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The PATCH program for caregivers of children with gastrostomy tubes: promoting and teaching confidence for the home

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Boston University

BOSTON UNIVERSITY
SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

**THE PATCH PROGRAM FOR CAREGIVERS
OF CHILDREN WITH GASTROSTOMY TUBES:
PROMOTING AND TEACHING CONFIDENCE FOR THE HOME**

by

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B.S., University of Pittsburgh, 2014
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Submitted in partial fulfillment of the
requirements for the degree of
Doctor of Occupational Therapy

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DEDICATION

To my parents, thank you for always believing in me and supporting my endeavors. Your love has been a constant companion through the celebrations and challenges of my academic journey. I am thankful for the values and dedication to one's passion that you taught me from a young age. I love you Mom and Dad and I dedicate this accomplishment to you.

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ABSTRACT

The PATCH Program: Promoting and Teaching Confidence for the Home is a distinct approach developed to address the problem of high emergency department visit (8.6%) and hospital readmission rates (3.9%) associated with pediatric gastrostomy tube (GT) placement (Goldin et al., 2016). Recent literature regarding negative outcomes associated with pediatric GT placement identified the failure of current GT education and training practices to properly prepare caregivers to manage care in the home (Berman et al., 2017; Franklin & Rodger, 2003; Russell, Jewell, Poskey, & Russell, 2018). Developed by an occupational therapist, the PATCH Program offers an innovative approach to reducing facility rates of negative pediatric GT-related outcomes through family-centered education and self-efficacy enhancing components. Theory-based and evidence-driven, the PATCH Program integrates problem-solving training, formal education, and interactive skills practice to empower caregivers in developing the skills and self-efficacy needed to manage their children's GT care. Adopting an occupational therapy perspective, the PATCH Program acknowledges that effective home management of a child's GT care is the product of careful integration of familial context, skills,

resources, and support systems. This doctoral project (1) summarizes the theory and evidence base supporting the PATCH Program's development, (2) describes the PATCH Program curriculum and approaches, and (3) outlines future directions for PATCH Program implementation, including evaluation, dissemination, and funding. The PATCH Program demonstrates the value occupational therapy offers to supporting families in successfully managing a child's medically complex condition, to reducing post-surgical emergency department visits and hospital readmissions, and to promoting health and wellness among caregivers and families.

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LIST OF ABBREVIATIONS

AJOT.....	American Journal of Occupational Therapy
AOTA.....	American Occupational Therapy Association
BFS.....	<i>Building on Family Strengths</i> Program
CDSR.....	Cochrane Database of Systematic Reviews
COTA.....	Certified Occupational Therapy Assistant
CPT.....	Current Procedural Terminology
CVICU.....	Cardiovascular Intensive Care Unit
GSE.....	General Self-Efficacy Scale
GT.....	Gastrostomy Tube
HFS.....	High-Fidelity Simulation
HPS.....	Human Patient Simulation
IADL.....	Instrumental Activity of Daily Living
IFSMT.....	Individual and Family Self-Management Theory
MIQ.....	Mastery of Information Quiz
NICU.....	Neonatal Intensive Care Unit
OT.....	Occupational Therapist
OTAC.....	Occupational Therapy Association of California
PATCH.....	Promoting and Teaching Confidence for the Home
PFCC.....	Patient- and Family-Centered Care
RCHSD.....	Rady Children’s Hospital – San Diego
RCT.....	Randomized Controlled Trial

SCT.....Social Cognitive Theory

CHAPTER ONE - Introduction

Children with complex medical conditions may require alternate or supplemental means of obtaining necessary nutrition and hydration. Enteral feeding, or the delivery of a complete nutritional feed directly into the gastrointestinal system through a tube, assists in ensuring that children who are unable to orally feed can access the nutrition required for healthy growth and development (Russell et al., 2018). A gastrostomy tube (GT), or G-tube, is one option for delivering enteral nutrition among children with complex medical conditions. Through surgical intervention, a feeding tube is inserted through the skin and stomach wall to allow for direct administration of feeds into the stomach (Davis, 2011). According to the United States Department of Health and Human Services Healthcare Utilization Project (HCUPnet, 2009), GT placement is the third most common non-cardiac inpatient surgical procedure performed within the pediatric population. Despite its status as a relatively routine pediatric procedure, a recent study found that GT placement is associated with high rates of emergency department visits (8.6%) and hospital readmissions (3.9%) within the initial 30-day period following hospital discharge (Goldin et al., 2016).

The origins of this problem are diverse and multifaceted, yet may be related to the effective delivery of preoperative and postoperative GT education and home management programs (Berman et al., 2017). GT education programs are considered best practice for ensuring caregiver competence with GT care skills prior to hospital discharge (Boullata et al., 2017). However, healthcare providers, as well as caregivers of children with GTs, have identified a need to reform GT education programs to lend greater focus to

providing family-centered education and to cultivating family empowerment (Berman et al., 2017; Franklin & Rodger, 2003; Russell et al., 2018). Similar to GT education programs, GT home management programs focus on preparing families to independently manage their children's routine GT care and to address GT complications. GT home management programs are unique, however, in their focus on enhancing individual and family quality of life in addition to health-related outcomes. Impacted by shorter postoperative inpatient stays and reimbursement limitations, GT home management programs executed pre- or postoperatively often fail to provide opportunities for caregivers and families to develop confidence and independence in GT care skills. Similar to GT education programs, GT home management programs require an increased focus on family-centered education and family empowerment to promote enhanced caregiver competence and confidence with managing a child's GT care.

The doctoral project presented here outlines the PATCH Program: Promoting and Teaching Confidence for the Home, a family-centered GT home management program aimed at promoting caregivers' competence and confidence with managing their children's GT care. Outcomes of this program will be evaluated by measurable and observable changes in the following two areas:

- (1) Change in caregiver-perceived feelings of self-efficacy related to managing daily GT care responsibilities and potential GT complications between pre- and post-program participation
- (2) Healthcare facility rates of GT-related emergency department visits and hospital readmission rates within the first 30-days status post-GT placement

and hospital discharge

Impact of the Problem

It is well documented in the literature that caregivers of children with GTs are faced with a multitude of physical and psychosocial challenges (Didehbani, Kelly, Austin, & Wiechmann, 2011; Franklin & Rodger, 2003; Hewetson & Singh, 2009; Russell et al., 2018). Concerns for GT site complications (i.e., irritation, infection, migration from the original location, tube obstruction) can inhibit families from participating in desired activities. Children with GTs also require continued follow-up with medical professionals and healthcare providers, imposing additional responsibilities and time constraints on caregivers and families. Stresses related to ensuring the child receives adequate nutrition can also negatively impact caregiver-child interactions and family meal times. Children transitioning from oral to enteral feeding may demonstrate behavioral difficulties, placing further stress on the caregiver-child relationship. Caregivers of children with GTs are also tasked with the recurrent need to cope with and problem-solve daily GT management challenges. These include planning for and delivering enteral feeds outside of the home, incorporating healthcare provider recommendations into daily routines, and balancing the needs of the child with a GT and those of other family members (Didehbani et al., 2011; Franklin & Rodger, 2003; Hewetson & Singh, 2009; Russell et al., 2018).

Preoperative and postoperative GT education programs can serve to educate and prepare caregivers to effectively complete GT care responsibilities and overcome GT management challenges. However, lack of comprehensive and client-centered pre-

discharge education places caregivers of children with GTs at an increased risk of poor health and wellness outcomes. Physical, emotional, social, and temporal demands associated with GT management can increase caregiver stress and anxiety, while also straining family dynamics and interactions (Franklin & Rodger, 2003; Hewetson & Singh, 2009; Russell et al., 2018). Caregivers may develop increased feelings of self-doubt in GT care abilities, consequently leading them to become reluctant or resistant towards problem-solving and addressing common GT care difficulties. This has the potential to lead to increased usage of emergency department and hospital services for minor or preventable GT care complications. Additionally, such complications may further disrupt the growth, development, and health and wellness of the child with a GT.

Role and Scope of Occupational Therapy

The *Occupational Therapy Practice Framework: Domain and Process (3rd Edition)* defines health management and maintenance as an instrumental activity of daily living (IADL) involving the development, management, and maintenance of health and wellness routines (American Occupational Therapy Association [AOTA], 2014). Based on this definition, the routine administration of enteral feeds for children with GTs qualifies as a health management and maintenance activity to promote the adequate nutrition and development of these children. Thus, it falls within the scope of occupational therapy practice to support caregivers and families of children with GTs in achieving optimal management of GT care responsibilities and challenges.

AOTA's statement, *Occupational Therapy in the Promotion of Health and Well-Being*, defines the role of occupational therapists in "the development and provision of

programs and services that promote health, well-being, and social participation of all people” (AOTA, 2013, p. S47). Occupational therapists are skilled in the assessment and consideration of physiological, psychosocial, cultural, and contextual factors in relation to individual and family participation in everyday occupations. This holistic, client-centered perspective enables occupational therapists to support individuals and families in achieving the highest level of participation, independence, and health and wellness in their daily lives. When this skill and perspective are applied in the context of GT home management programs, occupational therapists can complement the contributions of fellow healthcare providers to positively impact the health and wellness of caregivers and families of children with GTs through provision of client-centered education, training, and support for self-advocacy.

AOTA’s statement, *The Practice of Occupational Therapy in Feeding, Eating, and Swallowing*, outlines the role of occupational therapists in providing education and services related to the management of feeding, eating, and swallowing difficulties (AOTA, 2017). Feeding, eating, and swallowing are occupations considered “fundamental to living in a social world; they enable basic survival and well-being” (Christiansen & Hammecker, 2001, p. 156). For individuals who receive nutrition via enteral means, occupational therapists apply their knowledge and skill in the area of feeding to assist these individuals in maintaining positive meal time associations and in incorporating tube feedings into daily routines and social interactions (AOTA, 2017). In the context of GT home management programs, occupational therapists can provide caregiver education and recommendations for environmental modifications, mealtime

activities, and sensory strategies to support the participation and inclusion of the child with a GT during family meals.

Occupational therapists are also skilled in the evaluation and adaptation of individual and family performance patterns, or “the habits, routines, roles, and rituals used in the process of engaging in occupations or activities” (AOTA, 2014, p. S27). Occupational therapists understand that daily family routines provide a rich context for understanding familial interactions and identity and that altering these routines requires families to shift and adapt valued perspectives (Segal, 2004). Faced with increasing demands to adapt routines to accommodate enteral feeding requirements and schedules, caregivers and families of children with GTs may experience increased stress and anxiety. Occupational therapists are skilled and capable of providing client and family-centered psychosocial interventions within the context of health management programs to promote caregiver and familial empowerment, to enhance the child-caregiver relationship, and to support family involvement (Franklin & Rodger, 2003; Henton, 2018).

Factors Contributing to the Problem

Although GT placement is a commonly performed routine procedure within the pediatric population, it has been associated with high rates of post-discharge emergency department visits and hospital readmissions (Goldin et al., 2016). There is no singular factor responsible for these outcomes. Rather, these outcomes are the product of an interplay of personal, contextual, and cultural factors impacting effective and comprehensive delivery of postoperative GT caregiver education and instruction. The

scope of the doctoral project presented herein will focus on those factors immediately associated with GT home management program content and delivery. However, it does not do so without acknowledgement and consideration of larger scope contextual factors (i.e., institutional capability, healthcare policy). Following is a discussion of key factors contributing to the high rate of postoperative pediatric GT-related emergency department visits and hospital readmissions:

- (1) *Shorter durations of GT placement postoperative inpatient stays limit the amount of time available to provide comprehensive GT caregiver education and instruction.* Recent healthcare trends emphasize shorter inpatient stays as a means for reducing institutional financial burden and maximizing profit. For pediatric GT placement specifically, longer inpatient hospital stays have been associated with higher healthcare costs (Fox et al., 2014). As a result, there has been an increased push to facilitate quick postoperative discharge for children with GTs. However, the repercussions of this include decreased amount of time available for healthcare providers to deliver effective, comprehensive GT education and to ensure caregiver competence and confidence related to GT care and management. Healthcare providers are faced with the challenge of balancing daily job demands with effective GT home management program delivery within a limited duration of time. As a result, healthcare providers often opt for easier, less time-consuming methods for providing GT caregiver education and instruction. These include use of only didactic education, provision of handouts or booklets, and/or referral to support groups or community resources without consideration of caregiver

learning needs, focus on caregiver empowerment, or appropriate professional follow-up. Consequently, children with GTs and their caregivers return home inadequately prepared to manage routine GT needs or to address GT complications.

(2) *Reimbursement limitations for caregiver education and training de-incentivize delivery of comprehensive GT home management education and instruction.*

Within the healthcare arena, time is considered a valuable commodity. Healthcare providers are reimbursed by Medicare, Medicaid, and private insurance based on time spent treating patients and providing medical or therapeutic services. Healthcare institutions and systems set forth productivity expectations dictating the amount of time in a provider's day that should be billable or reimbursable. While regarded as a valuable service within pediatric healthcare settings, caregiver education and training are not always adequately reimbursed in comparison to provision of hands-on therapeutic care. Additionally, insurance providers place limitations on total amount of time per patient that can be reimbursed for caregiver education and training, the setting in which caregiver education is provided (i.e., inpatient versus community-based), as well as acceptable recipients of caregiver education (i.e., parent versus extended family involved in the child's care). Consequently, healthcare providers may fail to allot adequate time for delivery of comprehensive caregiver GT home management education and instruction due to lack of financial and institutional incentive.

(3) *Healthcare provider training for the delivery of caregiver GT home management programs fails to emphasize the importance of educational strategies promoting family-centered care and caregiver empowerment.* Healthcare providers tasked with delivering postoperative and pre-discharge GT home management programs are trained on adequate delivery of information and instruction of GT care skills. However, training often fails to emphasize the importance of applying educational and instructional strategies that support caregiver self-efficacy and that take into consideration the unique situations and needs of each caregiver and his or her family. As a result, healthcare providers focus primarily on ensuring caregiver competence with GT care skills, as opposed to also ensuring that caregivers feel confident in their ability to transfer newly learned skills to their daily lives post-discharge. As a result, although caregivers of children with GTs may be able to demonstrate adequate performance of GT management skills within the hospital, they may be unprepared to do so when discharged from the hospital and without the feedback and oversight of a trained healthcare professional. This may lead to caregivers' increased use of emergency department and hospital-based services to address routine or preventable GT care issues.

(4) *GT education and home management programs fail to incorporate family-centered education and instruction.* Shorter postoperative inpatient stays and lack of incentive for providing comprehensive caregiver education has resulted in a “one size fits all” delivery approach for GT education and home management programs. As a result, caregivers and families of children with GTs are presented

with education, instruction, and care recommendations that fail to consider their unique circumstances, learning needs, and resources. As a result, caregivers and families are discharged without proper preparation to manage their children's GT care and complications.

(5) *GT education and home management programs fail to enhance self-efficacy related to managing the child's GT care.* Healthcare providers delivering GT education and home management programs are faced with limited time to ensure family competence with GT management prior to hospital discharge. As a result, GT education and home management programs often focus on didactic education and instruction related to performance of routine GT care skills. There is limited focus on providing families with self-efficacy enhancing learning opportunities during the program. Without opportunities to actively increase confidence in GT management skills, families may feel inadequate in their ability to care for the child with a GT. This can result in increased utilization of formal healthcare services and systems to address routine or minor GT care complications.

