identified as level VI evidence.

The second search utilized the following search terms: *pediatric oncology* OR *pediatric cancer* OR *childhood cancer* OR *children with cancer* AND *discharge teaching* OR *discharge education* OR *patient education* OR *patient teaching*. The search was limited to studies in academic journals, in the English language, and between 2016-2022. The reference lists of identified studies were also reviewed and examined for possible inclusion even if outside of the search date range. Title and abstracts were screened using inclusion criteria of pediatric oncology focus and discharge teaching. Studies describing adult populations, physiotherapy, quality of life, and epidemiology were excluded (see Appendix B). Twenty-three articles were identified for inclusion in the review. Utilizing Polit and Beck's (2019) level of evidence guide, four articles were level I, two were level II, four were level III, four were level IV, seven were level V, and two were level VI.

2.1 Research Focused on How Caregivers Learn

In evaluating how caregivers acquire necessary skills and knowledge under condensed and stressful conditions, many parents reported not remembering anything past the word "cancer." Other parents reported being scared, concerned, frustrated, nervous, and overwhelmed at initial discharge (Feeg et al., 2018; Rogers, Laing, et al., 2016). Understanding the influence that caregiver stress has on a critical time point in patient care, combined with shorter hospitalization time trends (Flury et al., 2011; Reilly, 2018), makes it necessary to select focused educational topics.

Recognizing the need for industry-standardized teaching topics to capitalize on shorter educational windows (Haugen et al., 2016; Landier et al., 2016), the nursing discipline of Children's Oncology Group (COG) galvanized a powerhouse of nurse researchers to harmonize expert consensus into a cohesive, planned educational approach presented by Rogers et al. (2018). This guidance document divides the educational topics into three areas: primary topics suitable prior to initial hospital discharge, secondary topics necessary within the first month of diagnosis, and tertiary topics required before the end of treatment (Rogers et al., 2018). Literature clearly supports the importance of primary topics of fever care, central line care, and medication adherence, finding them to have profound, long reaching implications for delay of treatment and subsequent cure versus relapse (Bhatia et al., 2012, 2015; Hockenberry et al., 2021; Leonard, 2012; Meeske et al., 2015; Wilson Smith et al., 2018). Despite topic consensus, literature about methodology is less definitive. Literature does support that educational methodology should ensure consistency, consider caregiver needs surrounding timing/pacing, and be multimodal.

2.2 Education Should be Consistent

In a systematic review focusing on patient/family education, Landier et al. (2016) found strong evidence for recommending that the information be consistent across the healthcare team. In evaluating how caregivers of newly diagnosed pediatric oncology patients learn, caregivers reported wanting consistency, both in the person conducting the teaching and the information (Rogers, Stegenga, et al., 2016). Further, they wanted consistency between the written material and what they were taught. Education delivered within a multidisciplinary team model should use caution to ensure uniform information so the team can capitalize on consistent reinforcement when opportunities arise (Landier et al., 2016).

Considering Withycombe et al. (2016) reported that 57% of surveyed sites utilized a multidisciplinary approach to discharge education, Landier et al.'s (2016) guidance is critical. Bailie et al. (2021) explored central line care education and reported caregivers' frustration when they were provided multiple ways to perform tasks. Some nurses would show one way, others a different way, while still others would add tips or tricks, which created confusion. Understanding that consistency is paramount, Dobrozsi et al. (2019) piloted task lists with accountability measures for their multidisciplinary education team, attempting to ensure consistency in information. Literature supports the importance of consistency in information (between written and verbal, and among the healthcare team) to reinforce learning crucial skills.

2.3 Education Should Consider Timing and Pace

Literature focused on feedback from caregivers emphasizes timing and pace of education as important considerations when planning modalities and implementation. Often, education is provided on the healthcare team's ideal schedule rather than the caregiver's ideal schedule (Mills et al., 2021; Weiss et al., 2017). Time constraints of shortened hospitalization and limited staffing further stress the educational timetable (Weiss et al., 2017). The provision of family centered care, in the context of discharge education, needs to account for different family structures and caregiver models (Altounji et al., 2020; De la Maza et al., 2020; Di Giuseppe et al., 2021; Hamline et al., 2018; Landier et al., 2016; Rogers, Laing, et al., 2016) and the fact that caregiver focus is often distracted (sick child, fatigue, stress of diagnosis) during the educational teaching (Altounji et al., 2020; De la Maza et al., 2020; Di Giuseppe et al., 2019; Dobrozsi et al., 2019; Rogers, Laing, et al., 2016; Rogers, Stegenga et al., 2016). For these reasons, video educational modules (that are available for re-viewing) are increasingly being explored as a way to make education available to all caregivers (present at the hospital or not) and provide topic reinforcement at a time optimal for caregiver focus rather than healthcare providers' convenience (Di Giuseppe et al., 2019; Mills et al., 2021; Rogers, Laing, et al., 2016).

2.4 Education Should be Multimodal

Accounting for different learning styles in modality development is also supported in the literature. During pilot studies to improve central line care at home, Altounji et al. (2020) and De la Maza et al. (2020) reported the importance of educating using written, visual, auditory, and tactile modes. Their projects resulted in lower CLABSI rates compared to the regular methods. Park et al. (2020), striving to enhance the education for teens, piloted a Facebook-style education platform with multimedia clips which received high scores of patient satisfaction compared to previous efforts. Wilson Smith et al. (2018) completely overhauled their discharge education and found that the multimodal aspect created high satisfaction scores from caregivers and nurses. Mills et al. (2021) and Di Giuseppe et al. (2019) both explored the use of video to provide visual, written, and auditory modalities for their educational plan and reported decreased caregiver anxiety, increased confidence with tasks, and improved understanding of the information presented. A consistent theme among many of the studies that sought caregiver feedback was the desire for concise, take-home information that is readily available in the format of a single-page document or refrigerator magnet (Landier et al., 2016; Rogers, Laing, et al., 2016; Rogers, Stegenga, et al., 2016).

2.5 Research Focused on How to Measure Effective Discharge Education

There is no singular method to assess effectiveness of high-quality discharge education that is consistent, family centered, considerate of timing and pace, and multimodal. With an understanding of the link between unplanned medical utilization and discharge education, some studies used unplanned admissions to guide measurement of success (Bassal et al., 2021; Stephens et al., 2017); however, when considering unplanned medical utilization, generalizations should account for the complexity of measuring this metric. Using discharge diagnoses can be misleading as some readmissions are planned and might skew data (Auger et al., 2016; Ehwerhemuepha et al., 2018; Hoenk et al., 2021). Steineck et al. (2021), found that hospitalization rates among pediatric oncology patients were increasing and cited more aggressive treatment regimens as a cause, which makes comparisons year to year (even within one institution) hard to interpret. Evaluating emergency department (ED) admissions using simply discharge diagnoses or ICD-9 codes gives an inadequate picture of the symptomatology, or what could have been lacking in the discharge education, that brought the patient to the ED (Mueller et al., 2015; Mueller et al., 2020).

However, the importance of this metric cannot be disregarded either, as it seems to be predictive of future unplanned medical utilization and perhaps evidence of ineffective discharge teaching. In seeking to understand risk factors associated specifically with pediatric oncology readmissions, Hoenk et al. (2021) found an unplanned readmission rate of 41.2%. Further, Hoenk et al. (2021) found that unplanned readmission carries an 86.9% increase in odds for another readmission. Understanding that there are multiple entry points to a medical system, Mueller et al. (2016) studied pediatric oncology patients who are frequent ED utilizers (defined by this study to be four or greater ED visits in the last year). They found that 58% of their pediatric oncology ED visits were frequent utilizers, supporting the suggestion that previous unplanned medical utilization is a predictor for future unplanned utilization. Further, over half of Mueller et al.'s (2016) frequent ED utilizers were discharged to home from the ED (and would not have been included in Hoenk et al.'s (2021) data) which suggests that looking at all avenues of unplanned medical utilization might yield a rate higher than 41.2% found by Hoenk et al. (2021).