Proposal to Address the Problem

GT home management programs are best practice in ensuring family confidence and competence related to caring for a child with a GT. However, current GT home management programs fail to adequately involve and empower the family. There is an evident need for inclusion of family-centered education and efficacy-enhancing opportunities within GT home management programs as a means for reducing high rates of emergency department visits and hospital readmissions associated with pediatric GT

placement. To address this problem, I propose the PATCH Program, a family-centered home management program for caregivers of children with GTs. Core elements of the PATCH Program include the following:

- (1) *Pre-program individualized family interview:* Inclusion of an individualized family interview with prompts focused on family and caregiver learning preferences, health literacy, feelings of self-efficacy related to GT management, access to resources, available social supports, etc. will offer the healthcare provider with a basis for determining appropriate instructional techniques that serve the needs of the family and should therefore be incorporated during the program. Additionally, guided family interview emphasizes the importance of family-centered education and offers the caregiver and his or her family the opportunity to collaborate with healthcare providers and to be active participants in their own education and training.
- (2) *Problem-solving training:* Problem-solving training will focus on aiding caregivers in learning and applying problem-solving skills/steps. These include goal setting, reflective thinking, action planning, action implementation, and self-evaluation. Verbal discussion, case studies, and guided practice will be utilized to provide caregivers with opportunities to apply problem-solving skills to frequently encountered GT care complications and participant-identified GT care challenges.
- (3) *Practical skills training and practice:* During the program, caregivers will be offered opportunities to engage in active learning opportunities that fit their

learning styles and preferences. Guided step-by-step instruction, hands-on practice, problem-solving tasks, learning worksheets, and role playing may be used to promote active caregiver involvement. During interactive skills practice, caregivers will be provided with feedback and support from healthcare professionals. This will help facilitate increased caregiver competence with GT care skills, while also encouraging development of increased confidence in caregivers' abilities to manage their children's GT care.

(4) *Access to multimodal learning resources:* Caregivers will be provided with access to interactive and/or informative learning resources for continued support with performance of GT care skills. Interactive learning resources include online videos and learning modules reinforcing performance of GT care skills and problem-solving strategies. Informative resources include personalized booklets outlining caregivers' learned skills, preferred problem-solving strategies, and available resources and support groups.

CHAPTER TWO – Theoretical and Evidence Base to Support the Project

This chapter is composed of two main sections. The first section describes the theoretical framework informing the development and purpose of the PATCH Program: Promoting and Teaching Confidence for the Home. The second section examines and synthesizes the evidence used to inform the selection and inclusion of PATCH Program components (i.e., individualized guided family interview, formal education, interactive skills training and practice).

Theoretical Base to Support the Project

To ensure that the PATCH Program was well positioned to address the needs of caregivers and families of children with GTs, it was important to first identify and define the problem and its associated contributing factors. This was achieved by assessing the problem through an occupational therapy and family-centered lens, by developing an explanatory model depicting the relationships between factors contributing to the problem, and by evaluating the explanatory model relative to evidence garnered from the occupational therapy and self-management literature.

Family-Centered Theoretical Approach

Consideration of family-centered focus and self-efficacy enhancing components as influential factors contributing to increased rates of pediatric GT-related emergency department visits and hospital readmissions is informed by the Individual and Family Self-Management Theory (IFSMT). Influenced by traditional self-management models, the IFSMT focuses on understanding and describing the process by which individuals and families assume responsibility for the care of a chronic condition and achieve health

behavior change related to the condition. The IFSMT adopts a dynamic systems perspective, which acknowledges that the chronic health condition of one family member, such as a child, can affect other individuals in the family system (e.g., parents, siblings, extended relatives, etc.) and impact the function of the family unit as a whole (e.g., routines, habits, traditions, etc.). The IFSMT states that self-management is complex and dynamic in nature, requiring consideration of three dimensions: context, process, and outcomes (Ryan & Sawin, 2009).

The IFSMT equates the familial context with the risk and protective factors, including condition-specific features, physical and social environment, and family and individual characteristics, which have the potential to inhibit or support the individual's and family's self-management process. The IFSMT process dimension emphasizes three main components essential to enabling individuals and families to effectively self-manage health conditions: knowledge and beliefs, self-regulation skills and abilities, and social facilitation. Incorporated in these process components is an emphasis on the role of self-efficacy, or the degree of confidence that an individual or family has in their ability to address both positive and negative health condition-related situations. The IFSMT posits that both contextual and process components contribute to the individual's and family's self-management of a health condition. The degree to which contextual and process factors are considered and supported during interventions targeted at enhancing individual and family self-management determines the achievement of proximal (i.e., immediate) and distal (i.e., long-term) self-management and health outcomes (Ryan & Sawin, 2009).

The IFSMT was chosen as the theoretical basis for identifying and understanding the current problem of pediatric GT-related outcomes based on its emphasis of family-centered care and family empowerment, two components identified by Berman et al. (2017) to be lacking in current GT education programs. The IFSMT was also chosen for its dynamic approach to understanding self-management processes, which aligns with the holistic client-centered perspective of the occupational therapy field. When applied to the context of GT home management programs, the IFSMT offers a conceptual framework for understanding how program components influence caregiver competence and confidence.

Based on IFSMT propositions, GT home management programs that fail to incorporate a family-centered focus, as shown by a lack of provider-family collaboration and poor consideration of unique family abilities, beliefs, and situations during program delivery and implementation, are unprepared to support caregivers and families in developing the necessary skills and knowledge to effectively manage their children's GT care. Additionally, GT home management programs that fail to cultivate and enhance participant self-efficacy related to GT care and problem-solving may leave caregivers and families unprepared to engage in efficient management of their children's GTs after program completion. As a result, caregivers and families of children with GTs may lack the competence and confidence allowing for effective home management of their children's GTs. Proximal outcomes stemming from this include poor GT home management. As time elapses and caregivers continue to face difficulty managing their children's GT care, they may require additional support from formal hospital-based

services to address GT care needs or complications. This ultimately contributes to the distal outcome of increased rates of pediatric GT-related emergency department visits and hospital readmissions.

Proposed Explanatory Model of the Problem

Current hospital-based GT home management programs lack a family-centered education and instruction approach, resulting in failure to adequately consider the unique characteristics, circumstances, cultures, knowledge, beliefs, and resources of each caregiver participating in the program. Additionally, a lack of self-efficacy enhancing components (e.g., practice activities, role play, etc.) within these GT home management programs inhibits caregivers from enhancing their confidence related to managing their children's routine GT care and to problem-solving GT-related challenges. Both these factors mutually affect each other, such that a lack of family-centered education and instruction influences the exclusion of self-efficacy enhancing components that support and empower each caregiver. Likewise, a lack of self-efficacy enhancing components reflects a lack of family-centered focus guiding the delivery of GT education and instruction.

GT home management programs lacking family-focused education and instruction and self-efficacy enhancing components fail to prepare caregivers to effectively manage their children's GT care and to address challenges following hospital discharge. This impacts caregiver feelings of competence and confidence related to managing the child's GT care. These decreased feelings of competence and confidence with GT care abilities can lead caregivers to become reluctant or resistant towards

completing GT care tasks and resolving GT care challenges, resulting in increased caregiver usage of emergency department and inpatient hospital services to address GT care concerns. This ultimately contributes to increased facility rates of pediatric GT-related emergency department visits and hospital readmissions.

Figure 1 is the explanatory model for this doctoral project. This model depicts the proposed relationship between family-centered education/instruction, self-efficacy enhancing program components, caregiver self-efficacy, and facility rates of pediatric GT-related emergency department visits and hospital readmissions as described above.

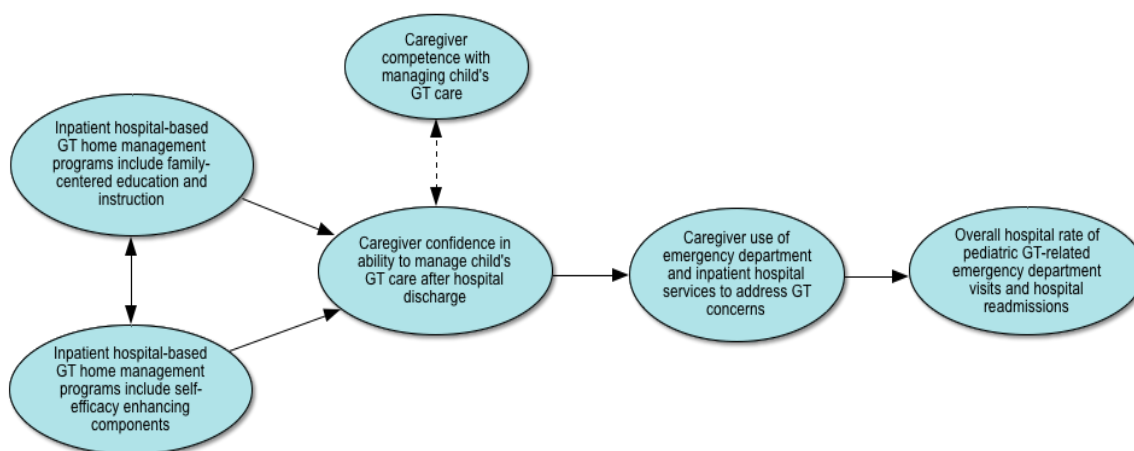


Figure 1: Explanatory Model of Identified Problem

Evidence for the Proposed Explanatory Model of Identified Problem

A recent analysis of United States healthcare utilization data has associated pediatric GT placement with high rates of emergency department visits (8.6%) and hospital readmissions (3.9%) within the initial 30-day period following hospital discharge (Goldin et al., 2016). Within the healthcare literature, GT education and home management programs, which focus on preparing caregivers to manage children's GT

care following hospital discharge, have been identified as likely contributors influencing these outcomes (Berman et al., 2017; Franklin & Rodger, 2003; Russell et al., 2018).

Focusing specifically on GT home management programs, I propose two main factors contributing both individually and jointly to this problem: (1) lack of family-centered focus in current GT home management programs and (2) lack of self-efficacy enhancing components within these same programs. Current GT home management programs fail to provide caregivers of children with GTs the family-centered instruction and efficacy promoting opportunities (e.g., guided practice, reinforcement) necessary to support caregiver competence and confidence with managing GT care. This results in ineffective GT management after hospital discharge leading to increased caregiver use of formal healthcare services to address GT concerns and complications.

To test this proposed relationship, a literature search guided by the following five questions was conducted:

- (1) Is there evidence that a lack of family-centered focus in parent education programs is associated with decreased parent-perceived self-efficacy after program completion?
- (2) Is there evidence that exclusion of self-efficacy enhancing components in parent education programs is associated with decreased parent-perceived self-efficacy after program completion?
- (3) Is there evidence that GT education and/or home management programs are related to participant competence with GT care skills?

- (4) Is there evidence that reduced parent-perceived self-efficacy impacts competence with GT care skills?
- (5) Is there evidence that GT education and/or home management programs impact pediatric GT outcomes (i.e., emergency department visit and hospital readmission rates)?

Pediatric GT home management programming is limited in scope and is an emerging healthcare initiative only beginning to garner increased attention. Based on this, it was anticipated that there would be limited evidence to draw from to establish the connection between GT home management program components and pediatric GT outcomes. As a result, literature searches were organized into two main focuses: (1) outcomes associated with GT education and/or home management programs and (2) outcomes associated with general parent education and/or training programs. It was intended that the broader search examining literature related to general parent education and/or training programs would fill the anticipated gap in literature related to outcomes associated with the exclusion of family-centered focus and/or self-efficacy enhancing components in GT programs.

Literature searches were completed using a combination of the following terms: gastrostomy, chronic condition, medically complex, pediatric, children, parent education, parent training, parent program, family centered care, self-efficacy, competence, disease management. Searches were repeated across several online databases, including CINAHL, PubMed, PsycINFO, American Journal of Occupational Therapy (AJOT), and Cochrane Database of Systematic Reviews (CDSR). Database searches utilizing a

combination of the above-named terms yielded a small number of relevant articles pertaining to the proposed factors. However, additional articles of relevance were identified within article reference lists and through the use of the Cited By feature available through the Boston University Library online database.

Evidence for each of the search questions is summarized below, followed by a general review of the evidence and a reflection of the proposed explanatory model.

Is there evidence that a lack of family-centered focus in parent education programs is associated with decreased parent-perceived self-efficacy after program completion? This literature search yielded one article (Ng et al., 2008) evaluating the efficacy of an asthma psychoeducational program for children and their parents. Program outcomes provide evidentiary support for the positive relationship between family-centered focus in parent education programs and parent-reported levels of self-efficacy (Ng et al., 2008). Despite the lack of clinical evidence obtained, several authors have discussed the need for a greater family focus in health management approaches. Influenced by this identified gap in healthcare practice, two sets of authors (Grey, Knafl, & McCorkle, 2006; Ryan & Sawin, 2009) have developed frameworks of health management that include a comprehensive analysis of familial context and characteristics to guide a more family-focused approach to problem-solving and health management.

Additionally, several authors (Berman et al., 2017; Edwards et al., 2016; Franklin & Rodger, 2003; Russell et al., 2018) have discussed the need for a greater family-centered focus within programs specifically for caregivers of children with GTs. Two of these articles (Franklin & Rodger, 2003; Russell et al., 2018) investigated the qualitative

experiences of parents of children requiring enteral nutrition. Both articles' results highlighted a common feeling of parental stress stemming from the expectation to apply feeding and care recommendations that failed to consider familial situations, resources, and/or preferences. As a result, these authors called for increased efforts to understand the unique familial contexts of families with children receiving enteral nutrition and to provide family-focused support when working with this population.

Is there evidence that exclusion of self-efficacy enhancing components in parent education programs is associated with decreased parent-perceived self-efficacy after program completion? This literature search yielded three relevant articles: one randomized controlled trial (RCT) evaluating the efficacy of an education curriculum for parents of children with a chronic physical health condition (Kieckhefer et al., 2014), one review of parent education programs (Liyana Amin, Tam, & Shorey, 2018), and one review of parental activation interventions (Mirza, Krischer, Stolley, Magaña, & Martin, 2018). Self-efficacy enhancing components reviewed included facilitated group discussion (Kieckhefer et al., 2014; Liyana Amin et al., 2018; Mirza et al., 2018), guided problem-solving (Liyana Amin et al., 2018; Mirza et al., 2018), hands-on practice (Kieckhefer et al., 2014; Liyana Amin et al. 2018), individualized action plans (Kieckhefer et al., 2014), instruction with return demonstration (Liyana Amin et al., 2018), peer mentoring and support (Mirza et al., 2018), positive praise (Liyana Amin et al., 2018), and role play (Liyana Amin et al., 2018; Mirza et al. 2018).

Only the Kieckhefer et al. (2018) study compares outcomes for participants in a self-efficacy enhancement program with those of waitlist group participants, providing an

indicator of the null effect on self-efficacy levels associated with non-participation in a self-efficacy enhancing program. In comparison, the reviews (Liyana Amin et al., 2018; Mirza et al., 2018) included articles that utilized comparison and control groups to determine the effectiveness of self-efficacy enhancing programs. Overall, these articles provide strong support for the converse of the question under investigation, demonstrating that inclusion of self-efficacy enhancing components in parent programs is associated with increased parent-perceived self-efficacy following program completion. However, only within group outcomes for program participants were analyzed in the reviews, making it difficult to conclude whether program participants experienced similar or different outcomes than comparison and control group individuals. Given this, the evidence obtained is inconclusive as to whether a lack of self-efficacy enhancing components in parent education programs is associated with decreased self-efficacy.

Is there evidence that GT education and/or home management programs are related to participant competence with GT care skills? The literature search yielded two relevant articles: one RCT examining the efficacy of an online diagnosis-specific parent information and support application (Swallow et al., 2014) and one review of parent competence programs (Ruiz-Zaldibar, Serrano-Monzó, & Mujika, 2018). The Swallow et al. (2014) study provides evidence supporting the conclusion that a parent health management program can positively influence parent-perceived competence to manage a child's chronic health condition. It is worth noting that the main construct examined in this study (Swallow et al., 2014) was parent-perceived competence as measured by parent-reported responses on a survey measuring the extent to which

families manage chronic condition care needs and incorporate management into daily life. In comparison, although the Ruiz-Zaldibar et al. (2018) study focused on interventions promoting parent competence and skill with promoting healthy child behaviors (e.g., healthy diet, active play, limited screen time), the main construct assessed in the majority of studies reviewed was parent self-efficacy. Both these articles (Ruiz-Zaldibar et al., 2018; Swallow et al., 2014) investigated programs and interventions stemming from a similar purpose: to support parent skill competence. While Swallow et al. (2014) appears to more closely assess the construct of parent competence than the studies reviewed by Ruiz-Zaldibar et al. (2018), both articles focus primarily on parent perceptions than on objective measurements of skill competence. This may indicate one or both of the following conclusions: (1) parent self-efficacy and skill competence are so intertwined that it is difficult to clearly separate the effects of one from the other and (2) parental perceptions of their ability to manage care may be more influential on behavior than objectively-defined skill competence. The first of these two conclusions will be further examined in the next section, while the second conclusion will be further considered in the reflection of the visual model of the problem.

Is there evidence that reduced parent-perceived self-efficacy impacts competence with GT care skills? The literature search produced a large body of evidence supporting the relationship between parent self-efficacy and competence. However, articles obtained were focused primarily in the realm of family and child psychology, focusing on general parenting skills such as parental responsiveness (Jones & Prinz, 2005; Sanders & Woolley, 2005), limit setting and discipline (Jones & Prinz,

2005; Sanders & Woolley, 2005), monitoring (Jones & Prinz, 2005), and promotive parenting (i.e., use of strategies that cultivate child talents and skills; Ardel & Eccles, 2001). Although not directly related to GT care, this body of literature contributes strong evidence that there exists a relationship between parent levels of self-efficacy and parent competence and/or behavior demonstration. The overwhelming majority of articles examined only the positive relationship between these two factors (i.e., increased self-efficacy leads to increased competence). However, several authors (Ardelt & Eccles, 2001; Jones & Prinz, 2005) discuss the reverse and reciprocal effect: low parent self-efficacy leads to decreased competence, which further lowers perceived self-efficacy as parents are unable to effectively demonstrate necessary parenting skills. One study examining the relationship between maternal self-efficacy and parenting practices (Sanders & Woolley, 2005) contributes additional understanding to this question, finding that parents seeking assistance to increase skill competence are likely to have low self-efficacy. Based on these findings, Sanders & Woolley (2005) recommend increased focus on promoting parent self-efficacy within programs geared at supporting parent skill development. This indicates an understanding within the literature that practices supporting self-efficacy may also have benefits for competence.

One additional article more closely related to the area of parent-child health management was obtained: a descriptive study on parent asthma management (Brown, Gallagher, Fowler, & Wales, 2014). Study findings contribute valuable understanding of the within person variability of self-efficacy levels as they relate to different health management tasks. Data obtained from parents of children with asthma indicated higher

levels of self-efficacy for completing simple, skill-based, and frequently performed tasks. In comparison, lower levels of self-efficacy were reported for tasks that involved higher levels of problem-solving, judgment, and decision-making (Brown et al., 2014).

Is there evidence that GT education and/or home management programs impact pediatric GT outcomes (i.e., emergency department visit and hospital readmission rates)? The literature search yielded one study (Schweitzer et al., 2014) evaluating the effectiveness of a standardized GT education protocol on reducing negative pediatric GT patient outcomes (e.g., unplanned clinic visits, emergency department visits, phone calls) within the initial three-month period after surgery. Historical comparison of pre- and post-protocol cohort rates found that despite having similar incidence rates of GT complications, the pre-protocol cohort had more unplanned emergency department visits while the post-protocol cohort was less likely to call providers regarding GT management concerns, as well as more likely to pre-schedule appointments to address GT concerns. Although only a singular study, Schweitzer et al. (2014) provides evidence that a GT education protocol may not only impact pediatric GT outcomes, but may also influence more appropriate caregiver use of resources to address GT concerns that arise.

To the author's knowledge, the Schweitzer et al. (2014) study is the only published article examining the direct association between GT education initiatives and pediatric GT outcomes. Despite this gap in the literature, several authors (Berman et al., 2017; Correa et al., 2014; Goldin et al., 2016) have emphasized a connection between GT education programs and pediatric GT rates of emergency department visits and hospital

readmissions, specifically within the first 30 days following discharge. One study (Berman et al., 2017) examining both the GT surgical and educational approaches of high-performing pediatric institutions specifically concluded that the technical aspects of GT surgery and postoperative complication management were not as important for optimizing pediatric GT outcomes. Rather, it was more essential to focus on caregiver education and training. Overall, these authors (Berman et al., 2017; Correa et al., 2014; Goldin et al., 2016) propose that high rates of negative pediatric GT-related outcomes are impacted by the failure of current pre-discharge caregiver education and training practices to prepare and empower families to feel capable in their ability to manage GT care and complications.

Review of the Evidence

This review of the literature produced limited evidence supporting the causal relationships portrayed in the proposed visual model. The elements most strongly supported by the literature were (1) self-efficacy and its association with parent behavior/competence and (2) the general relationship between GT home management programs and pediatric GT outcomes. Despite the lack of definitive evidence, the available literature affirms the proposed problem and its components, citing the qualitative experiences of caregivers and healthcare professionals, as well as theoretical frameworks, primarily Bandura's social cognitive theory (1977). The overwhelming majority of qualitative and descriptive studies compared to clinical trials obtained may stem from both the limited understanding of the scope of the problem, as well as from a gap in the literature.

Current trends in healthcare emphasizing the reduction of healthcare utilization costs and prevention of patient readmission rates may have contributed to the more recent increased attention given to reducing pediatric GT-related rates of emergency department visits and hospital readmissions. Related researchers and healthcare providers are likely still in the process of understanding and evaluating the problem at hand, resulting in limited availability of definitive evidence.

Additionally, family-centered care and caregiver support programs are two areas of healthcare practice that while frequently discussed in the healthcare literature, appear to have been given limited focus in the realm of clinical research. It is possible that these areas of practice are only beginning to be recognized for their benefits and useful applications, as evidenced by the fact that conducted reviews were small in nature and only published within the past few years. Several authors of recent reviews support this claim that a gap in the literature exists, calling for further research examining the following areas: (1) application of family-centered care during pediatric care delivery (Shields et al., 2012); (2) effect of parental self-efficacy/activation on child health outcomes (Mirza et al., 2018); (3) interventions for caregivers of tube-fed children (Edwards et al., 2016); and (4) interventions for enhancing parent self-efficacy and competence with child health promotion (Ruiz-Zaldibar et al., 2018).

Revision of the Proposed Explanatory Model of Identified Problem

Based on the evidence reviewed, the following revisions were made to the proposed explanatory model (depicted visually in Figure 2): (1) separation of caregiver competence and confidence into two elements and (2) addition of potential interaction

between caregiver competence and confidence as indicated by a dotted arrow. Caregiver competence continues to be relevant within the discussion of GT home management. However, the evidence supports a possible reciprocal relationship between the two phenomena primarily driven by the caregiver's level of confidence, such that decreased confidence may translate into reluctance or resistance towards GT care, ultimately influencing overall competence with GT management. These revisions indicate a shift in understanding that emphasizes caregiver self-efficacy as the primary element influencing caregiver use of formal healthcare services to address GT concerns. Additionally, literature specifically related to GT outcomes supports this transition towards greater emphasis on the role of self-efficacy in GT management, as indicated by a call for increased focus on family empowerment and self-efficacy promotion within GT education and home management programs.

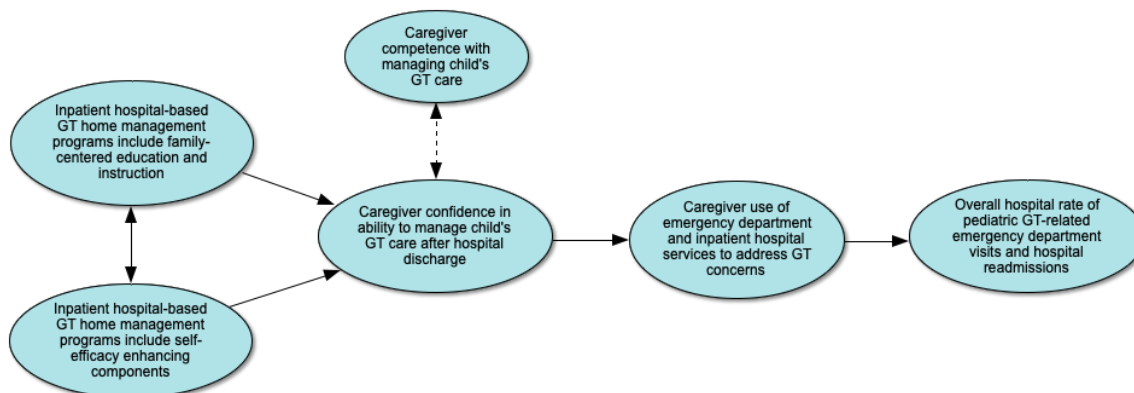


Figure 2: Revised Explanatory Model of Identified Problem

Evidence Base to Support the Project

A Synthesis of Current Approaches and Methods

Introduction

A literature review on caregiver education and health management programs was conducted to gather information regarding current methods and approaches for enhancing caregiver self-efficacy and promoting improved health outcomes for children post-GT placement. The following six questions served as a guide for the literature searches:

- (1) What interventions exist for achieving increased self-efficacy for caregivers of children with medically complex children and what is the evidence of their effectiveness?
- (2) What interventions exist for reducing negative outcomes for medically complex children after hospital discharge and what is the evidence of their effectiveness?
- (3) Is there evidence about what features of parent/caregiver education programs are associated with positive outcomes for parents/caregivers?
- (4) Is there evidence about what features of parent/caregiver education programs are associated with positive outcomes for children?
- (5) Is there evidence about which caregivers benefit most from these interventions?
- (6) Is there evidence about which children benefit most from these interventions?

Information garnered from these literature searches was utilized to structure the PATCH Program, an outpatient-based caregiver GT home management program (see Chapter 3) intended to reduce the rates of pediatric GT-related emergency department visits and hospital readmissions within the 30-day period following initial discharge. When possible, searches were focused on caregiver programs related to pediatric GT management. However, to ensure a comprehensive review of current methods, searches were broadened to include support and education programs for parents of children with

medically complex conditions as well. All articles included in the following evidence review focus primarily on parents and/or caregivers of children with chronic and/or medically complex conditions. For the remainder of this chapter, “caregiver” will be used as a collective term referring to parents and/or primary caregivers of the children being discussed.

Literature searches were completed using a combination of the following terms: parents, caregivers, education, training, self-efficacy, gastrostomy tube, enteral nutrition, medically complex, medically complicated, hospital discharge. Searches were repeated across several databases including CINAHL, PsycINFO, Embase, PubMed, and Cochrane Database of Systematic Reviews (CDSR). Several high-impact journals related to pediatric medicine, occupational therapy, and enteral feeding were also examined to identify additional articles of relevance. These journals included the American Journal of Occupational Therapy (AJOT), Journal of Parenteral and Enteral Nutrition, Journal of Family Nursing, and Journal of Pediatric Nursing. The evidence obtained through these literature searches is organized by theme and summarized as follows.

Theme 1: Peer-Peer Support

A significant number of articles obtained describe group-based caregiver education and/or training programs (Churchill & Kieckhefer, 2018; Goodier et al., 2014; Jackson, Liang, Frydenberg, Higgins, & Murphy, 2016; Kieckhefer et al., 2014; Mirza et al., 2018; Ufer et al., 2018). One article described an intervention approach that while predominantly delivered on a one-to-one basis also incorporated a peer mentoring and support component (Hartnick et al., 2017).

A recent literature review of support interventions for caregivers of children with special health care needs indicated no significant benefit associated with group-based versus individual therapeutic approach. The review found no difference in outcomes of caregiver self-efficacy, caregiver confidence, caregiver psychosocial status (i.e., depression, stress, anxiety, strain), and/or child psychosocial status (i.e., adjustment, psychological functioning) between group-based and individual intervention delivery (Mirza et al., 2018). Similarly, an expert panel review of intervention approaches associated with reducing hospitalizations among children with medical complexity rated peer-peer connection as “median,” indicating uncertainty regarding the effectiveness of peer-peer connection in reducing hospitalization for children with medical complexity (Coller et al., 2017).

Despite these findings, the overwhelming consensus among the articles presenting group-based approaches was that group-based delivery is advantageous in that it provides a context for modeling, social reinforcement, peer support, and peer exchange of knowledge, skills, and personal experiences. Specifically, Kieckhefer et al. (2014) present the *Building on Family Strengths (BFS)* program, a non-diagnosis-specific caregiver education program to enhance caregiver self-efficacy and management of a child’s chronic condition. Derived from an adult self-management program model, the BFS utilizes group-based sessions co-facilitated by a healthcare professional and a caregiver of a child with a chronic condition to create the conditions for peer modeling and practice of positive coping strategies with opportunity for social reinforcement. Participant outcomes immediately post-program completion, as well as at six and twelve

months post-program completion, indicated significantly better outcomes in caregiver self-efficacy for BFS participants compared to individuals in a waitlist, no intervention control group (Churchill & Kieckhefer, 2018; Kieckhefer et al., 2014). One study (Goodier et al., 2014) specifically obtained qualitative data regarding participants' perceptions of a skills-based group workshop intended to teach caregivers of children and adolescents with eating disorders practical and interpersonal skills for managing the child's/adolescent's condition. Following participation in the workshop, caregivers reported that sharing with and listening to peers discuss personal concerns, questions, and lived experiences was beneficial in normalizing their own experiences and in helping them learn new ideas and skills (Goodier et al., 2014).

In examining the evidence obtained, it is worth noting that Mirza et al. (2018) acknowledges a gap in the literature regarding caregiver support interventions. This resulted in a limited number of articles to review, making it difficult to generalize its conclusions at this time. Additionally, the Coller et al. (2017) review states that while the relationship between peer-peer connection and hospitalization of children with medical complexity was considered to be uncertain, it was not rated as "ineffective" by the expert panel. Coller et al. (2017) interpret this as confirmation of the possibility that peer-peer connection may in fact contribute to the reduction of hospitalizations for children with medical complexity, but that it cannot be concluded with certainty at this time.