2.6 Measuring Skill and Knowledge Acquisition

Considering the complexities noted above, measuring discharge education solely through the metric of unplanned medical utilization likely would provide an incomplete picture of effectiveness. Other researchers have explored measuring knowledge/skill acquisition to assess discharge education effectiveness (Mills et al., 2021; Wilson Smith et al., 2018). Assessing skill or task proficiency (such as central line care or medication administration) is particularly suited to this methodology. However, when combined with parental feedback this could better reveal otherwise-missed opportunities for program improvement.

2.7 Measuring Caregiver Feedback

Literature has shown that caregivers have distinct views and a unique perspective about what constitutes effective education. Therefore, other researchers have chosen to measure the strength of discharge education models using tools that measure caregiver feedback. Some researchers chose to explore caregiver satisfaction (Bailie et al., 2021; Park et al., 2020; Wilson Smith et al., 2018) or decision making (Bailie et al., 2021; Morgan et al., 2020; Mueller et al., 2020) as indicators of effective discharge education. These measurement tools have used a combination of Likert scale items or open-ended items with thematic analysis to understand nuances that can enhance future efforts in discharge education.

The Quality of Discharge Teaching Scale (QDTS) for parents of hospitalized children (Weiss, et al., 2008) is a validated tool that collects caregiver feedback to evaluate discharge teaching over the course of the hospitalization. It has been validated in general pediatrics (Weiss et al., 2017), complex pediatric transplant patients (Lerret et al., 2015), and high-risk neonatal patients (Rio et al., 2021). Interestingly, Weiss et al. (2017) studied the relationship between quality of discharge teaching (as measured using the QDTS) with nurse assessed caregiver readiness and caregiver self-readiness assessments for discharge assessment scores and readmission rates. They found a positive association between caregiver QDTS scores and both nurse assessed caregiver readiness and self-assessed caregiver readiness for discharge scores and an indirect association between increased QDTS scores and decreased likelihood for readmissions.

In general, literature supports educational approaches that favor quality over quantity (Rogers et al., 2018; Weiss et al., 2017). Caregiver learning is influenced by, among other things, consistency, pace/timing, and multimodal approaches. Evaluative techniques to assess the effectiveness of caregiver learning should include behavioral modification and skill acquisition. In addition, there should be a method for understanding whether caregivers are able utilize information from the discharge education to support appropriate decision making at home when medical concerns arise.

2.8 Conceptual/Theoretical Framework

The theoretical framework supporting this project was derived from blending the Quality Caring Model (Duffy, 2018) with the Individual and Family Self-Management Theory (Ryan & Sawin, 2009). The Quality Caring Model (QCM) provides overarching support for the influence of caring relationship development on self-advancing systems (Duffy, 2018). The Individual and Family Self-Management Theory (IFSMT) guides more specific interventions through inclusion of contextual factors and process domains (Ryan & Sawin, 2009). Both theories seek to influence proximal and distal outcomes of self-management, empowerment, and unplanned healthcare utilization and emphasize use during transitional care time periods (Duffy, 2018; Ryan & Sawin, 2009).

Since the clinical intervention site follows the QCM framework, its use in this project leverages an existing foundation of well-established behaviors from which to work. At its core, QCM proposes that the foundation of effective care derives from humans in relationship with each other. Caring behaviors, enacted through relationship-centered encounters, produce a feeling of being cared for which promotes self-advancing systems (see Appendix C). It is a theory that values the creation of the nurse-patient relationship and considers it to be an important step in achieving quality outcomes. Feeling cared for by health professionals seems to "buffer stress, promote resilience, relieve the burden of expectations, lessen some uncertainty, and increase confidence and comfort" (Duffy, 2018, p. 153). These seemingly unquantifiable elements translate to improved self-management and decreased hospital readmission rates for patients with chronic illness states (Duffy, 2018). Promotion of self-management and decreasing unplanned healthcare utilization are outcome measurement goals of this project, which makes QCM a well-aligned theory. However, while the QCM sets the stage for relational support, more contextual and process-oriented guidance is required for successful implementation of this project.

The IFSMT (see Appendix D) describes how interventions accounting for patient-specific context (condition complexity/prognosis, physical/social environment, and family dynamics) with the goal of promoting self-management (through knowledge, planning, collaboration, and skill acquisition) can increase self-management behaviors, improve health, and influence cost of healthcare (Ryan & Sawin, 2009). The focus of this framework is the how the child's diagnosis impacts the family and its ability to gain self-management skills (Ryan & Sawin, 2009), making it ideal for use in this project. Given the varying differences of family structure, as well as cultural, economic, and educational backgrounds in the project population, this theory allows for flexibility in individually shaping contextual and process needs while still maintaining focus on the desired outcomes using a multidimensional family lens.

The influence of these frameworks is woven throughout this project. In a time of chaos and uncertainty, the nurse, strengthened with using the QCM, establishes a relationship with the caregiver(s). This foundational relationship allows the caregiver to feel cared for and becomes the basis from which every other learning experience can springboard. Once relationship is established, the IFSMT allows the nurse to layer education that is personalized for the caregiver, while being considerate of family structure, culture, and educational background. This education is applied through the lens of the impact the diagnosis has on the family structure and coping abilities. Utilizing both theories allowed this project to align more closely with the family and strengthens the caregiver ability to develop crucial self-management skills.

Chapter 3: Methods

Guided by findings from the literature review, this project utilized topic suggestions to create focused teaching through video and with QR codes to distribute the content. Using a video modality aligns with literature recommendations for consistency, timing/pace, and multimodal qualities. Quantitative and qualitative data analysis informed effectiveness of the intervention and sought to understand caregiver feedback, skill/behavior acquisition, and decision making.

3.1 Setting

The setting was an urban medical center in the southeastern United States, encompassing a thirty-bed general pediatric floor, a nine-bed pediatric intensive care unit, a high-volume pediatric emergency department, and an outpatient pediatric hematology/oncology clinic where 30-40 patients are seen per day for medical care. Between 40 and 60 newly diagnosed pediatric oncology patients enter the system yearly. These patients range from 4 weeks to 22 years old and represent a wide socioeconomic, multicultural, and multilingual population. Additionally, the patients are supported by differing support structures ranging from the traditional nuclear family structure to foster care to extended/blended family.

3.2 Sample

The sample was adult caregivers of newly diagnosed pediatric oncology patients who were diagnosed in the hospital and received ongoing care in the outpatient clinic. A convenience sample was recruited from the primary caregivers of all newly-diagnosed pediatric oncology patients admitted to an inpatient unit (one primary caregiver per patient). While this setting serves a linguistically diverse population, the validated Parent QDTS is only available in English. Therefore, selection was limited to English-speaking participants.

3.3 Intervention

While expert consensus (Rogers et al., 2018) honed evidence-based topic selection, specific institutional input guided the tailoring of the videos to fit within the system processes and guidelines, creating a more focused intervention. For example, what defines a fever might vary institution to institution. Additionally, an aspect of discharge teaching increasingly reinforced in the interventional site is the concept of bringing medications to each clinic visit to facilitate a more accurate medication reconciliation and promote medication adherence practices. This might not be a recommended practice at other facilities. Thus, reproduction of this project in another institution should account for differences in institution-specific practice that could alter certain educational elements.

Video scripting was crafted by the project leader and validated by medical experts and the institutional health literacy department. Following script approval, the project lead created the videos using Doodle Maker. Each video was linked to a QR code using the program QR Tiger (see Appendix E). The videos lasted between two minutes and 27 seconds and three minutes and 46 seconds long. A computer-generated voice was used, allowing for a neutral accent, to reduce any acceptance bias based on English language accents (Nee et al., 2022). The video format was a whiteboard style video where a hand appears on the screen. The hand draws the images and writes the text corresponding to the audio content. This style of video format has been shown to be more engaging and solicit greater retention of content (Li et al., 2020; Turkay, 2016).