Overall, quantitative and qualitative data obtained from studies examining the effectiveness of group-based caregiver interventions on self-efficacy and child health management skills reflect a benefit associated with inclusion of peer-peer connection

components, specifically group-based delivery, facilitated group discussion, and opportunities for peer modeling and social reinforcement. Positive outcomes associated with peer-peer connection intervention components include increased caregiver self-efficacy (Churchill & Kieckhefer, 2018; Goodier et al., 2014), enhanced caregiver coping and mental health (Churchill & Kieckhefer, 2018; Jackson et al., 2016; Mirza et al., 2018), increased feelings of peer support (Ufer et al., 2018), and enhanced caregiver problem-solving (Jackson et al., 2016).

Theme 2: Formal Education

The majority of articles obtained (Arnold & Diaz, 2016; Churchill & Kieckhefer, 2018; Goodier et al., 2014; Hartnick et al., 2017; Kieckhefer et al., 2014; Mirza et al., 2018; Schweitzer et al., 2014; Shahine, Badr, Karam, & Abboud, 2014; Sullivan-Bolyai et al., 2015; Ufer et al., 2018) present predominantly education-based programs intended to teach caregivers the knowledge and skills necessary to effectively manage a child's health condition and to promote positive health outcomes for the child. Educational approaches applied include in-person didactic presentation (Goodier et al., 2014; Mirza et al., 2018; Shahine et al., 2014; Sullivan-Bolyai et al., 2015), expert lectures (Mirza et al., 2018), pre-defined curriculum and objectives (Arnold & Diaz, 2016), printed handouts and manuals summarizing lessons (Caldwell et al., 2018; Jackson et al., 2016; Kieckhefer et al., 2014; Schweitzer et al., 2014; Shahine et al., 2014; Ufer et al., 2018), and video/online methods (Hartnick et al., 2017; Thrasher et al., 2018). A review of complex care interventions also identified approaches focused on caregiver knowledge and skills as "effective" for reducing hospitalizations among children with medical complexity

(Coller et al., 2017). This review highlighted the following educational methods as specifically associated with reducing hospitalizations: (1) creation of videos and manuals on the use and maintenance of relevant medical technologies and (2) adoption of national initiatives or an established curriculum focused on caregiver healthcare education (Coller et al., 2017).

There is general agreement among these articles that formal, structured education approaches when applied to caregiver support programs enhances caregiving knowledge and understanding of the child's health care needs. Specifically, there is an emphasis on inclusion of formal education focused on the child's medical condition explanation, course, and prognosis (Shahine et al., 2014); anticipation and early recognition of possible health concerns and emergencies (Coller et al., 2017); technical aspects of medical care (e.g., GT replacement, cleaning, flushing, etc.; Arnold & Diaz, 2016; Schweitzer et al., 2014; Thrasher et al., 2018); problem-solving strategies (Arnold & Diaz, 2016; Caldwell et al., 2018; Kieckhefer et al., 2014; Shahine et al., 2014); and accessing and using resources (Mirza et al., 2018).

Several studies applying formal education practices in their caregiver support programs were associated with positive outcomes related to caregiver self-efficacy, knowledge, and competence, as well as with child emergency department visit and hospital readmission recurrence. Specifically, Schweitzer et al. (2014) compared participants' pre- and post-program scores on a Mastery of Information Quiz (MIQ) intended to measure change in knowledge following participation in a standardized interdisciplinary pediatric GT education protocol. A statistically significant increase in

knowledge scores from pre- to immediately post-program, as well as to three months post-program, indicate the significant impact that a GT education protocol can have on information mastery. Additionally, caregivers participating in the GT education protocol reported an increase in confidence in ability to manage the child's GT home care at immediately post-program and three months after. Schweitzer et al. (2014) provides evidence for the effectiveness of formal education approaches on enhancing not only GT care knowledge, but also confidence of caregivers of children with newly placed GTs. It is also worth noting that qualitative data obtained through caregiver interview following participation in a skills training workshop for managing and reacting to child and adolescent eating disorders indicated that caregivers considered the use of PowerPoint presentations, printed materials, and readings to be useful in promoting their sense of competence and confidence in responding to their child's/adolescent's eating disorder (Goodier et al., 2014).

As indicated by the articles obtained, formal education practices, particularly when applied in a multimodal approach and when covering a broad variety of care and condition-related topics, holds benefits for enhancing the knowledge and self-efficacy of caregivers of children with chronic and medically complex conditions.

Theme 3: Practical Skills Training and Practice

Within the literature, there is a consensus that skill mastery is achieved not only through formal education, but through a combination of education and active participation in skills training. Within the literature, primary methods used for incorporating practical skills training into intervention included role play (Goodier et al.,

2014), hands-on skills practice (Caldwell et al., 2018; Coller et al., 2017; Jackson et al., 2016; Kieckhefer et al., 2014; Mirza et al., 2018; Thrasher et al., 2018; Ufer et al., 2018), and simulated practice with GT dolls (Schweitzer et al., 2014). Several articles utilized human patient simulation (HPS; Sullivan-Bolyai et al., 2015) or high-fidelity simulation (HFS; Arnold & Diaz, 2016; Thrasher et al., 2018) to enhance caregiver training and problem-solving skills. HPS and HFS both involve the use of a computerized anatomically correct, lifelike child or infant mannequin to simulate emergency or care situations. This provides caregivers with an interactive experience to actively practice skills, to receive both immediate (from the mannequin) and delayed (from facilitators or video review) feedback, to further enhance critical thinking and problem-solving skills, and to learn consequences of actions while avoiding danger or harm to the caregiver's child (Arnold & Diaz, 2016; Sullivan-Bolyai et al., 2015; Thrasher et al., 2018).

Thrasher et al. (2018) specifically applied HFS in discharge preparedness training for caregivers of children requiring long-term mechanical ventilation such as through a tracheostomy. Of note, study data suggested an association between HFS implementation and decreased 7-day readmissions following discharge, although it was unable to be confirmed due to small sample size (Thrasher et al., 2018). Additionally, in examining caregiver perceptions of HFS post-program, this study identified that caregivers considered simulation debriefing, which involved review of video-recorded performance paired with one-to-one identification and discussion of performance gaps, to be the most beneficial component of the program (Thrasher et al., 2018). This serves as an indicator of the potential benefit of direct, performance-based feedback and debriefing in

promoting skill development and ultimately promoting positive health outcomes for children with medically complex conditions. While HPS and HFS have been associated with positive effects on caregiver self-confidence (Sullivan-Bolyai et al., 2015), problem-solving (Sullivan-Bolyai et al., 2015), and child readmission rates (Thrasher et al., 2018), it is worth noting that two (Arnold & Diaz, 2016; Thrasher et al., 2018) of the three studies reviewed focused primarily on medically complex children who were hospitalized at the time of program participation. Consequently, this method of skills training and practice may be better suited for caregivers of children currently hospitalized and who are learning necessary medical care skills for the first time.

Overall, application of skills training and practice in caregiver education and support programs has been associated with positive outcomes for both caregivers and their children with chronic and medically complex conditions. These outcomes include increased caregiver self-efficacy (Goodier et al., 2014; Kieckhefer et al., 2014; Mirza et al., 2018), improved use of learned strategies following program completion (Caldwell et al., 2018), enhanced problem-solving skills (Jackson et al., 2016), improved familial quality of life (Kieckhefer et al., 2014), improved caregiver coping (Kieckhefer et al., 2014; Mirza et al., 2018), decreased caregiver depressive symptoms (Kieckhefer et al., 2014), reduced rates of unplanned emergency department visits (Schweitzer et al., 2014), and reduced rates of hospital readmission post-discharge (Coller et al., 2017; Thrasher et al., 2018). Given this evidence, it can be concluded that skills training and practice is a practical and viable method for supporting caregivers in confidently managing the health and care needs of their children with chronic or medically complex conditions.

Theme 4: Supplementary Learning Materials and Resources

A common practice noted across many studies (Caldwell et al., 2018; Coller et al., 2017; Hartnick et al., 2017; Jackson et al., 2016; Kieckhefer et al., 2014; Schweitzer et al., 2014; Shahine et al., 2014; Thrasher et al., 2018; Ufer et al., 2018) was the use of printed and/or virtual materials to reinforce and supplement lessons and skills learned during the education or support program. Additionally, several articles (Breneol, Belliveau, Cassidy, & Curan, 2017; Coller et al., 2017; Ufer et al., 2018) discussed providing caregivers with printed or virtually accessible information regarding available financial, emotional, and/or care coordination resources. As discussed in previous thematic sections, these studies and reviews describe education and support programs that have been shown to be associated with positive caregiver psychosocial and child health outcomes. As a component of these effective programs, it may be reasonable to conclude that provision of resources and supplementary materials holds benefit for enhancing caregiver self-efficacy, psychosocial health, and management of child health needs.

Shahine et al. (2017) specifically found that within a caregiver education program, culturally sensitive printed materials written at a fifth-grade reading level contributed to a statistically significant decrease in number of hospitalizations among children with sickle-cell disease from pre- to post-program implementation. Additionally, caregivers who participated in a training workshop for managing and reacting to child and adolescent eating disorders commented that supporting materials, such as supplementary readings and handouts, were useful for helping them learn and retain skills (Goodier et al., 2014).

Two reviews (Breneol et al., 2017; Coller et al., 2017) examining the literature related to supporting hospital to home transitions and reducing hospitalizations among children with medical complexity specifically discussed the use of comprehensive care plan documents. These care plans are collaboratively created printed documents outlining the child's major medical and care needs, medication lists, emergency and contingency care plans, recommended action plans for commonly encountered situations, and directory of professionals to call in case of concern. An expert panel review of intervention strategies for children with medical complexity rated early recognition and contingency plans as "effective" for reducing hospitalizations (Coller et al., 2017), indicating potential benefit of developing and providing comprehensive care plans within caregiver education and support programs.

Overall, provision of supplementary learning materials and resources has the potential to enhance the learning experience of recipients by supporting knowledge and skill retention during and beyond program participation. The use of supplementary learning materials within caregiver education and support programs has been well received by participants and has been associated with positive outcomes including reduced rates of child hospitalization (Coller et al., 2017; Shahine et al., 2017), increased caregiver skill competence (Schweitzer et al., 2014), improved knowledge retention (Goodier et al., 2014), and enhanced caregiver confidence (Goodier et al., 2014; Schweitzer et al., 2014). Based on the evidence reviewed, supplementary learning materials may be most effective when they are comprehensive, multimodal, culturally sensitive, and written at a middle-school reading level.

Theme 5: Family-Centered Approach

Several reviews (Breneol et al., 2017; Coller et al., 2014) emphasized the importance of adopting a patient- and family-centered care (PFCC) approach when educating and supporting caregivers to manage the health and care needs of their children with chronic and medically complex conditions. They call for a shift to emphasize the needs of caregivers, as well as to better validate their knowledge and skills in an effort to promote the health and well-being of their children with medical complexities who are transitioning home.

Several studies (Arnold & Diaz, 2016; Caldwell et al., 2018; Coller et al., 2014) specifically highlighted the importance of family-centered planning when determining learning objectives, selecting training activities, providing resources, and developing care plans. This includes considering the various contexts (e.g., home, community, school, travel) in which caregivers will be expected to administer their children's care and adapting activities and lessons in accordance. Additionally, an expert review panel stated that among interventions reviewed, training was more effective when multimodal teaching approaches were utilized, as this better accommodated a variety of individual caregiver learning preferences (Coller et al., 2014). The inclusion of a family needs assessment prior to participation in a group-based caregiver education program was also identified as a practical means for initiating one-to-one collaboration with caregivers and for identifying individual needs and priorities to focus on throughout the program. This needs assessment also served to assist training facilitators in developing and selecting instruction and practice activities that collectively best reflect the needs, priorities, and

situations of the caregivers participating in the education program (Arnold & Diaz, 2016).

Collaborative goal setting completed at the start of program participation and at the beginning of each session, was also applied in a training program for caregivers of children with sensory food aversion. Goal setting served as a means for focusing caregiver and facilitator efforts and for promoting caregiver self-efficacy throughout the program. This component contributed to an overall increase in caregiver use of learned techniques and a decrease in children's undesirable mealtime behaviors from pre- to post-training (Caldwell et al., 2018). The benefit of collaborative goal setting is demonstrated in this study as enhanced behavior adoption that consequently led to positive impacts on the child's health and behavioral status.

Adopting a patient- and family-centered care perspective within caregiver education and support programs demonstrates a consideration for the unique circumstances of each participating caregiver and family. By understanding the distinct situations and goals of each participant, program facilitators can structure lessons and select activities in a way that best supports the needs of their group. Use of family-centered care approaches has been associated with improved caregiver adoption of learned skills and enhanced child health and behavior (Caldwell et al., 2018). Methods for incorporating a family-centered approach into caregiver education and support programs include use of collaborative goal setting practices, a pre-program family needs assessment, and multimodal teaching strategies.

Theme 6: Population Characteristics

In examining the effectiveness of education and support interventions for caregivers of children with chronic and medically complex conditions, several articles (Churchill & Kieckhefer, 2018; Mirza et al., 2018; Ufer et al., 2018) identified associations between specific caregiver characteristics and program outcomes. One study implementing a group-based care coordination training program found that on knowledge assessments of program content, caregivers of children with special health needs belonging to the lowest income group scored significantly lower than their counterparts belonging to the two highest income groups. This same study found that Hispanic caregivers also scored lower than their non-Hispanic counterparts (Ufer et al., 2018).

An association was also found between caregivers' baseline scores and their post-program outcomes. Within group comparisons of caregivers of children with complex and/or chronic health conditions suggests that caregivers with lower pre-program outcome baselines benefited most from the intervention provided (Churchill & Kieckhefer, 2018; Mirza et al., 2018). Specifically, it was found that caregivers with pre-program low self-efficacy were most positively impacted by participation in an education program focused on enhancing competence and confidence with managing the care of children with special health needs (Churchill & Kieckhefer, 2018). This reflects the phenomenon that caregivers most lacking in the strengths and skills necessary to effectively manage the care needs of a child with a chronic and/or medically complex condition are the same caregivers who benefit most from the implementation of caregiver education and support programs.

These findings are beneficial in that they indicate which populations of caregivers respond best to education and support programs, as well as which populations may require additional attention or supports to ensure that a benefit is achieved. Application of this information to program development and implementation serves to ensure that education and support interventions are best suited to address the needs of the caregiver population being served.

Conclusion

This chapter presented an overview of the theoretical approach used to define and understand the current problem of high rates of post-surgical pediatric GT-related emergency department visits and hospital readmissions. Applying concepts from the Individual and Family Self-Management Theory (IFSMT), this problem was framed as the result of a lack of family-centered focus and self-efficacy enhancing approaches within current GT education and support programs. A literature review on caregiver education and health management programs was then conducted to identify and understand the current methods and approaches for enhancing caregiver self-efficacy and promoting improved health outcomes for children post-GT placement. Given the limited availability of evidence specifically pertaining to the health outcomes of children with GTs and their caregivers, evidence related to caregivers of children with medically complex conditions was examined.

The review of the evidence base produced six primary themes related to enhancing caregiver self-efficacy and promoting enhanced outcomes for children with medically complex conditions: (1) peer-peer support, (2) formal education, (3) practical

skills training and practice, (4) supplementary learning materials and resources, (5) family-centered approach, and (6) population characteristics. The evidence examined demonstrated the positive benefits of family-centered care, group-based delivery, structured educational curriculum, interactive skills training and practice, and multimodal, culturally-sensitive, health literacy conscious learning materials on caregiver and child health and wellness. Based on this literature review presented, it can be concluded that caregiver programs incorporating these elements have the potential to enhance caregiver competence and self-efficacy and to reduce hospitalization rates among children with medically complex conditions.

CHAPTER THREE – Description of the PATCH Program

Introduction

Healthcare utilization data has shown pediatric gastrostomy tube (GT) placement to be associated with high rates of emergency department visits (8.6%) and hospital readmissions (3.9%) within the initial 30-day period following hospital discharge (Goldin et al., 2016). Current research indicates that GT education and home management programs may insufficiently prepare caregivers of children with GTs to effectively manage the child's GT care following hospital discharge, thus contributing to poor post-discharge outcomes (Berman et al., 2017; Franklin & Rodger, 2003; Russell et al., 2018).

Occupational therapy is equipped to meet the needs of this population through provision of comprehensive, family-centered education and training focused on empowering families and facilitating caregiver self-efficacy. This project focused on the development of the PATCH Program: Promoting and Teaching Confidence for the Home. The PATCH Program is a home management program intended to promote caregivers' confidence and competence with managing their children's GT care. By empowering families to more effectively and confidently manage their children's GT care, this program will also contribute to a reduction in facility rates of pediatric GT-related emergency department visits and hospital readmissions.

Presented in this chapter is a description of the design and content of the PATCH Program. This chapter also includes a discussion of intended program outcomes, as well as potential barriers and challenges impacting program implementation.

Program Design

The PATCH Program is a theory-driven, evidence-based home management program for caregivers of children with GTs. Its distinct value comes from its occupational therapy foundation, distinguishing it as unique among current GT education and training programs. Developed by a pediatric occupational therapist, the PATCH Program emphasizes family-centered care by encouraging and honoring the unique skills and goals of all participants involved. Through an occupational therapy lens, the PATCH Program acknowledges that successful GT home management is a product of careful consideration of the child's and family's environment, context, structure, and circumstances. Through this occupational therapy approach, the PATCH Program goes further than to provide solutions; it empowers caregivers of children with GTs to competently and confidently problem-solve and create solutions that best fit their needs and priorities.

The PATCH Program is designed to be delivered to caregivers of children with GTs on an outpatient basis following the child's initial hospital discharge post-GT placement. Influenced by the evidence-based literature (Berman et al., 2017; Goldin et al., 2016) identifying the first 30 days after surgery as a critical period for addressing negative pediatric GT-related outcomes, the PATCH Program is specifically intended to be delivered to caregivers within the first four weeks after the child with a GT has been discharged home. Outpatient delivery of the PATCH Program within this timeframe allows the program to provide support and resources to caregivers of children with GTs during a critical time period after a family's return home following the child's GT

placement. By adopting an outpatient delivery model, the PATCH Program serves as a continuation of currently established, facility-provided pre-discharge GT education protocols by reinforcing the knowledge learned during hospitalization and by providing opportunities for caregivers to practice and gain confidence with routine and emergency care skills.

The PATCH Program also adopts a strong family-centered focus to understanding and addressing caregiver education and pediatric GT home management. Incorporating a family-centered focus, the PATCH Program begins with an initial one-to-one guided interview between the program facilitator and each participating caregiver (see Appendix A). Influenced by the Individual and Family Self-Management Theory (IFSMT; Ryan & Sawin, 2009), this interview serves to initiate the facilitator-caregiver collaborative relationship; to gather preliminary information regarding the unique needs, skills, and circumstances of each caregiver and his or her family; and to identify meaningful goals to work towards during program participation. This individualized family interview signifies the PATCH Program's understanding of pediatric GT home management as a highly individualized process shaped by each caregiver's and family's unique circumstances.

Following this initial one-to-one family interview, the program consists of four weekly 90-minute group-based sessions. The author's selection of this group format was informed by best available evidence supporting the use of group-based delivery in facilitating enhanced caregiver learning, skill performance, and confidence through peer modeling, support, and discussion (Churchill & Kieckhefer, 2018; Goodier et al., 2014;

Jackson et al., 2016; Mirza et al., 2018; Ufer et al., 2018). Additionally, the author's choice to incorporate a four-session design was based on evidence suggesting that caregivers of children with special health care needs benefit more from education and training delivered in multiple sessions over time compared to a single longer duration session (Arnold & Diaz, 2016; Jackson et al., 2016). Weekly sessions are planned to begin within one to two weeks following the child's hospital discharge to ensure that caregivers are provided with timely access to training, education, and resources.

Program sessions are facilitated by a team consisting of an occupational therapist and rotating group of co-facilitators (e.g., general surgery or gastroenterology physician and/or nurse practitioner, registered dietician, social worker, peer mentor, etc.) who can provide education and skill training specific to each session's primary theme. The occupational therapist will have previous experience treating children with GTs and working with their families in a therapeutic capacity. The co-facilitators will differ among the various four weeks such that co-facilitators are best matched to a session based on their applicable knowledge, skills, and or training. For example, a gastroenterology and/or general surgery nurse or physician would serve best as a co-facilitator during sessions discussing GT complications and care skills, while a peer mentor with long-term experience managing a child's GT care may be best suited to co-facilitate discussions on problem-solving GT care in the home and community.

Program Content

Influenced by the evidence-based literature supporting interventions associated with increased caregiver self-efficacy (Caldwell et al., 2018; Goodier et al., 2014;

Kieckhefer et al., 2014; Mirza et al., 2018), the PATCH Program integrates formal education with practical skills training and practice. This combined education and training approach has been shown to be effective for encouraging not only skill mastery among caregivers of children with chronic and/or complex medical conditions, but for enhancing caregiver self-efficacy related to practically applying learned skills to everyday life as well (Caldwell et al., 2018; Coller et al., 2017; Goodier et al., 2014; Jackson et al., 2016; Kieckhefer et al., 2014; Mirza et al., 2018; Schweitzer et al., 2014; Thrasher et al., 2018; Ufer et al., 2018). The PATCH Program content is presented in a modular format such that each weekly session is comprised of educational presentations, group discussions, skill practice, and/or additional learning activities covering a similar topic or theme. Although the program adopts a modular format, topics will be revisited and related throughout the program to provide participating caregivers with ample opportunities to review material, to clarify questions, to create connections between sessions and real-life experience, and to further practice learned skills.

Integrating the evidence-based literature (Coller et al., 2014) regarding effective strategies for promoting learning during caregiver education programs, each PATCH Program session incorporates multimodal instructional methods and learning activities to accommodate individual learning preferences and needs. Educational and instructional methods to be applied throughout the program include PowerPoint presentation, instructional video, live demonstration, printed worksheets, role play scenarios, simulated practice with GT learning dolls, and verbal discussion. Supplementary learning materials and resources in the form of printed handouts, pamphlets, online videos, and online

learning modules will also be provided throughout the PATCH Program to support caregivers in retaining learned skills and in accessing GT care information outside of program sessions. To accommodate diversity within the population of caregivers of children with GTs, all efforts will be made to ensure that interpretation services are offered and available during the program and that supplementary materials provided are translated and offered in the preferred language of participating caregivers. This demonstrates a respect and consideration for the cultural and language preferences of participating caregivers, as well as promotes greater access to the program.

The evidence-based literature regarding caregiver education programs suggests that supplementary learning materials that are culturally sensitive and written at a fifth-grade reading level are associated with reduced hospitalization rates among children with medically complex conditions (Shahine et al., 2017). Integrating this evidence, the PATCH Program supplementary learning materials will be written and compiled in a format that is considerate of varying cultures and literacy levels. All PATCH Program learning materials will be regularly reviewed by the team of program facilitators and co-facilitators to ensure their cultural and literacy appropriateness. Additional input will be sought from outside sources experienced in developing culturally sensitive and literacy-considerate materials (e.g., multicultural organizations and community leaders, marketing and public relations teams, etc.) as needed.

Following is a general overview of the four major themes/topics and content to be addressed during the program, as well as relevant supporting evidence and theoretical perspectives:

Table 1: PATCH Program Curriculum

Week 1	
Conquer the Tube: Skills for Managing GT Care Beyond the Hospital	
Content	<ul style="list-style-type: none"> • <i>Educational lesson:</i> Review of GT care skills (i.e., administering feeds and medication, venting GT, preventing tube blockage, inserting emergency red robin tube, etc.) first introduced during the hospital’s established pre-discharge GT education protocol will be provided. • <i>Simulated practice:</i> GT learning dolls will be used for hands-on practice with reviewed GT care skills • <i>Group discussion:</i> Session will end with group discussion of caregiver feelings, concerns, and/or questions related to completing GT care skills outside of the session. Participants will be encouraged to share any strategies they have developed or feel are helpful for completing GT care skills.
Theoretical Grounding	<ul style="list-style-type: none"> • <i>Social cognitive theory - behavioral capability:</i> Education promotes increased caregiver knowledge of GT care. • <i>Social cognitive theory - observational learning:</i> During simulated practice, participants learn by watching their peers trial methods and achieve skill competence. • <i>Social cognitive theory - reinforcement:</i> Group discussions and simulated practice provide opportunity for program providers and peer participants to offer verbal praise and encouragement. <p style="text-align: right;">(Bandura, 1977)</p>
Evidence Base	<p><i>Schweitzer et al., 2014:</i> This study applied multimodal teaching methods in a standardized pre-discharge pediatric GT education protocol. Post-program positive effects were found for caregiver confidence and GT knowledge.</p>

Week 2	
Re-think the Problem: Steps for Approaching GT Challenges	
Content	<ul style="list-style-type: none"> • <i>Educational lesson:</i> Facilitators introduce and explain problem-solving steps of problem assessment, goal setting, reflective thinking, action planning, action implementation, and self-evaluation. • <i>Family-centered case scenarios and studies:</i> Facilitators present the group with case studies based on situations that are commonly encountered with GT care and that participants expressed interest in addressing during initial one-to-one interviews. • <i>Guided instruction:</i> Using open-ended questioning, participants are led to apply problem-solving steps to the presented case studies. • <i>Simulated practice:</i> Hands-on practice with GT learning dolls can be used to supplement guided instruction.
Theoretical Grounding	<ul style="list-style-type: none"> • <i>IFSMT - consideration of familial circumstances:</i> Information from the initial one-to-one interviews is used to develop case studies that are relevant to participants' situations and goals (Ryan & Sawin, 2009). • <i>IFSMT - self-regulation skills and abilities:</i> Problem-solving is a highlighted component of the self-management process. Interventions that focus on enhancing participant problem-solving skills support the achievement of desired health outcomes (Ryan & Sawin, 2009). • <i>Social cognitive theory - behavioral capability:</i> Problem-solving education and training promotes increased caregiver knowledge and skill mastery. If caregivers are instructed on problem-solving skills, then they are more likely to adopt and apply them in everyday life (Bandura, 1977).

<p>Evidence Base</p>	<p><i>Arnold & Diaz (2016), Caldwell et al. (2018), Jackson et al. (2016), Kieckhefer et al. (2014), Shahine et al. (2014), and Sullivan-Bolyai et al. (2015):</i> All studies noted the application of problem-solving education and/or training during parent/caregiver programs. Overall, these studies resulted in increased caregiver self-efficacy, skill competence, and positive behavior adoption.</p> <p><i>D’Zurilla and Nezu (2010):</i> This review of studies examining the effectiveness of problem-solving training interventions with different populations of caregivers found that problem-solving training was associated with positive outcomes including decreased caregiver stress, improved caregiver participation and role functioning, and reduced feelings of caregiver burden.</p>
<p>Week 3</p> <p>Be Empowered: Problem-Solving Your Child’s GT Care</p>	
<p>Content</p>	<ul style="list-style-type: none"> • <i>Guided instruction:</i> Facilitators offer recommendations for how to apply problem-solving strategies in the context of everyday routines and activities. • <i>Practice opportunities:</i> Participants work in pairs or small groups to apply problem-solving strategies to situations they are interested in addressing or have experienced. • <i>Group discussion:</i> Participants are asked to share perspectives gained from applying problem-solving skills to personal situations and goal areas. If caregivers developed unique strategies not previously discussed, they are encouraged to share these with their peers to enhance overall group learning.

Theoretical Grounding	<ul style="list-style-type: none"> • <i>Social cognitive theory – self-efficacy</i>: As caregivers practice successfully applying problem-solving skills to personal challenges or GT care situations, they develop increased confidence in their ability to apply these skills outside of program sessions. • <i>Social cognitive theory – observational learning</i>: Partner and group work provides participants with opportunities to observe peers applying problem-solving skills to everyday situations that may also be relevant for the caregiver. Observation of peers successfully applying problem-solving skills to care scenarios can prompt caregivers to adopt similar strategies and apply them to their own situations. <p style="text-align: right;">(Bandura, 1977)</p>
Evidence Base	<p><i>Coller et al. (2017)</i>: An expert panel of reviewers recommended providing education and training that prepares caregivers to address a variety of care situations and/or contexts.</p>
<p>Week 4</p> <p>Know Your Resources: Supports to Help You Continue Succeeding</p>	
Content	<ul style="list-style-type: none"> • <i>Group discussion</i>: Participants are asked to share examples of how they successfully applied program lessons or strategies in their everyday lives. Facilitators offer verbal praise and encourage peers to do the same. • <i>Resources</i>: Participants are provided with access to printed and virtual/electronic supplemental learning materials and resources.

Theoretical Grounding	<p><i>SCT reinforcement:</i> Participants are prompted to reflect on the positive outcomes of applying learned strategies to everyday life. Verbalizing the positive benefits reaped by applying these strategies helps participants link their behavior change with positive outcomes, increasing the likelihood that they will continue to demonstrate these behaviors. Praise from providers and peers also helps to motivate caregivers to continue demonstrating the behaviors they are being praised for.</p> <p style="text-align: right;">(Bandura, 1977)</p>
Evidence Base	<p><i>Coller et al. (2017):</i> This literature review recommends providing families with comprehensive care plans and access to resources in an effort to reduce hospitalizations among medically complex children.</p> <p><i>Schweitzer et al. (2014):</i> Participants were provided with an individualized education booklet and DVD covering aspects of GT care during a pre-discharge GT education protocol. This study found a statistically significant increase in caregiver confidence from pre- to post-program.</p>

Objectives and Expected Outcomes

Influenced by current practices in caregiver education and support programs, the PATCH Program presented here combines family-centered care principles with formal education and practical skill training related to the care of a child with a GT. The PATCH Program draws from theoretical perspectives and evidence-based literature emphasizing the relationship between individual self-efficacy and program components of group-based delivery, problem-solving training, and experiential learning. Through the integration of components discussed here, the PATCH Program supports caregivers of children with GTs in developing the skills and self-efficacy needed to effectively manage their children's routine GT care needs and to problem-solve GT complications that arise

following hospital discharge. The expected outcomes of this program are as follows: (1) increased caregiver self-efficacy regarding management of the child's GT and (2) reduced hospital/facility rates of pediatric GT-related emergency department visits and hospital readmissions after the child's discharge home. An evaluation plan to assess the achievement of these expected outcomes is discussed further in Chapter 4.