An advantage of the video creation program was the ability to tailor the skin tone of the hand used to draw the images or text which is an important element in culturally competent educational materials (Spinner et al., 2021). Lastly, this video creation program, engaging the computer generated voice, can easily translate content to different languages. While not applicable in this project, it can be an advantage for future exploration to understand the video effectiveness with non-English speakers.

Project implementation took place between September 2022 and December 2022. Implementation proceeded using the following steps.

1. The project leader was notified by the inpatient provider about any new diagnosis pediatric oncology admissions.
2. The project leader initiated a face-to-face discussion with the patient's caregiver to explain the project purpose and aims. Voluntary written consent and phone contact information were obtained. A participant number was assigned upon consent.
3. Each caregiver was given a log (see Appendix F) to complete at home following discharge. It had been screened for health literacy and scored at a second grade reading level. This log helped guide recollection of events to be discussed during the phone conversation 30 days after discharge.
4. Following the standard education, the intervention was implemented which was comprised of two short, educational, recap videos on fever care and getting ready for the first outpatient clinic visit. The videos were viewed with the project leader and caregiver on an institution-provided iPad to enable clarification if necessary. The video was accessed through a QR code, which was also given to the caregiver so they could continue to access it post-discharge. The project leader verified the caregiver was able to access, use, and share the QR video from their personal device.

5. The primary caregiver was given a medication bag and instructed to bring all medications to the outpatient clinic appointment (date verified with project leader at discharge) as directed in the video.

3.4 Measurement Tools and Data Collection Procedure

Understanding that assessment of effective discharge education should include caregiver feedback, self-management skill acquisition, and appropriate decision making, three different data collection tools were utilized, each at a different timepoint. The QDTS was administered just prior to hospital discharge, the readiness for clinic assessment was performed at the first outpatient clinic visit (usually a few days to one week after discharge) and the 30-day post discharge phone interview was conducted a month after discharge (see Figure1).

Caregiver feedback. Before discharge, the QDTS was administered to all participants. This validated tool collects caregiver feedback about the discharge education. The QDTS is an 18-item tool administered with pencil and paper. The items are scored using an eleven-point Likert scale ranging from ranging from ‘0’ (none or not at all) to ‘10’ (a great deal or always). It is divided into two subscales focusing on quantity and quality of the discharge education.

The quantity subscale compares caregiver perception about how much information was needed versus how much information was received. The domains measured in the quantity subscale are care of the child at home, home treatment and medication knowledge, home treatment and medication practice, when to call the provider, expected emotions, and educational needs of other caregivers (Weiss, n.d.). The quality subscale measured values associated with the education’s (and educator’s) ability to actively listen and address specific questions, thoughtfully consider personal beliefs and values, provide information in a clear and consistent way, increase caregiver confidence to care for the child at home and know what to do in an emergency, decrease caregiver anxiety about going home, and provide teaching at times that were good for immediate and extended caregivers (Weiss, n.d.). Permission was granted to utilize this tool without modifications (Weiss, n.d.). This tool has good internal consistency reliability with a Cronbach's alpha of 0.89 among samples of parents of hospitalized children (Weiss et al., 2008).

Skills/behaviors. Self-management skills/behaviors were evaluated by the project leader at the first clinic visit. Three behaviors were assessed as yes, no or not applicable: bringing medications to clinic, intact or ready central line, and child wellness at the clinic visit. These behaviors were reviewed and demonstrated in one of the videos. Assessment of the behaviors determined the effectiveness of education to build self-management behaviors. This was tracked using a data collection tool (see Appendix H) created by the project leader.

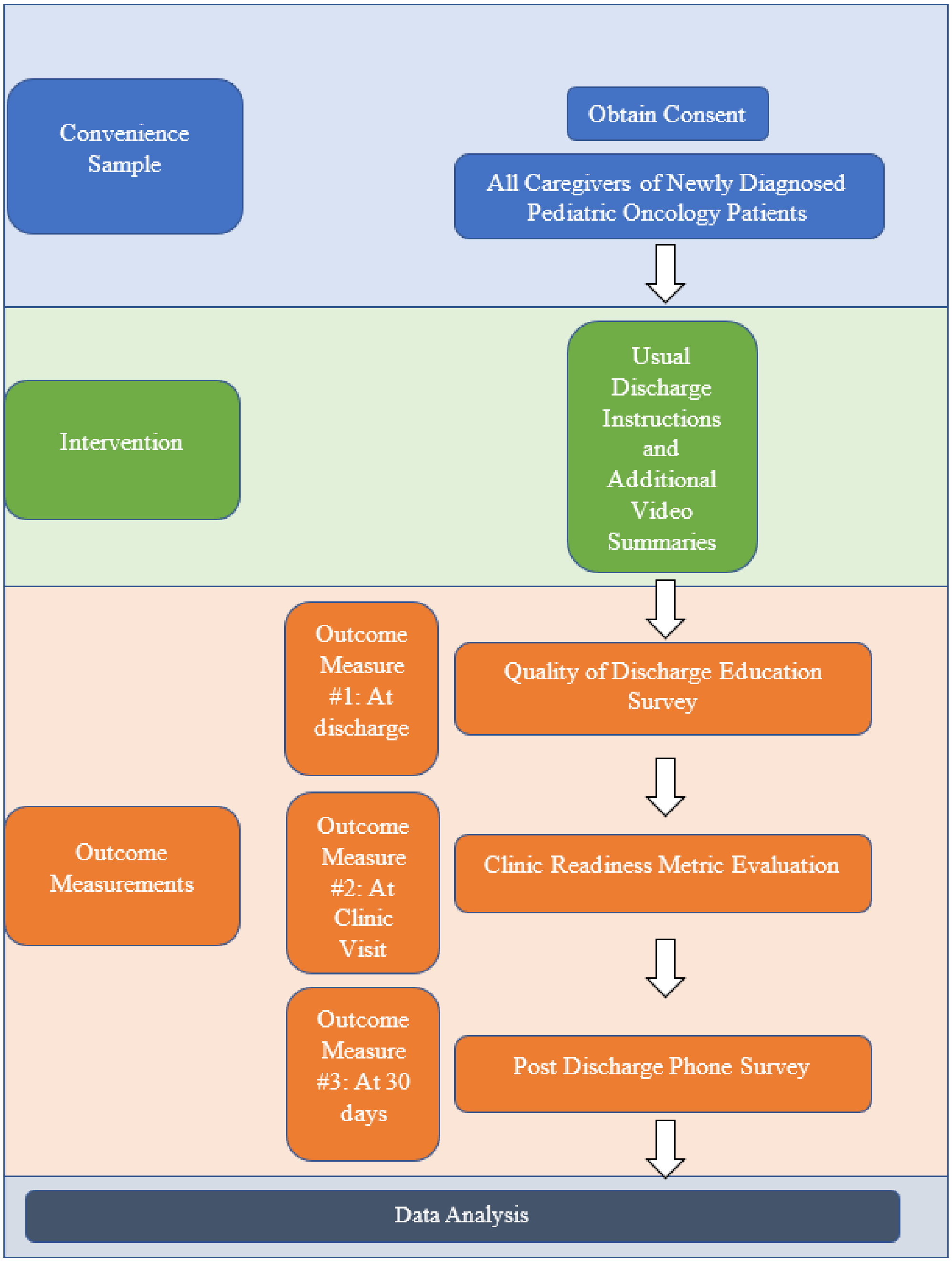
Decision-making. The project leader contacted all participating caregivers by phone 30 days after hospital discharge. A scripted ten-question interview guide created by the project leader (see Appendix I) was utilized to explore effectiveness of discharge education to guide caregiver decision making for medical concerns. The interview guide was screened for health literacy and scored at a second-grade reading level. Open ended qualitative questions were designed to facilitate the caregiver sharing their experiences of medical concerns at home and the decision-making process they utilized to seek help or answers to those concerns.

Caregivers were asked about their unplanned medical utilization (triage line, emergency room, sick clinic visit) in the context of understanding if the medical concern was appropriate for the resource utilized. For example, utilization of the ED for a question about medication dosing would not be an appropriate resource utilization. However, the triage phone line would be an appropriate resource for that question. The conversations lasted approximately 10 minutes and the project lead took detailed notes on the interview guide of the information relayed by the caregivers.

Throughout the data collection process, the only demographic information that was obtained was the caregiver’s name and phone number (to facilitate contact for the phone interview). This was a limitation placed by the institutional IRB approval, and names/phone numbers were collected with the consent and not associated with the data collected. To aid in data analysis and promote organization, quantitative data was entered into an Excel data collection workbook. Participant answers to open-ended questions remained on the original data collection tool (the interview guide) to avoid losing nuances of the original answers via translation to a different tool.

Figure 1

Implementation Overview



3.5 Data Analysis

Both quantitative and qualitative data were utilized in analysis. Collecting both data sources provided a deeper understanding of the impact of the intervention on this sample. Additionally, evaluating discharge education utilizing tools to measure caregiver feedback, behavior acquisition, and decision-making provided a more complete picture of the intervention's effectiveness.

Analysis of QDTS was completed using descriptive statistics (mean, standard deviation, and range). The QDTS is separated into two subscale scores, reflective of caregiver feedback on both quantity and quality of discharge teaching. Modification of the QDTS to utilize questions supporting only one scoring subscale was not permitted by the tool author, so data on both subscales were collected and scored. However, given literature supports that quality of discharge education is of greater importance than quantity of education (Weiss et al., 2017), scores for quality of discharge education were an emphasis and more heavily weighted in the interpretive discussion.

Readiness for the first clinic visit assessment data was evaluated based on overall readiness. A patient was considered to have performed the necessary skills/behaviors to be completely ready for the first clinic visit if they brought their medications to the visit, had an intact or ready central line, and the child was not acutely ill for the visit. In the case where the child was not prescribed any medication or they did not possess an external central line to be intact, those assessment areas were indicated as not applicable (NA) and did not contribute to the overall readiness assessment. A deficiency in one or more areas resulted in a 'not ready' denotation.

The 30-day post-discharge phone interview was conducted to understand the patterns of decision making that guided the caregivers to resolve unexpected medical concerns at home. The nature of the concern and the resource utilized were discussed and evaluated for appropriate decision making. Caregiver-reported unplanned medical utilization (ED visits, triage calls or sick clinic visits) was documented primarily as a context for understanding caregiver decision making. However, given the literature support for the predictive nature of unplanned medical utilization, the costly clinical and financial implications, and the indirect link of the QDTS with readmission rates, the raw number of utilizations was tracked, but its interpretation in the context of this project was viewed with caution. Next, thematic analysis of open-ended questions helped explore the education's ability to guide the caregiver actions when confronted with a medical concern. Additionally, this survey asked for caregiver feedback concerning areas of education they perceived as weak or missing. This is a valuable question since the caregivers, having 30 days of experience at home, are better able to reflect on items they felt needed more emphasis. This data was collected to enhance the ability to inform future iterations of discharge education tools.

3.6 Ethical Considerations

Institutional board approval (IRB) at the project site required presentation and approval by the Patient Education Committee and the Nursing Research Council prior to IRB board approval. Following approval by the project site's IRB, a reliance agreement from the project lead's university was obtained. This process preceded implementation.

Participation in this project was voluntary and this was explained to potential caregiver participants when the project lead reviewed the informed consent. Caregivers, upon providing written informed consent, were assigned a participant number which was used to track participant data on each subsequent data collection tool. The consent was scanned to an institution-encrypted folder and secured on a password protected computer. This file was kept in a separate computer folder from the data collection tool storage location. Files will be destroyed after six years as required by the IRB.

To facilitate data collection at the first clinic visit and the post discharge phone conversation, information such as participant number, first name of the caregiver, date of clinic appointment, and phone number was maintained on a document stored in an encrypted folder separate from other project documents and secured on a password protected computer. This file was permanently deleted after the discharge phone interview was completed. No other identifying data was collected from participants. Due to the small sample, participant confidentiality was further maintained by not stating caregiver gender. Data on patients was not collected.

Caregiver confidentiality was protected by encrypting files stored on password protected computers, de-identifying data collection documents, and storing files in separate locations on the password protected computer. All data collection forms were identified using only the participant number. Upon each collection data point, any caregiver completed forms were scanned to a folder and stored on an encrypted file on a password protected computer. The original paper copy was shredded.

Chapter 4: Project Results

This DNP project was open to recruitment from September 2022 to December 2022, with subsequent data collection (i.e. 30-day phone call interviews) occurring through January 2023. During the recruitment period, ten caregivers were identified who met the inclusion criteria. Four non-English-speaking caregivers were excluded from this population since the validated QDTS was only available in English. One caregiver was excluded because the child's treatment would not require ongoing care at the outpatient clinic. Another caregiver was excluded after transferring care to another institution, eliminating the ability for complete data collection to occur. The final sample consisted of four caregivers who were included in the project; the subsequent results and analysis are presented below. Descriptive statistics were used to report results.

4.1 Results of Quality of Discharge Teaching Survey

The QDTS is an 18-question validated tool designed to elicit caregiver perception about discharge teaching. It was administered just prior to hospital discharge. It is divided into two subscales focusing on quantity and quality.

The quantity subscale of the survey asks a series of paired questions based on how much content the caregiver perceived they needed versus how much the content the caregiver received in the discharge education process. The 'need' and 'receive' mean scores were calculated. Post-education prior to hospital discharge, the caregivers reported overall receiving more information (mean 6.375, SD 2.88) than they felt that they needed (mean 5.13, SD 2.76). Scores for each domain were also calculated (see Table 1). The domains receiving the highest scores for perceived content need were 'information about care of the child at home' (mean 7, SD 2.58) and 'who and when to call' (mean 6.25, SD 2.99). The domains receiving the lowest scores for perceived content need were ‘practice with medical treatments’ (mean 3, SD 2.16) and ‘expected emotions’ (mean 3.75, SD 1.71). The domains receiving the highest score for content received were ‘who and when to call’ (mean 8.25, SD 1.26) and ‘information about care of the child at home’ (mean 8, SD 1.83). The domains receiving the lowest scores for content received were ‘expected emotions’ (mean 5.16, SD 1.29) and ‘practice with medical treatments’ (mean 5.25, SD 3.77). It is important to note that throughout this section of the survey, most domain areas had large ranges of participant scores.

Table 1

QDTS Quantity of Education Results (n=4)

Domain	Need (mean)	Need (SD)	Need (range)	Receive (mean)	Receive (SD)	Receive (range)
Taking Care	7	2.58	4-10	8	1.83	6-10
Emotions	3.75	1.71	2-6	5.17	1.29	1-4
Medical Needs	5.5	3.12	3-10	7.5	1.91	6-10
Practice	3	2.16	1-6	5.25	3.77	0-9
Who/When to Call	6.25	2.99	3-10	8.25	1.25	7-10
Family Members	5.25	3.2	3-10	6.75	2.5	4-10

The second subscale of the QDTS focused on understanding caregiver perceptions concerning the quality of the teaching. Mean scores on quality of teaching were positive (see Table 2). Overall, the quality of discharge teaching was rated favorably (mean 8.46, SD 1.58). The highest areas scored included the ‘way caregivers were taught’ (mean 9.25, SD 0.96), and ‘check for understanding’ (mean 9.25, SD 0.96). The lowest areas scored included ‘knowing what to do in an emergency’ (mean 7.25, SD 2.06) and ‘decrease anxiety’ (mean 7.25, SD 2.06).

While the quantity section had large ranges, this section of the survey (on quality) had a tighter range of answers for most domains.