Barriers and Challenges to Implementation

Several challenges to implementation can be anticipated for the PATCH Program. First, several articles (Mirza et al., 2018; Ruiz-Zaldibar et al., 2018) identified a limited body of evidence regarding interventions to support parent and/or caregiver self-efficacy. The literature informing the development of the PATCH Program focused primarily on children with varying chronic and/or medically complex conditions. These populations of children may have different sets of care needs and expectations than children with GTs, potentially limiting the effectiveness of utilized approaches and the generalizability of findings to the PATCH Program described here. Second, the PATCH Program targets primary caregivers of children with GTs. Participation in program sessions may be perceived as a greater burden if the program is unable to assist these caregivers with aspects such as childcare, transportation, and flexibility regarding the date and time of sessions. To promote program participation, the funding plan (described in detail in Chapter 5) may need to account for these aspects when considering expense needs of the program. Additionally, a program evaluation will need to ensure that a method is in place to identify caregivers' perspectives on how the program meets or fails to meet their needs and expectations so that positive changes can be made accordingly. A description of

program evaluation, including data measurement and analysis, is provided in Chapter 4.

Conclusion

The PATCH Program: Promoting and Teaching Confidence for the Home is a home management program designed to empower and enable caregivers of children with GTs to effectively manage and problem-solve the care needs of their children. Developed to address a gap in current GT education and training programs, the PATCH Program offers a unique approach to reducing facility rates of pediatric GT-related emergency department visits and hospital readmissions by enhancing the self-efficacy, or confidence in one's skills and abilities, of caregivers of children with GTs. The PATCH Program achieves this through its integration of theoretical perspectives with evidence-based approaches identified as effective for increasing caregiver self-efficacy. Specifically, the PATCH Program's four-week outpatient curriculum utilizes group-based delivery, formal education, practical skills training and practice, collaborative goal setting, and provision of supplementary learning materials and resources to support caregivers in developing enhanced competence and confidence for managing their children's GT care needs.

The PATCH Program's distinct value originates from its occupational therapy foundation, which values and prioritizes family-centered care and family empowerment. The PATCH Program acknowledges that GT home management is a highly individualized process shaped by the unique experiences, values, routines, and goals of each participating caregiver and family. The PATCH Program is unique from current GT education and training approaches because it does not offer solutions, but rather empowers caregivers to problem-solve and create care solutions that best fit the needs of

their children and that promote the health, wellness, and daily participation of their families.

CHAPTER FOUR – Evaluation Plan

Introduction

According to data obtained through the United States Department of Health and Human Services Healthcare Utilization Project (HCUPnet, 2009), gastrostomy tube (GT) placement is one of the most commonly performed inpatient procedures among children in the United States. Although considered to be a routine procedure involving short inpatient stays and low morbidity, pediatric GT placement has been associated with high rates of emergency department visits (8.6%) and hospital readmissions (3.9%) within the initial 30-day period following hospital discharge (Goldin et al., 2016). GT education programs, while considered best practice for promoting caregiver competence with GT care, have been identified as a potential contributor to these high rates of pediatric GT-related negative outcomes (Berman et al., 2017; Boullata et al., 2017). Specifically, discussions regarding current GT education practices have led to a call for greater focus on family empowerment and self-efficacy promotion within GT education programs (Berman et al., 2017; Franklin & Rodger, 2003; Russell et al., 2018). The PATCH Program: Promoting and Teaching Confidence for the Home aims to ultimately reduce pediatric facility rates of GT-related emergency department visits and hospital readmissions by increasing caregiver-perceived self-efficacy with managing GT care and complications.

The PATCH Program offers a distinct, family-centered approach to enhance the well-being and health of children with GTs and their caregivers. Developed by an occupational therapist, the PATCH Program considers and honors the unique

circumstances, abilities, and goals of participating caregivers and families. Its group-based format allows caregivers the opportunity to learn from and be supported by peers experiencing similar situations, while its outpatient-based delivery provides caregivers with support during a critical period in the recovery and home re-integration of children with GTs. Theory-driven and evidence-based, the PATCH Program integrates formal education and practical skills training to empower caregivers to develop GT care strategies and solutions that best fit their child's and family's needs, routines, and values. The PATCH Program is unique in that it was developed specifically to support caregivers of children with GTs, a population whose needs are only beginning to receive recognition and attention as evidenced by the sparsity of literature related to outcomes of children with GTs and their caregivers.

The PATCH Program has not yet been implemented. It is likely that Rady Children's Hospital-San Diego (RCHSD), a large Level I pediatric hospital, will be the first location to launch the PATCH Program as this is the author's current site of employment. RCHSD has in place an established pre-discharge GT education protocol for caregivers, as well as post-surgical clinic and follow-up services to monitor the child's GT tolerance and recovery. When implemented at this hospital, the PATCH Program will target adult primary caregivers of children (ages 0-18 years) discharged from the pediatric hospital post-GT placement. Primary caregivers will be identified as providing at least four to eight hours of care daily, five days per week to the child with a GT. An outline for the PATCH Program evaluation purpose, methods, and data analysis as they relate to RCHSD is presented in this chapter.

Program Evaluation Vision

The intended purpose of the program evaluation described herein is twofold: (1) determine program efficacy in promoting desired outcomes of increased caregiver-perceived self-efficacy with GT management and reduced hospital rates of pediatric GT-related emergency department visits and hospital readmissions post-GT placement and (2) examine participant satisfaction with and perceptions of program components, strengths, and weaknesses. It is intended that through the use of quantitative and qualitative information gathering methods, data and information gathered will serve a summative purpose by determining overall program efficacy, as well as a formative purpose by providing information that serves to guide continued program modification and improvement. The program evaluation results and information are intended for the following three stakeholder groups: (1) caregivers and families of children with GTs interested in knowing whether participation in this program is valuable for their own experiences, (2) funding sources (i.e., grant providers, hospital departments, sponsors), and (3) program personnel interested in knowing how to modify the program to best serve the priority population.

PATCH Program Logic Model

A logic model (see Appendix B) was constructed to provide a visual representation of the anticipated relationship between program inputs/resources, activities, outputs, and expected outcomes. Included in the logic model is a description of the problem being addressed by the program, as well as the theoretical basis underlying the logic model's proposed interactions and relationships.

Evaluability Assessment

An evaluability assessment will be conducted prior to the initiation of a full-scale program evaluation to ensure program evaluation goals and objectives are clearly defined, to determine whether program activities and delivery methods are practical and financially feasible, and to prompt commitment from stakeholders to utilize and apply evaluation results and findings after they are received. To ensure that program evaluation goals and objectives reflect the unique perspectives of the various professions involved in the interdisciplinary delivery of this program, the evaluability assessment team will consist of an occupational therapist, a gastroenterology or general surgery physician, a nurse or nurse practitioner, a dietician, a social worker, and a certified occupational therapy assistant (COTA). Additional team members to be included are a data analyst currently employed through the hospital to provide input on data collection feasibility and one to two caregivers of children with GTs to provide personal perspectives on the needs and priorities of the population being served.

The evaluability assessment will incorporate a brief presentation discussing an overview of the evidence indicating the need for initiatives to support pediatric caregivers and to reduce negative pediatric GT-related outcomes, as well as outlining the value and utility of key program features (i.e., family-centered focus, group-based delivery, self-efficacy enhancing components) in addressing this need. Round table discussions will then be utilized to engage team members in identifying program elements in need of further consideration, negotiating and agreeing to program evaluation goals and objectives, and determining overall program evaluation feasibility and methodology.

Program Evaluation Core Purpose

This program evaluation is intended to serve both a causative and descriptive purpose. As will be discussed in this chapter, program evaluation will utilize a two-group design consisting of an intervention group who receives standard care (i.e., established hospital GT education protocol) followed by participation in the GT home management program and a waitlist control group of caregivers who receive only the established hospital GT education protocol. This two-group intervention and control design allows for an estimation of the causal relationship between program participation and participant outcomes of self-efficacy and utilization of emergency department and hospital services to address GT-related concerns. This program evaluation will also serve a descriptive purpose through its incorporation of survey and semi-structured interview. The information gathered through these methods provides a descriptive overview of participant degree of program satisfaction, as well as participant perspectives on program strengths and weaknesses, areas for improvement, and value or impact on daily lives and routines.

Program Evaluation Scope

Following is a detailed overview of varying key components related to the scope of the program evaluation:

- *Retrospective Hospital Data Analysis:* To allow for pre- and post-program data comparison, pre-program hospital rates of pediatric GT-related emergency department visits and hospital readmission rates will need to be calculated and averaged. The patient information to be included in the retrospective data analysis

will be based on the following criteria: (1) patient age <18 years and (2) Current Procedural Terminology (CPT) code 43246 (Upper gastrointestinal endoscopy including esophagus, stomach, and either the duodenum and/or jejunum as appropriate; with directed placement of percutaneous gastrostomy tube) or 49440 (Insertion of gastrostomy tube, percutaneous, under fluoroscopic guidance) within one year prior to program evaluation. A retrospective analysis of hospital data will be conducted by one research data analyst currently employed by the hospital such that separate pre-program hospital averages for both GT-related emergency department visits and hospital readmissions will be available prior to the start of program evaluation.

- *Caregiver-Perceived Self-efficacy*: This program evaluation also includes use of a pre- and post-program outcome measured adapted from the General Self-Efficacy Scale (GSE; Schwarzer & Jerusalem, 1995; see Appendix C for program-specific measurement) to assess caregiver-perceived self-efficacy. This measure will be administered to intervention and control group caregivers via hospital-owned electronic tablets and/or desktop computers according to the following timeline: one-week prior to program participation during a post-discharge GT follow-up clinic or office visit, immediately following program participation during the final session of the PATCH Program, and one month following program completion during a post-discharge GT follow-up clinic or office visit. The administration of the measure during already scheduled GT follow-up clinic and/or office visits, as well as during the PATCH Program's final session is intended to increase

response rate and to avoid placing extraneous demand on caregivers outside of already required program and health visits. This data will be analyzed by the same hospital data analyst who performed the retrospective hospital data analysis. The data analyst will be blinded to individuals' group assignment.

- *Participant Program Perceptions:* At the end of the final program group session, all program participants will be provided with access to a hospital-owned electronic tablet or desktop computer to complete a post-program survey consisting of Likert-scale items and open-ended questions related to participant program satisfaction and perceptions of program activities, strengths, and weaknesses (see Appendix D). The Likert-scale data from these surveys will be summarized by the same hospital data analyst to identify trends in participant satisfaction and perceptions. By applying the principles of content analysis, participant responses to open-ended questions will be reviewed and categorized based on similarity such that the most common opinions and themes expressed by participants can be identified (Hsieh & Shannon, 2005). To gain additional in-depth understanding of participant perspectives regarding areas for program improvement and participant-perceived program impact, all program participants who completed the post-program survey will be asked to participate in a semi-structured interview one month after program completion. All interviews will be conducted by a trained hospital-employed COTA who has experience interacting with patients and their families. These interviews will be scheduled in conjunction with a GT-related clinic or office visit and caregivers will be notified by clinic

receptionists at the time of scheduling that this clinic visit will require additional time (up to one hour) to complete. If this increased time requirement was to place additional burden or inconvenience on the caregiver, the interview will be scheduled for a time and date that is mutually convenient for the caregiver and COTA. All interviews will be recorded via hospital-owned tape recorder and reviewed at a later date by a data analyst trained in qualitative data coding to identify core themes regarding personal program impacts and areas for improvement.

- *Inclusion and Exclusion Criteria for Program Evaluation Participants:* The caregivers to be included in program evaluation must be the primary caregivers, identified by providing at least four to eight hours of care daily, five days per week, as well as be the primary individual attending all four PATCH Program sessions and GT-related clinic/office visits. The reasoning for this is that caregivers need to be present for both the PATCH Program and GT follow-up visits to be able to complete program outcome measures and to answer survey questions based on actual program participation. The exclusion criteria for involvement in the program evaluation includes having a child with a GT and a secondary medically complex or chronic condition, including but not limited to neurodevelopmental and/or neurodegenerative disease, chronic musculoskeletal diseases, asthma, or diabetes. The reasoning for this is that caregiver responses may not accurately represent only their perceptions and experiences with GT management, but rather may be influenced by their experiences managing another

pediatric chronic health condition as well.

Program Evaluation Questions

Following is a table outlining key questions the program evaluation intends to answer. The questions are organized based on the information needs and priorities of primary stakeholders.

Table 2: Program Evaluation Questions

Stakeholder	Program Evaluation Question
Caregivers and families of children with GTs	<ul style="list-style-type: none"> • Will I feel more confident in my ability to manage and problem-solve my child's GT care? • Will my child be healthier (i.e., less complications, less emergency department visits or hospital stays) as a result of my participating in this program?
Interdisciplinary team delivering the program	<ul style="list-style-type: none"> • Is the home management program achieving desired outcomes (i.e., increased caregiver self-efficacy, decreased hospital rates of pediatric GT-related emergency department visits and hospital readmissions)? • Are participants satisfied with program components (i.e., organization, delivery, activities, lessons, resources, etc.)? • Are there any program components that need to be modified to better serve the priority population? • What is the perceived value that caregivers gain from participation in this home management program?
Hospital administrators, funding sources, and sponsors	<ul style="list-style-type: none"> • Do program benefits justify the cost? • Is the program leading to a decrease in pediatric GT-related emergency department visits and hospital readmissions?

Program Evaluation Design and Methods

A comparison group design consisting of an intervention group and a control group will be utilized. At the time of the child's hospital discharge, caregivers who received standard care (i.e., established hospital GT education protocol), who meet program evaluation inclusion criteria, and who consented to participation in both the PATCH Program and program evaluation will be randomized to one of two groups: (1) intervention group participating in the PATCH Program and (2) waitlist control group. This randomized comparison group design was chosen based on its utility in providing an estimation of the impact of program participation on desired outcomes, as well as its feasibility given the hospital setting. The use of a waitlist control group is also ethically appropriate to ensure that no caregiver who may benefit from participation in the home management program is denied program access, as all waitlisted individuals will subsequently receive the intervention at a later date.

As previously described, data for both intervention and control groups will be collected based on an interrupted time-series design, such that the measure being utilized to assess caregiver-perceived self-efficacy will be administered pre-program approximately one week prior to program start, immediately post-program at the conclusion of the final session, and again post-program one month after program completion. The repeated measurement of both intervention and control group participants allows for determinations to be made regarding whether pre- to post-program change occurred for caregiver-perceived self-efficacy and whether change followed an upward or downward trend. Additionally, repeated administration of measures post-

program helps indicate whether changes in self-efficacy were sustainable long-term.