Table 2

QDTS Quality of Education Results (n=4)

Paraphrased Question	**Mean**	**SD**	**Range**
Answer your specific questions and concerns?	8.75	1.5	7-10
Listen to your concerns?	8.5	1.91	6-10
Sensitive to your personal beliefs and values?	8.5	1.73	7-10
The way you were taught?	9.25	0.96	8-10
Given in a way you could understand?	9	1.5	8-10
Break up your teaching into small amounts?	9	0.82	8-10
Check to make sure you understood?	9.25	0.96	8-10
Receive consistent (the same) information?	7.5	2.08	5-10
Given at times that were good for you?	8.75	1.25	7-10
Given at times your family or others could attend?	8	2.16	5-10
Help you feel confident in your ability?	9	1.15	8-10
Know what to do in an emergency?	7.25	2.06	5-10
Decrease your anxiety about going home?	7.25	2.06	5-10

4.2 Results from QR Code Use

An unexpected benefit of the company chosen for QR code creation was the ability to track how often the QR codes were scanned and how many of the scans were from unique IP addresses. Rather than relying on caregiver memory for how many other caregivers viewed the video, this data allows a more reliable method to understand dissemination of the interventional materials. After accounting for video scans in the hospital for initial teaching, the video QR codes were scanned an additional 52 times post-discharge. Of those scans, 37 were from unique IP addresses.

4.3 Results from Readiness for the First Clinic Visit

Effective discharge teaching can influence caregiver behavior and skill acquisition. There are many new skills and behaviors the pediatric oncology caregiver needs to master over a short period of time. The clinic readiness evaluation tool, administered at the first post-discharge clinic appointment, assessed the discharge teaching's ability to help caregivers acquire new skills or behaviors necessary for safe home care. Behaviors/skills assessed were bringing medications to the clinic visit, placing numbing cream on the port, having an intact central line dressing, and having a well (not urgently sick) child at the visit. All the project participants' children presented fully ready (based on the above criteria) for their first clinic visit (See Table 3). Incidentally, the non-English speaking caregivers, unable to enroll in the study or receive the educational intervention, were informally assessed using the clinic readiness checklist in use at the clinic. Of the four caregivers excluded because of the language barrier, none of the caregivers' children presented to the clinic ready for their first clinic visit. They were each deficient in one or more areas of assessment (See Table 3).

Table 3

Results of Readiness for First Clinic Visit

Participant #	Medications Brought to Clinic?	Numbing Cream on the Port?	Central Line Dressing Intact?	Child Well at Visit?	Overall Readiness?
10	NA	Yes	NA	Yes	Ready
9	Yes	Yes	NA	Yes	Ready
8	Yes	NA	Yes	Yes	Ready
7	Yes	Yes	NA	Yes	Ready
EXCLUDED	No	No	NA	Yes	Not Ready
EXCLUDED	No	NA	No	No	Not Ready
EXCLUDED	No	No	NA	No	Not Ready
EXCLUDED	No	No	NA	Yes	Not Ready

4.4 Results from the 30-Day Post-Discharge Phone Interview

To understand how discharge teaching may have influenced decision making in the context of unexpected medical concerns at home, a phone survey was conducted 30 days after discharge. Caregivers were asked about what unexpected medical concerns they encountered after discharge and what resources they used to resolve the concern. Three of the caregivers utilized the caregiver log provided (See Appendix F) to recall the experiences of the past 30 days. One caregiver stated they lost the log, but recounted the concerns from memory. Content analysis revealed areas of concerns, and resources utilized for addressing the concern. An open-ended question solicited suggestions for future discharge education topics and techniques from the caregivers.

All four of the project participants felt the discharge teaching prepared them to care for their child at home. However, all participants also experienced at least one unexpected medical concern in the 30 days after discharge. The topics of concern included medications (4), vomiting (2), fever (2), bleeding (2), and central line (1).

When faced with an unexpected medical concern at home, the caregivers cited several resources that helped them resolve the concern. The triage phone line was utilized by all 4 caregivers. Three caregivers utilized the triage line more than once. Questions to the triage line ranged from guidance regarding redosing vomited medications, tips for medication administration in a child (crushing, timing, diluting), nosebleed duration in the context of platelet counts, bruising/petechiae, interpretation of blood counts, and fever care. The ED was utilized by three caregivers for the medical concerns of fever and bruising/petechiae. The educational video for this project was referenced in helping one caregiver resolve questions about whether a central line dressing was intact.

Caregiver suggestions for supplementary discharge teaching strategies were gathered to help guide future revisions of the discharge teaching process. One caregiver was frustrated that the medical team did not look at the medications when they were brought to the clinic as instructed. Another caregiver requested an expanded video library inclusive of blood counts interpretation, medication teaching, and external central line flushing. The lack of anticipatory teaching about expectations of bruising/petechia was a disappointment voiced by one caregiver. Suggestions for nurses to encourage the parent (rather than nurses) to administer oral medications in the hospital prior to discharge were made.

Chapter 5: Significance and Implications

This DNP project explored how the use of focused video instruction might enhance the usual discharge teaching process for the newly diagnosed pediatric oncology patient’s caregivers. Effectiveness of the intervention was measured using three different evaluative tools at three timepoints. Analysis of caregiver perceptions of discharge teaching, skill acquisition, and decision-making informed the significance of this project.

5.1 Caregiver Perceptions of Discharge Teaching

Overall, caregivers perceived, at the time of hospital discharge, that they received more information in the discharge instruction process than they needed. These values could indicate that the education surpassed the expectations of the caregivers. However, literature consistently revealed that caregivers often felt overwhelmed by the amount of information they are given (Feeg et al., 2018; Rogers et al., 2016). These results could echo that finding, indicating that the education provided may have been more than the caregivers felt they could process. The QDTS scores for quantity of education had a wide range of values which indicate some caregivers felt they received too much education while others felt it was an appropriate or even not enough education. Another consideration about the wide range of values for this section is that varying diagnoses have varying initial care needs immediately following discharge. A patient following intense chemotherapy could have greater home needs than a patient following biopsy while waiting on pathology for a treatment plan. In interpreting the results of the quantity subscale of the QDTS, literature cautions that educational quality should be considered over quantity (Weiss et al., 2017). This point is especially poignant for the newly diagnosed pediatric oncology caregiver. Literature suggests that the caregivers, in the initial period following diagnosis, do not have a realistic understanding to be able to assess how much information is needed (Flury et al., 2011; Rogers et al., 2016).

The second part of the QDTS assessed the quality of the education received prior to hospital discharge. In the literature, emphasis was placed on caregiver feedback suggesting that education should be consistent, considerate of timing and pace, and multimodal (Altounji et al., 2020; Bailie et al., 2021; De la Maza et al., 2020; Di Giuseppe et al., 2019; Dobrozsi et al., 2019; Landier et al., 2016; Mills et al., 2021; Rogers, Laing, et al., 2016; Rogers, Stegenga, et al., 2016). Those topics, addressed in the second part of the QDTS, were of particular interest. Overall, QDTS quality subscale scores were positive and ranged from mean values of 7.25 to 9.25 out of 10.

The caregivers rated consistency as one of the lowest values, comparatively, with a large range and SD. Since the videos were consistent each time they were played, and they were scripted from the written educational material, this likely indicates a mismatch between what was presented in the video and what was verbally discussed by others on the healthcare team. This bears further inquiry in future iterations of this project and has important clinical practice implications.

Caregivers gave higher scores for the domain associated with pace and timing, which could indicate the advantage of the video for reinforcement. However, the scores indicated that teaching could have been better planned for when others in the family could attend. An advantage to utilizing video discharge education supplements is that other caregivers, unable to attend in-person discharge education, can receive consistent education to help care for the child at home. In future studies with this workflow and technology, it would be interesting to understand if the videos helped to mitigate this lower score on the QDTS.

One of the highest areas of scoring occurred in the domains the ‘way you were taught’ and ‘break up teaching into small amounts.’ These areas had both high scores with lower ranges and SDs. Further exploration is needed before interpreting this value as pertaining specifically to the video format of the educational platform as participants could have been reflecting on the entirety of the discharge education they received. A larger participant pool that allows for research using a control group (usual discharge education only) and an interventional group (usual discharge education plus videos) could help to better understand the video methodology’s effect on this domain.

There are inconsistencies when comparing some of the results from the domains of the quantity subscale with the quality subscale. Caregivers reported perceiving a low ‘need’ regarding emotional support (mean 3.75, SD 1.71), however, when asked if the quality of the teaching helped to decrease their anxiety about going home, that value was one of the lowest scored (mean 7.25, SD 2.06). Conversely, caregivers reported perceiving a high amount of information ‘received’ for who and when to call with medical concerns at home (mean 8.25, SD 1.25), yet on the quality subscale domain ‘know what to do in an emergency’ the caregivers scored this item among the lowest (mean 7.25, SD 2.06). Given the low number of participants, interpretation of these inconsistencies should be made with caution. However, it suggests that future variations of this project should explore these inconsistencies and, perhaps, the variations in interpretation of the wording ‘emotional needs, anxiety, and emergency’ which could clarify results.

The number of times the QR code was scanned outside of the initial intervention, coupled with the high number of unique IP addresses, was encouraging. There were four caregiver participants, and the videos were accessed 52 times. Family structure can widely vary and often the parents are supported by a wider caregiver net. Post-pandemic visitor restrictions have hindered the ability to educate the extended caregivers in person, which can compromise patient safety at home. The high number of QR code scans and those with unique IP addresses can be explained through dissemination of the videos to extended caregivers and/or ongoing review by the immediate caregivers. Either scenario strengthens the safety net for the newly diagnosed oncology patient to receive safe care at home and lends support to this methodology.

5.2 Readiness for First Clinic Visit

Literature supported the use of video as a teaching tool uniquely suited to helping to develop skill acquisition (Mills et al., 2022). Its ability to be paused and replayed, and the combination of visual, auditory, and written cues help reinforce skills in many ways. Given this literature support, the fact that all the participating caregivers performed the skills necessary for the first clinic visit is encouraging. One of the videos in this project reinforced all the skills/behaviors assessed at the first clinic visit. Each of the caregivers who viewed the video demonstrated preparedness for the first clinic visit. However, it was found that that none of the Spanish-speaking caregivers (unable to participate in the video intervention) were ready for the first clinic visit. This could lend support for translation of the videos to multiple languages, or it could indicate deficits in the standard discharge education for non-English speakers. This finding should be explored further. Future foci of this project should expand to include non-English speakers to further understand the impact of video education on this population.

5.3 Thirty-Day Post Discharge Survey

It is not surprising that the scripted interview revealed that each caregiver had unexpected medical concerns in the first 30 days following discharge. These patients are medically complex, and their care regimen and sequelae are also complicated. It was encouraging that each caregiver engaged their resources appropriately. The ED visits were for concerns that were out of the scope of a caregiver to manage at home, and therefore justified. Their calls to the triage line indicated understanding of the education that informed triage is a first-line resource. Especially encouraging was a caregiver’s use of the video to determine what constituted an occlusive dressing on a central line.

The caregivers’ feedback revealed many future project pathways and suggestions for refinement of current educational practices. Expanded video offerings, encouragement for parents to administer medication (rather than the nurse) as practice for home care, anticipatory education about expected symptoms, and the observation that physical medications were not utilized as a learning tool in a medication reconciliation were suggestions expressed in the interviews. Soliciting caregiver feedback at discharge and at 30 days post-discharge is a strength of this project design. Many, but not all, of the suggestions could be addressed with an expanded video topic offering.

In contrasting the themes elicited from the 30-day post discharge interview with the scores from the QDTS, administered just prior to discharge, a few interesting points emerge. The lowest perceived ‘need’ of the caregivers was in the domain of ‘practice with your child’s medical treatments or medications’ (mean 3.00, SD 2.16). However, at the 30-day post discharge interview, medications were voiced as the largest concern (4 times) with questions ranging from guidance regarding redosing vomited medications to tips for medication administration in a child (crushing, timing, diluting). Additionally, at the 30-day post discharge interview, a parent asked for future education to emphasize encouraging the parent to administer oral medications in the hospital to gain practice prior to going home. This may indicate caregiver difficulty judging discharge education needs prior to going home and assuming full care of the child. Meanwhile, the lowest value of the quality subscale was in the domain ‘what to do in an emergency’ (mean 7.25, SD 2.06). The caregiver interpretation of an emergency might vary which can skew interpretation; however, when faced with unexpected medical concerns at home (identified at the 30-day post discharge interview), they utilized appropriate resources each time.

5.4 Limitations

Caregiver accrual was limited by the small number of patients diagnosed with pediatric cancer, the short implementation timetable, and the need to exclude non-English speakers. Results should be interpreted with caution as they are based on four caregiver participants with wide ranges for some survey items. However, the results do support continued use and evaluation of the intervention, likely over a long period of time as the patient population is small, yet deserving of best care practices. Next, this project was implemented at one site which limited sample accrual as well as the project’s ability to be generalizable across multiple institutions. The video education, specially tailored for one institution’s workflow, might not translate to the workflow of another program. However, more generalizable topics, such as medication side effects, could be useful across programs. Lastly, the utilization of technology should be viewed through the lens of equity. For the implementation site, all caregivers, regardless of economic standing, were provided with access to a phone and the ability to view and share the videos. This might not be within the scope of resources for other programs, so the use of this technology might not be appropriate across all programs. However, the expanding subsidization of a cell phone provision, and the pervasive use of them in society encourages thoughtful exploration of this technology.

5.5 Recommendations and Future Projects

The surprising frequency of dissemination of the QR codes outside of the intervention indicates that this may be an effective method for providing consistent information to extended caregivers and for reinforcing information to immediate caregivers. Given the use of the videos outside of the initial teaching moment at discharge, and the direct caregiver request for more videos 30 days later, expansion of the video topic library is advised. However, paramount to the success of this method is the health care team being consistent in what is verbally taught and what is in the teaching materials. Variations of information lead to confusion and distrust (Bailie et al., 2021; Dobrozsi et al., 2019; Landier et al., 2016; Rogers, Stegenga, et al., 2016).

The video creation software was chosen with future versions of this project in mind. A unique feature of the software used to create the videos is the ease of translation to many different languages. It would be helpful to include videos for non-English-speaking caregivers, which might increase their preparedness for clinic visits. An intriguing aspect of the video software is the ability to easily tailor the skin tone of the hand that writes the script on the video. Future versions of the videos should allow representation of many skin tones to appeal to a variety of ethnicities which could deepen inclusion and acceptance of the information.

Future iterations of this project should include demographic data collection and a longer implementation window which would allow a larger participant number. Age, ethnicity, diagnosis, and family structure of the patient can help to better understand the impact of discharge education on varying demographic pools. A larger participant pool could allow a project design to include an interventional group and a control group. This would allow a better understanding of the value of the addition of the video modules to the standard discharge education platform. While the QDTS is validated only for use immediately prior to initial hospital discharge, another avenue of future exploration would be to ask similar questions at 30 days post hospital discharge. It would be interesting to understand how perceptions changed during that time.

5.6 Conclusion

The importance of focused, effective discharge education for the newly diagnosed pediatric oncology caregiver is paramount to successful patient outcomes. The gap in resources and literature for the use of video modules as a supportive element in caregiver education merits exploration. While project results showed favorable caregiver feedback, skill acquisition, and impact on caregiver decision making for unexpected medical concerns, this project was limited by low participant accrual and findings should be interpreted with caution. Further exploration is warranted before including this methodology as best practice.