Planned Approach for Data Gathering

A combined approach to data collection incorporating both quantitative and qualitative methods will be utilized within the program design as described. Following is a detailed overview regarding the plan for quantitative and qualitative data collection:

- *Quantitative Data Collection:* Quantitative methods to be applied include use of past and present hospital data to calculate mean rates of pediatric GT-related emergency department visits and hospital readmission rates retrospectively and for the home management program participants involved in the program evaluation. A program-specific adapted version of the General Self-Efficacy Scale (GSE; Schwarzer & Jerusalem, 1995), which utilizes a Likert-scale rating system to describe the extent to which caregivers agree or disagree with posed statements, will also be used to collect quantitative data. This program-specific adapted version of the GSE (see Appendix C) will consist specifically of statements related to caregiver confidence with GT care skills and problem-solving. The adapted GSE will be converted into an electronic form and administered to intervention and control group individuals pre- and post-program via hospital-owned electronic tablets and/or desktop computers. The post-program surveys will also incorporate Likert-scale style questions, which will be used primarily to gather formative data related to whether or not participants liked program features (e.g., location, time of session, duration) and found content (e.g., lessons, learning activities) to be useful. These post-program surveys (see

Appendix D) will be administered only to intervention group individuals during the final home management program session via hospital-owned electronic tablets and/or desktop computers.

- *Qualitative Data Collection:* The qualitative methods to be applied include post-program survey inclusion of open-ended questions related to program strengths and weaknesses, areas for improvement, and value or impact of the program on participants' daily lives and ability to manage children's GT care. Follow-up semi-structured interviews will also be conducted with intervention group individuals to acquire a more in-depth understanding of their perceptions regarding program strengths/weaknesses, effectiveness, and overall value. As noted previously, semi-structured interviews will be completed with program participants one month after program completion during a required GT follow-up clinic or office visit. The reasoning for this is to allow participants a sufficient period of time after program completion to incorporate skills and knowledge learned into their daily lives and to subsequently experience the impact of the program on their daily lives and routines. As a result, participants may be better able to answer interview questions as they will have a longer time period from which they can draw examples of how the program influenced their daily lives, routines, GT care skills, and GT care confidence. Additionally, delaying the semi-structured interviews provides an opportunity for learning whether the program was effective in promoting increased caregiver-perceived self-efficacy that was sustainable by the participant even after program completion. See Appendix E for

a sample of questions to be addressed during this semi-structured interview.

Data Analysis and Reporting

As discussed previously, pre-program hospital mean rates for pediatric GT-related emergency department visits and for GT-related hospital readmissions will be calculated by a data analyst prior to program evaluation start. At the end of the four-week PATCH Program, this same data analyst will utilize individual chart review for each of the children whose caregivers participated in the home management program to identify frequency of these negative GT outcomes. Using these frequencies, a home management program group mean for GT-related emergency department visits and hospital readmissions will be calculated. Using a single-sample t-test, the data analyst will then be able to compare the home management program group means to the corresponding pre-program hospital means. This can serve to indicate whether the home management program may have influenced change or no change in hospital rates of negative GT outcomes from pre- to post-program.

The quantitative data obtained via survey Likert-scale questions will be subject to basic statistical analysis to identify the percentage of participants who responded positively (i.e., Strongly Agree, Agree), negatively (i.e., Strongly Disagree, Disagree), and/or neutrally (i.e., Neutral, Neither), as well as the frequency with which these responses occurred. A comparison of the different response percentages and frequencies obtained indicates whether more or less participants felt a specific way about program components, lessons, and/or activities. Additionally, this use of descriptive statistics provides a summary of the data that can be translated into visual representations (e.g.,

charts, graphs) that may be more easily understood by program stakeholders.

The quantitative data obtained via the program-specific adapted version of the GSE will be analyzed using inferential statistics, which allow for examination of differences and relationships between the intervention and control groups. Three adapted GSE score means will be calculated for the intervention and control groups: pre-program mean, immediate post-program mean, and one month post-program mean. A t-test will be conducted for each of the three sets of means to determine statistically significant difference between intervention and control groups at each of the three specified time periods. A comparison of the post-program means will be especially useful for indicating whether participation in the home management program led to significantly different outcomes than the waitlist condition. A regression analysis may also be employed to indicate correlation between participation in the home management program and scores on the program-specific adapted version of the GSE. As noted previously, the same hospital data analyst who performed the retrospective hospital data analysis will also perform the quantitative data analyses.

The qualitative data obtained via semi-structured interviews and survey open-ended questions will be subject to content analysis as a means for identifying recurrent and overarching themes expressed by program participants in the areas of personally experienced program impacts and perceived areas for improvement. As noted previously, a hospital-employed data analyst trained in qualitative data analysis methods will be responsible for coding, categorizing, and interpreting the information gained through survey and semi-structured interview.

Enumerative methods will be employed when analyzing data obtained from survey and semi-structured questions eliciting participant opinions regarding program strengths, weaknesses, and areas for improvement. Through enumerative analysis, the frequency with which specific topics or ideas are expressed can be identified and displayed visually for stakeholders through a graph or chart. A benefit of this is that topics most frequently addressed by participants may signify areas of greatest importance to maintain or modify, therefore providing guidance to program stakeholders when making decisions for program development and allocation of resources.

Hermeneutic methods, specifically thematic analysis, will be employed when analyzing semi-structured interview and survey question responses regarding perceived impact of the program on personal lives, abilities, and confidence. Predetermined data categories developed from the self-management program literature and Bandura's social cognitive theory (1977) will be used to guide the data analyst's initial categorization of data. Examples of predetermined categories to be included are as follows: (1) increased confidence, (2) increased competence, (3) decreased feelings of fear and/or anxiety, (4) knowing how to access resources, and (5) knowing how to problem-solve unexpected events. However, the data analyst will also have the freedom to develop additional categories as they emerge from the data. This is to ensure that data categorization is not limited to labels that do not appropriately match or convey their meaning. Through an iterative process of data analysis and categorization, the data analyst will identify patterns of similarities or differences, developing additional categories as necessary. The relationships between varying categories will also be identified, such that greater

overarching themes may be identified to summarize the qualitative data obtained. While the data analyst will be responsible for completing qualitative data analysis, input from the COTA who conducted the semi-structured interviews will be sought out to confirm or suggest categories not previously predetermined or considered. Additionally, the data analyst will have electronic access to scanned copies of the COTA's written field notes, providing the data analyst with further information to guide data coding, categorization, and interpretation.

Program Evaluation Data Management Plan

As previously discussed, all program outcome measures will be administered during required GT-related clinic and/or office visits via hospital-owned electronic tablets and/or desktop computers. The use of an electronic data collection system allows for quick and efficient uploading of caregiver-reported responses immediately after outcome measure completion via the internal hospital network. The clinic receptionists will be cued by the Epic medical records and documentation database to provide the outcome measure to program participants via electronic tablet or desktop computer based on the previously described timeline, such that when intervention and control group program participants sign into clinic, an alert appears on the screen indicating inclusion in the program evaluation. The clinic receptionists will also be trained to answer potential questions regarding the purpose of the measure and to provide objective clarification of measure questions if needed. Upon caregiver submission of the completed outcome measure, data will be routed to a hospital-owned internal drive specifically created for access and use by the PATCH Program data analyst team. During data routing, each

participant's submitted data will receive a unique numerical identifier code that will remain constant across all measures and surveys completed by that individual. Within the internal drive, data will be organized based on this identifier code and the date it was submitted. This de-identifies the information submitted and also allows data analysts to clearly see when data was submitted, such that the earliest date would indicate pre-program measure data and the latest date would indicate one-month post-program measure data.

Post-program participant surveys will also be administered via hospital-owned electronic tablets or desktop computers during the final program session. Program personnel delivering the final program session will be trained on how to objectively describe the purpose of the survey and to clarify questions appropriately. The data and information from these surveys will also be uploaded to the program evaluation internal drive utilizing the same data submission, organization, and storage procedures as were described for the program outcome measures.

Semi-structured interviews will be recorded via audio recorder by the same COTA completing the interview. The COTA will be trained on how to appropriately use and troubleshoot the audio recorder. He or she will be instructed and trained on how to upload each participant's complete audio file to the same program evaluation internal drive, as well as how to label the audio file so that data analysts accessing the internal drive clearly recognize that the audio file is separate from the data obtained for the program outcome measures and post-program participant surveys. Additionally, any field notes written by the COTA during interviews will be electronically scanned, uploaded to

the program evaluation internal drive, and labeled to match the corresponding participant audio file.

Conclusion

This chapter presents a plan for PATCH Program evaluation, data collection, data analysis, and data management. The PATCH Program evaluation aims to address the following objectives: (1) demonstrate program efficacy for increasing caregiver self-efficacy and reducing facility rates of pediatric GT-related emergency department visits and hospital readmissions and (2) identify program areas for improvement. The PATCH Program evaluation plan presented in this chapter utilizes both quantitative and qualitative methods to ensure that evaluation is comprehensive and captures both objective and subjective outcomes. Data analysis and management for the PATCH Program presented in this chapter relies significantly on the organizational structure and resources of RCHSD. The PATCH Program evaluation, if conducted at a facility other than RCHSD, would need to modify the above evaluation plan and timeline to best fit available resources, organizational culture, and facility protocol.

CHAPTER FIVE – Funding Plan

Introduction

The PATCH Program: Promoting and Teaching Confidence for the Home is a home management program that empowers caregivers of children with gastrostomy tubes (GTs) to develop the necessary confidence and skills to effectively manage and problem-solve the care needs of their children with GTs. The PATCH Program achieves this through an integrated formal education and skills training approach delivered via group-based sessions occurring after the child with a GT has been discharged from the hospital post-GT placement. The evidence-based literature regarding pediatric post-surgical GT outcomes identified a gap in family-centered, efficacy-promoting GT education and training initiatives. The PATCH Program addresses this gap and serves as a bridge between inpatient-based GT education and post-discharge follow-up services. By enhancing caregiver self-efficacy and GT care skills needed to care for the child with a GT in the home, the PATCH Program will reduce facility rates of pediatric GT-related hospital readmissions and emergency department visits following the child's hospital discharge.

As discussed in Chapter 4, the PATCH Program has not yet been implemented in a clinical setting. It is likely that the author's current place of employment, Rady Children's Hospital-San Diego (RCHSD), a large Level I pediatric hospital, will be the first location to launch the PATCH Program. A multi-year funding plan outlining available resources, associated program costs, and anticipated sources of funding is outlined in this chapter

Available Facility and Community-Based Resources

As stated, RCHSD will likely serve as the introductory site for the PATCH Program. The author and program developer is currently employed by RCHSD as an occupational therapist, allowing access to RCHSD facilities and on-site resources. Additionally, the author has cultivated partnerships with and developed a personal network of San Diego-based businesses and creative professionals. These partnerships offer additional access to in-kind services that can assist with off-setting program costs. The available facility and community resources are outlined as follows:

RCHSD Resources and Services

- **Conference Room:** The hospital has a number of available conference rooms at the main campus and at satellite sites. All conference rooms are equipped with chairs and tables. If given advanced notice, facility staff are also available to assist with room set-up and acquisition of additional furniture if needed. Once hospital approval to conduct the program is acquired, the author can reserve a weekly conference room to host the program sessions.
- **Audiovisual (AV) services:** A number of conference rooms in the main hospital are equipped with dual monitors, laptop connection capability, and Zoom video and microphone access. If these conference rooms are not available, then additional conference rooms with pull down screens and projection/audio equipment may also be reserved to host the program sessions.
- **GT simulation and training kits:** These kits consist of a baby doll with a GT, tubing, clamps, and syringes. These kits were developed as part of a hospital-wide

initiative to improve pre- and post-surgery GT education and training. Kits are owned by the hospital and are stored on inpatient nursing units, including but not limited to the neonatal intensive care unit (NICU) and cardiovascular intensive care unit (CVICU). The author can arrange to use these kits during program sessions through collaboration and communication with the nursing coordinators and managers responsible for monitoring and distributing the kits.

- **Printing and copying services:** Once hospital approval is acquired to host the program on site, then the author can collaborate with the Developmental Services, Gastroenterology, and/or General Surgery Departments, all of which are involved with the care and treatment of GT surgery patients, to print and copy program booklet pages, session handouts, and worksheets.
- **Web, phone, and fax services:** Once hospital approval to conduct the program on site is obtained, the author can utilize the facility's phone, web, and fax services to contact program participants, program co-facilitators, and community-based businesses and partners.
- **Professional collaboration with healthcare providers:** As an employee of RCHSD, the author has access to a variety of healthcare professionals involved in the care and treatment of children with newly placed GTs. These professionals include gastroenterology physicians, general surgeons, nurse practitioners, bedside nurses, nursing managers/coordinators, dietitians, and social workers. Through her daily work and involvement with hospital-based clinics, the author has developed professional relationships with a number of these individuals. As a result, the

author is able to reach out to these individuals to learn additional strategies for GT home management, to brainstorm program ideas, to obtain assistance with recruiting participants, and to find co-facilitators for weekly sessions. The knowledge and support that can be garnered from these professional collaborations is invaluable to ensuring that the program adopts a comprehensive approach to supporting caregivers of children with GTs.

Community-based Resources and Services

- **Web design and social media management:** The author has developed personal relationships with individuals currently or previously employed as webmasters or computer engineers. These individuals have a wide range of talents, including but not limited to web design, coding, and website data analysis and management. Additionally, the author has developed relationships with public relations professionals who have experience with marketing and social media management. The author can collaborate with these individuals to obtain either in-kind consulting or assistance with creating a web platform accessible to program participants and intended to provide supplemental educational resources and materials. Additionally, the author can collaborate with these professionals to develop an effective dissemination plan that accounts for the intended trajectory of the program.
- **Photography and video services:** Program materials will benefit from high-resolution images of GT equipment and care skill performance. The author has developed personal relationships with San Diego-based professional

photographers and videographers. The author can collaborate with these individuals to curate a photo shoot to obtain these images. Additionally, videographers can assist in creating and editing program-specific videos to supplement live sessions.

- Food donation: The author has developed personal and professional relationships with a network of restaurant and food service vendors. The author can collaborate with these contacts to obtain food donations, both pre-packaged and catered, that can be served to program participants during weekly sessions. These food donations are beneficial to the program as they incentivize enrollment and participation, as well as demonstrate a consideration for the time and effort that participants are investing to participate in the program.

Program Expenses

Table 3 presents a detailed overview of the expenses anticipated for the PATCH Program during its first three years of operation. It is important to note that the funding plan presented here adopts the following assumptions: (1) RCHSD will serve as the primary site of operation during the PATCH Program's first year, (2) costs reported will be for one occurrence of the PATCH Program, which translates to four weekly sessions with a maximum of 12 participants, and (3) the author will expand the PATCH Program and make it available to outside facilities. When the PATCH Program is conducted within RCHSD and the San Diego area, a number of first year costs related to printing, copying, GT simulation dolls, etc. will not need to be accounted for as the hospital will provide these as discussed in the previous section. The second-year budget presented

focuses primarily on the costs that an outside facility separate from RCHSD would need to consider if they are to implement the PATCH Program at their site.