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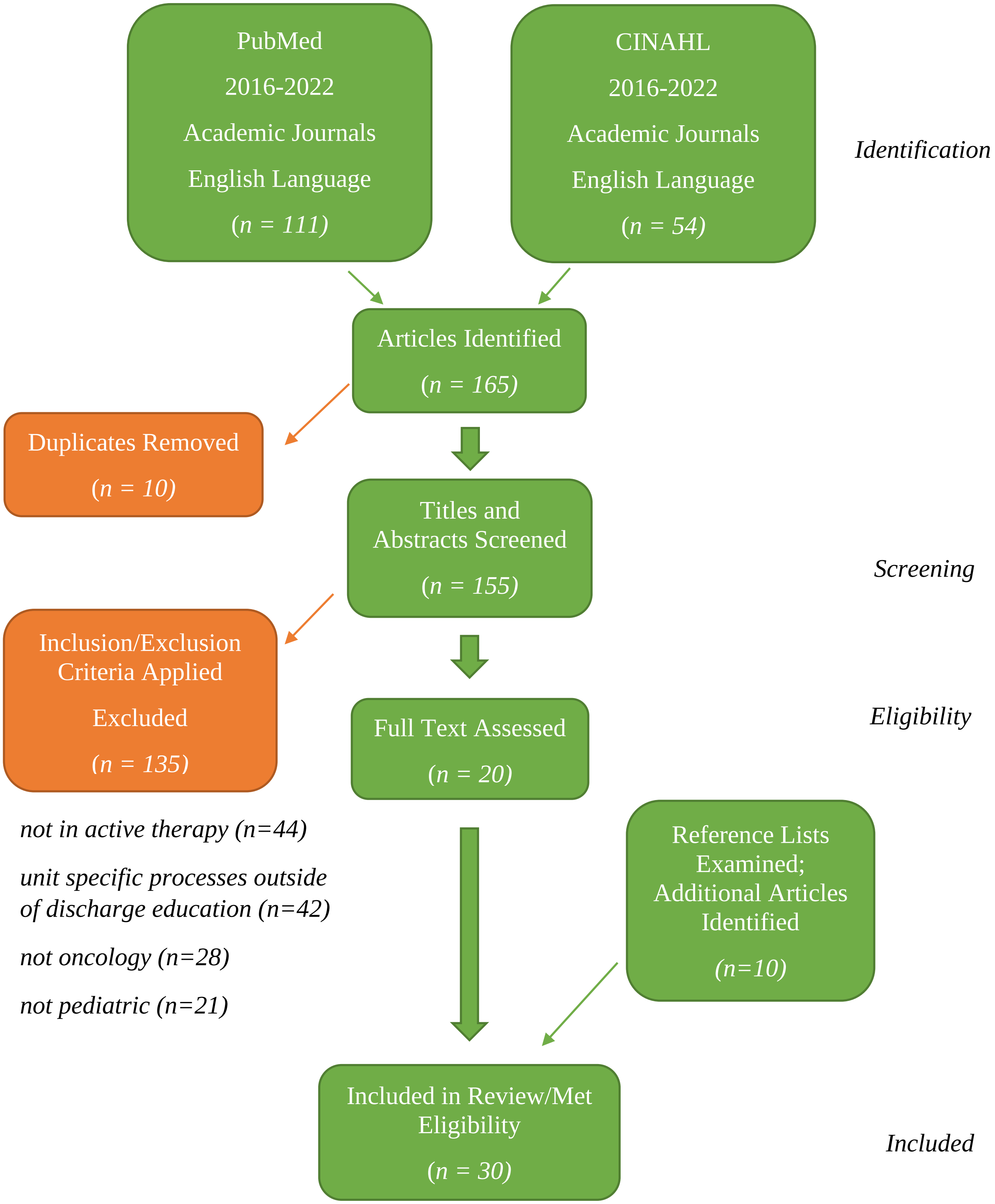
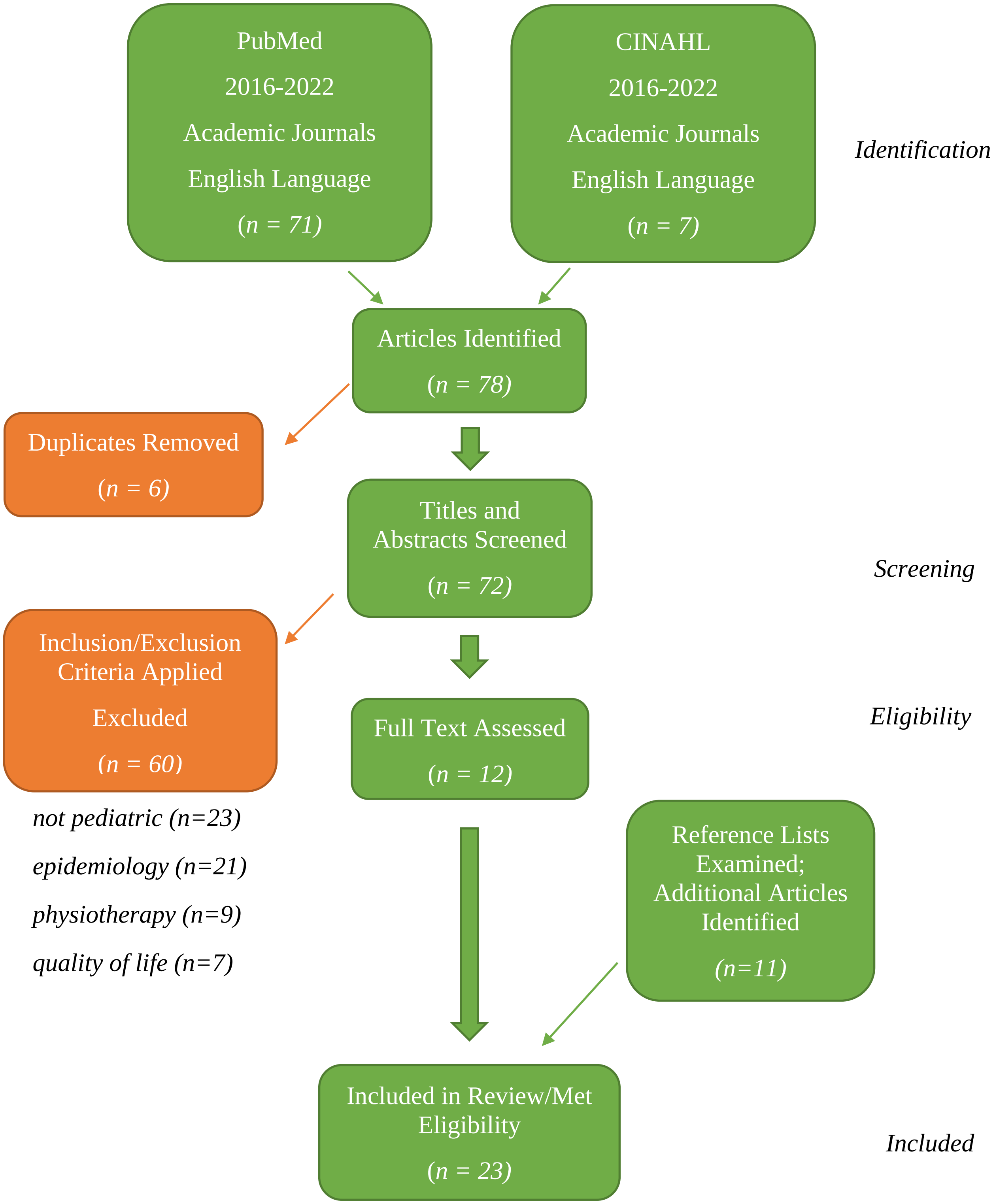
Appendix A

Literature Review: Unplanned Medical Utilization



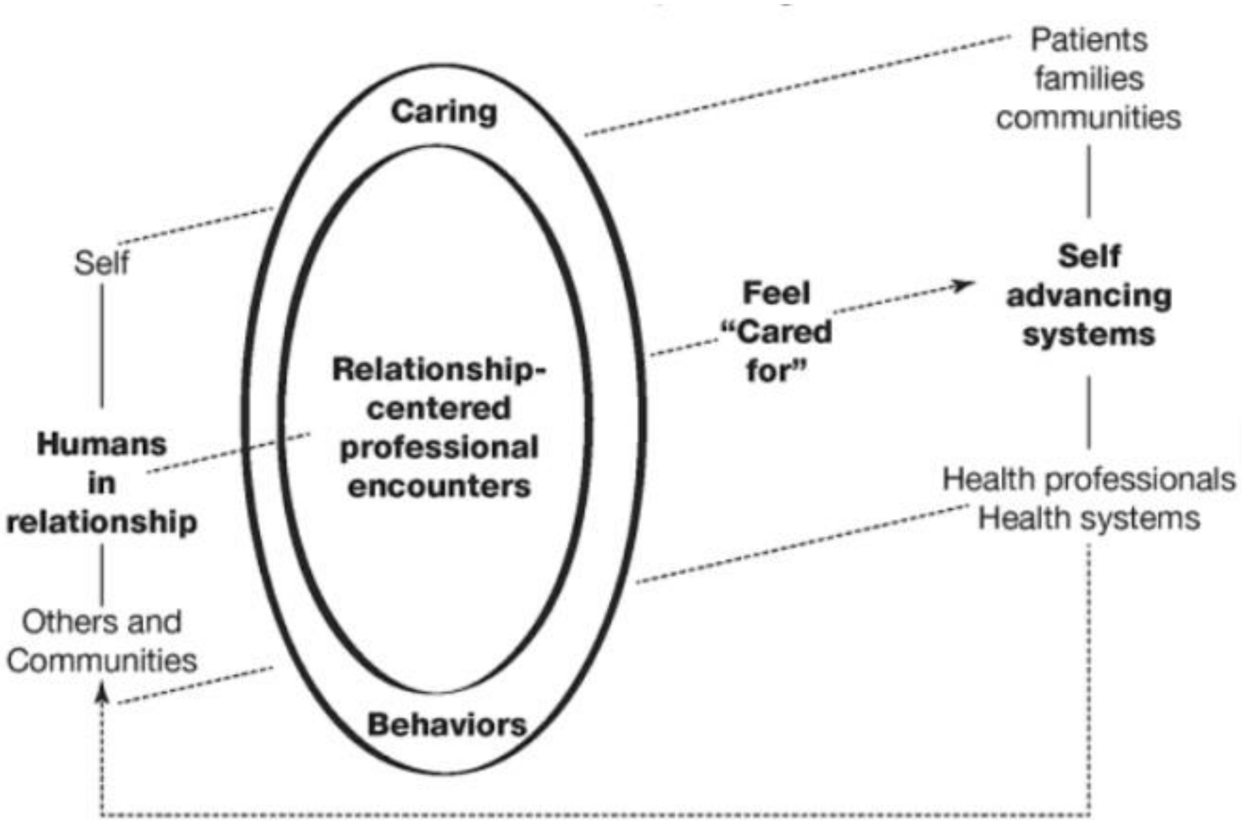
Appendix B

Literature Review: Discharge Education



Appendix C

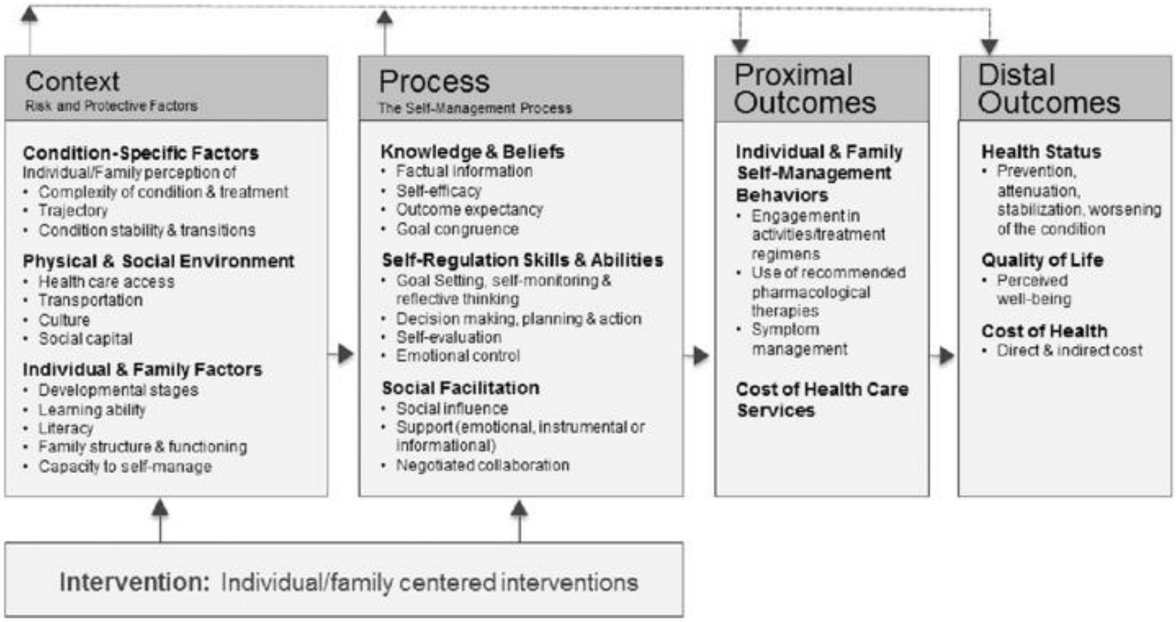
Quality Caring Model



Note. From *Quality Caring in Nursing and Health Systems. Implications for Clinicians, Educators, and Leaders* (p. 49), by J. R. Duffy, 2018, Springer Publishing, Copyright 2018 by Springer Publishing Company, LLC.

Appendix D

Individual and Family Self-Management Theory



Note. From *Individual and Family Self-Management Theory [Revised Figure]*, by P. Ryan & K. Sawin, 2014 (https://uwm.edu/nursing/wp-content/uploads/sites/538/2021/05/IFSMT_manuscript_no_copyright_07_31_2019-002.jpg). In the public domain.

Appendix E

QR Codes

Port a Cath Line; English Speaking

Clinic Visit

Fever

External Central Line; English Speaking

Clinic Visit

Fever

Appendix F

Caregiver Log

We are interested in understanding how the teaching you got before you went home helped to prepare you to handle medical concerns at home. Please complete this log for the first thirty days following discharge. A nurse will call you to discuss your experiences. Thank you for your help as we understand how to better prepare you to care for your child at home.

Date	How did you get help for your child's medical concern? Check all that apply.					What were you worried about? Check all that apply.						Did the discharge teaching help you decide what to do about your child's medical concern? Please explain what teaching helped you decide how to handle the situation?
	Call Triage	Sick Visit at Clinic	Emergency Department Visit	Admission to Hospital	Call 911	Fever	Nausea/ Vomiting	Central Line Problem	Pain	Medication Question	Other	

Appendix H

Readiness for Clinic Appointment Data Collection Tool

Readiness for First Clinic Visit Data Collection Tool						
Participant #	Date of Visit	Medications Brought to Clinic? 1=Yes 0=No	Numbing Cream on Port (if applicable) 1=Yes 0=No	Central Line Dressing Intact? (If applicable) 1=Yes 0=No	Child Well at Visit? 1=Yes 0=No	If no, explain

Appendix I

Thirty-Day Post-Discharge Phone Call Script

Participant #: ________________________

1. Did the teaching you got while in the hospital prepare you to care for your child at home?
    1. Yes
    2. No
        1. If no, please explain.
2. Since you took your child home from the hospital has your child had a medical problem you were not sure how to handle (such as fever, nausea or vomiting, pain, a medication question)?
    1. Yes (proceed to question #3)
    2. No (proceed to question #6)
3. If you have had medical help for your child due to something unexpected, how did you get an answer to your concern?
    1. Call triage
    2. Have a sick visit at clinic
    3. Go to the emergency department
    4. Be admitted to the hospital
    5. Call 911
4. What was your concern?
    1. Fever
    2. Central Line Problem
    3. Nausea or Vomiting
    4. Diarrhea
    5. Pain
    6. Medication Question
    7. Other
5. What was done to help you with the medical concern?
6. How did the teaching in the hospital help you decide how to handle the unexpected medical concern?
7. Please explain what helped you decide how to handle the situation.
8. How many times did you watch the video again after you went home from the hospital?
9. Who did you share it with?
10. Is there anything else you would like to share with me about the discharge education process?