Table 3: Projected Two-Year Financial Budget for the PATCH Program

Budget Item	First Year Costs <i>Implementation at RCHSD</i>	Second Year Costs <i>Implementation at Outside Facility</i>
<i>Personnel</i>	<ul style="list-style-type: none"> • Lead occupational therapist - direct program time (i.e., program planning, preparation, execution): 40 hrs./4 weeks x \$36.11/hr. = \$1,444.40 • Lead occupational therapist - indirect program time (i.e., grant-writing): 20 hrs./4 weeks x \$36.11/hr. = \$722.20 • Assisting certified occupational therapy assistant (COTA): 10 hrs./4 weeks x \$32.72/hr. = \$327.20 <p><i>Total Personnel Cost: \$2,493.80</i></p> <p>The lead therapist will dedicate approximately 40 hours over four weeks of the program to planning, material preparation, session execution, and debriefing. The lead therapist will also dedicate approximately 20 hours</p>	<ul style="list-style-type: none"> • Lead occupational therapist - direct program time (i.e., program planning, preparation, execution): 40 hrs./4 weeks x \$40.00/hr. = \$1,600.00 • Lead occupational therapist - indirect program time (i.e., grant-writing): 20 hrs./4 weeks x \$40.00/hr. = \$800.00 • Assisting certified occupational therapy assistant (COTA): 10 hrs./4 weeks x \$28.51/hr. = \$285.10 <p><i>Estimated Total Personnel Cost: \$2,685.10</i></p> <p>According to the Bureau of Labor Statistics (2018), the median hourly wages for an occupational therapist and a certified occupational therapy assistant in 2017 was \$40.00 and \$28.51 respectively. This serves as an estimate of the cost associated with having an occupational</p>

	<p>in total to grant-writing; this is a necessary task to ensure that funds are available to cover program expenses and therapist time related to this should be compensated. The lead therapist will likely only need to dedicate 20 hours to grant-writing once or twice per year; this will be reflected in the total yearly budget for the program.</p> <p>The COTA will dedicate 10 hours over the four weeks to assisting with session execution and preparation. Although the purpose of the PATCH Program aligns with the mission and purpose of RCHSD, participation in the development and execution of this program is considered separate from employee responsibilities. Therefore, RCHSD will be unable to pay for clinician time dedicated to the program.</p>	<p>therapist implement the program if his or her site of employment is unable to pay for the clinician time involved.</p>
<p><i>Consultants</i></p>	<p><u>Program Co-Facilitators</u> (PayScale, 2018a; 2018b; 2018c)</p> <ul style="list-style-type: none"> • Medical social worker: 2 hrs. x \$29.62/hr. = \$59.24 • Nurse practitioner: 2 hrs. x \$49.48/hr. = \$98.96 • Registered dietician: 2 hrs. x \$25.78/hr. = \$51.56 	<p><u>Program Co-Facilitators</u> (BLS, 2018)</p> <ul style="list-style-type: none"> • Healthcare social worker: 2 hrs. x \$26.38/hr. = \$52.76 • Nurse practitioner: 2 hrs. x \$49.94/hr. = \$99.88 • Registered dietician: 2 hrs. x \$28.56/hr. = \$57.12

	<p><u>Additional Consultants</u></p> <ul style="list-style-type: none"> • Webmaster: \$300/month for 5 hrs. of work (The Webmaster Company, 2018) <p><i>Total Consultant Cost: \$509.76</i></p> <p>Each co-facilitator listed above will assist with caregiver education and training during one designated 2-hour program session. The co-facilitators will likely be RCHSD employees. However, the cost of their time is separate from current employee responsibilities and will need to be accounted for. The author has access to webmasters who may provide services and consultation free of charge. However, the cost of a webmaster has been included in the event that the author's personal connections are unable to assist.</p>	<p><u>Additional Consultants</u></p> <ul style="list-style-type: none"> • Webmaster: \$300/month for 5 hrs. of work (The Webmaster Company, 2018) <p><i>Estimated Total Consultant Cost: : \$509.76</i></p> <p>Co-facilitator hourly compensation is presented above as indicated by the BLS (2018). This serves as an estimate of the cost associated with including these individuals in program delivery if the outside facility is unable to pay for the clinician time involved. If the outside facility chooses to incorporate a website for sharing supplemental resources, it will need to account for the costs of a webmaster as well.</p>
<p><i>Equipment</i></p>	<ul style="list-style-type: none"> • GT practice kits (includes doll with GT, tubing, clamps, syringes, and laminated instructional materials) x 4: \$0.00 • Audiovisual equipment: \$0.00 <p><i>Total Equipment Cost: \$0.00</i></p> <p>RCHSD owns multiple GT practice kits that can be utilized</p>	<p>GT Practice Kit = \$615.16 each</p> <ul style="list-style-type: none"> • Doll with GT (3B Scientific, 2018): \$464.00 • Feeding tube kits (includes tubing, clamps, and syringes; Vitality Medical, 2018): \$136.19 • Printed and bound instructional materials (FedEx Office, 2018): \$14.97 for 7 pages <p>Audiovisual equipment = \$499.98</p>

	<p>during PATCH Program sessions. Additionally, the hospital is equipped with either built-in or portable conference room AV equipment. Given this, there is no cost associated with equipment for the first year.</p>	<ul style="list-style-type: none"> • Portable projector (Dell, 2018): \$349.99 • Portable projection screen (Dell, 2018): \$149.99 <p><i>Estimated Total Equipment Cost (4 GT Kits and AV Equipment):</i> \$2,960.62</p> <p>GT practice kits are essential to providing caregivers with an opportunity to engage in hands-on skill training and to build confidence in completing care skills. AV equipment enhances caregivers' learning experience and allows for the application of multimodal teaching methods. If an outside facility does not currently have its own GT practice kits or AV equipment, then the facility will need to purchase these.</p>
<p><i>Supplies</i></p>	<ul style="list-style-type: none"> • Printed handouts, worksheets, and resources: \$0.00 • Participant handbooks (color print and bound in individual binders; FedEx, 2018): \$20.00 each, \$240.00 for 12 participants <p><i>Total Supplies Cost: \$240.00</i></p>	<ul style="list-style-type: none"> • Printed handouts, worksheets, and resources: \$0.06 per black and white page; \$0.30 per colored page. Recommended total budget of \$100.00 for 4 weeks • Participant handbooks (color print and bound in individual binders; FedEx, 2018): \$20.00 each; \$240.00 for 12 participants <p><i>Estimated Total Supplies Cost:</i> \$340.00</p>

<p><i>Rental of facilities</i></p>	<ul style="list-style-type: none"> • Hospital conference room: \$0.00 <p><i>Total Facility Rental Cost: \$0.00</i></p> <p>RGHSD has multiple conference rooms at its main and satellite sites. These can be reserved for program sessions free of cost.</p>	<ul style="list-style-type: none"> • Facility Program Space = Varies depending on site. Recommended budget of \$150-200 per week. <p><i>Total Facility Rental Cost: \$600-800 for 4 weeks</i></p> <p>It is likely that an outside facility, such as a hospital, healthcare center, or community center will have access to an on-site conference room or programming space. However, in the event that the facility does not have a space to use, it is recommended that the above estimate be included in the program budget to provide for a program space.</p>
<p><i>Other expenses</i></p>	<ul style="list-style-type: none"> • Website domain cost (Google, 2019): \$12/month for .com address • Food: \$100 per week <p><i>Total Other Expenses Cost: \$412.00</i></p> <p>Although the author has connections with food vendors, a budget for food to be provided to participants during the session has been included in the event that vendors are unable to provide donations. The cost of a Google website has also been included to account for a program-specific</p>	<ul style="list-style-type: none"> • Website domain cost (Google, 2019): \$12/month for .com address • Food: \$100 per week <p><i>Estimated Total Other Expenses Cost: \$412.00</i></p>

	webpage with supplemental learning materials and resources.	
<i>Total Cost per 4-week PATCH Program</i>	\$3,655.56	\$7,707.48
<i>Estimated Yearly Cost to Implement PATCH Program (12 monthly occurrences)</i>	\$36,644.72 Note: This estimate takes into consideration that the lead occupational therapist will only need to participate in grant-writing two times per year.	\$51,922.94 Note: This estimate takes into consideration that the lead occupational therapist will only need to participate in grant-writing two times per year. Additionally, this estimate takes into consideration that GT kits and AV equipment will only need to be purchased once.

Potential Funding Sources

Table 3 presented an overview of the budgets needed to implement the PATCH Program at the author's current site of employment, RCHSD, as well as at an outside facility that may not have access to the same resources or services available to this author. Table 4 presents a listing and description of applicable funding sources that can be pursued to cover program costs. The funding sources were identified based on their relevance to funding the PATCH Program at the author's current site of employment, RCHSD. However, some of the identified funding sources may also be pursued by outside facilities if they meet the requirements.

Table 4: Funding Sources Applicable to PATCH Program Implementation at RCHSD

Funding Source	Description	Monetary Value
Alliance Health Education Initiative (AHEI) Health Grant	<p>AHEI provides grant money to community initiatives and projects dedicated to promoting community health education. AHEI requires that applying programs be endorsed by a local physician. Additionally, AHEI encourages projects to collaborate with local medical organizations and/or hospitals to promote health-related collaboration (Alliance Health Education Initiative [AHEI], 2019).</p> <p>The PATCH Program qualifies for this grant as it will be affiliated with a healthcare facility as discussed above. Additionally, the author will collaborate with general surgery and gastroenterology physicians to ensure that caregiver education and training is comprehensive. These physicians may serve as the endorsing individuals for the grant application. Given the monetary value of this grant, funds acquired through this grant would most likely be applied towards direct program costs associated with printing and compiling participant materials and workbooks.</p>	Up to \$2,500 for direct program costs
California Health Care Foundation (CHCF) Grant	CHCF is dedicated to advancing and improving healthcare services and health access for the people of California. CHCF grants are awarded to California-based programs or initiatives that align with at least one of the foundation's three program goals: (1) improving	Up to \$150,000 for a one to two-year period

	<p>access to coverage and care, (2) promoting high-quality care, and (3) laying the foundation through market analysis, health journalism, leadership development, and/or health system innovation (California Health Care Foundation [CHCF], 2019).</p> <p>The PATCH Program aligns with the goal of promoting high-quality care by improving the health home management skills of caregivers and reducing negative outcomes among children post-GT placement. Funds acquired through CHCF are able to be applied towards both direct (i.e., personnel and benefits, materials, meeting costs) and indirect costs (i.e., general and administrative).</p>	
<p>Chronic Condition Self-Management in Children and Adolescents (R01 Clinical Trial Optional) Funding Opportunity</p>	<p>This funding opportunity is offered by the National Institutes of Health (NIH) and National Institute of Nursing Research (NINR). Its purpose is to fund research initiatives focused on improving the self-management of children with chronic health conditions and their families. This funding opportunity especially emphasizes the need for research initiatives that consider the various person, family, environment, and situation factors that influence effective self-management (National Institutes of Health [NIH], 2017). Within the literature, pediatric GT placement resulting in long-term enteral nutrition dependence has been considered a chronic health condition.</p> <p>The PATCH Program aligns with the goals of this funding opportunity by focusing on parent education and empowerment that leads to improved management</p>	<p>Up to \$275,000 for a two-year period</p>

	<p>of the children’s GT care. Additionally, the PATCH Program adopts a family-centered approach to addressing pediatric GT home management that considers and respects the multitude of unique familial, environmental, and contextual variables that can affect the child and family’s ability to manage GT care. Funds acquired through this opportunity would be allocated towards program and personnel costs, as well as costs associated with implementing a program evaluation plan to determine the effects of program participation on caregiver-perceived self-efficacy and facility rates of pediatric GT-related emergency department visits and hospital readmissions.</p>	
<p>The San Diego Foundation (TSDF) Grants</p>	<p>TSDF offers a number of grants throughout the year to fund programs and initiatives that serve and advance the San Diego community. TSDF aims to improve the quality of life for San Diego residents in a variety of social impact areas, including Health & Human Services (The San Diego Foundation [TSDF], 2019).</p> <p>The PATCH Program aligns with the goals of the Health & Human Services impact area: to provide effective services and to advance services that protect the health and well-being of San Diego individuals (TSDF, 2019). No active Health & Human Services grants exist at this time. However, this can change throughout the year as grants and calls for proposals are released at various times and intervals.</p>	<p>Variable, dependent on the specific grant offering at the time</p>

Conclusion

Presented in this chapter is an outline of anticipated costs associated with implementing the PATCH Program at the author's current facility of employment, as well as at an outside facility. The greatest costs for the program can be seen in personnel, or those costs associated with the time and labor dedicated by the facilitating and co-facilitating healthcare professionals. Potential sources for funding were chosen and reviewed in Table 4 given their applicability to the PATCH Program and their ability to fund program costs related to personnel, materials, and equipment. PATCH Program costs and funding opportunities are likely to change and evolve over time. As a result, financial considerations discussed in this chapter will need to be reviewed and modified as needed to ensure that estimations and funding sources remain consistent with program needs and growth.

CHAPTER SIX – Dissemination Plan

Introduction

The PATCH Program: Promoting and Teaching Confidence for the Home is a home management program designed to empower and enable caregivers of children with gastrostomy tubes (GTs) to effectively manage and problem-solve the care needs of their children with GTs. Drawing from the evidence-based literature regarding self-efficacy enhancement and parent education, the PATCH Program adopts a combined formal education and interactive skills training approach to support caregivers in acquiring the necessary knowledge and skills needed for successful GT home management. Through a group-based delivery format, the PATCH Program creates a communal and supportive context that allows participants to learn from and grow with peers.

The PATCH Program is unlike other programs that have been developed to support parents of medically complex children. Its distinct value comes from its occupational therapy roots. Developed by a pediatric occupational therapist, the PATCH Program adopts a strong family-centered perspective that honors the unique skills and goals of all participants involved. Through an occupational therapy lens, the PATCH Program acknowledges that successful GT home management is a product of careful consideration regarding an individual's environmental, contextual, familial, and personal circumstances. Through this occupational therapy approach, the PATCH Program goes further than to offer solutions; it empowers caregivers of children with GTs to competently and confidently problem-solve and create solutions that best fit their needs.

As discussed in previous chapters, Rady Children's Hospital - San Diego

(RCHSD) will likely be the first site to implement the PATCH Program as this is the author's current place of employment. The dissemination plan discussed in this chapter presents an overview of goals, target audiences, dissemination activities, and budget. As will be discussed further, dissemination of the PATCH Program will be focused on within hospital communication for the first two to three years of the program before transitioning to dissemination of the PATCH Program beyond the hospital.

Dissemination Goals

RCHSD is a large Level I pediatric hospital system offering a wide variety of inpatient, outpatient, and community-based services within the San Diego area. During the first two to three years after the PATCH Program has been initiated, dissemination will focus primarily on communicating the program's purpose and benefits to RCHSD healthcare professionals and to caregivers of children undergoing GT placement at RCHSD. It is anticipated that after these initial two to three years, the focus of program dissemination can then shift towards communicating the program's existence, purpose, and benefits to the greater occupational therapy and healthcare-related field. While consideration will be given to the long-term plan for dissemination, the remainder of this chapter will focus primarily on the short-term dissemination of the PATCH Program within RCHSD.

Following are the goals related to the dissemination of the PATCH Program at both periods of time discussed.

Table 5: Goals for the Dissemination of the PATCH Program

Short-Term Goals <i>To be met by end the of the first 2–3 years</i>	Long-Term Goals <i>To be met by the end of years 3–5</i>
<ol style="list-style-type: none"> 1. At least 95% of RCHSD gastroenterology and general surgery physicians and nurse practitioners will have attended an in-service on the purpose and benefits of the PATCH Program. 2. At least 95% of RCHSD inpatient social workers will have attended an in-service on the purpose and benefits of the PATCH Program. 3. A one-sheet overview detailing the purpose of the PATCH Program along with upcoming session dates and times will be included in 100% of GT care binders provided to families following the child’s GT placement. 4. Social workers will recommend participation in the PATCH Program to caregivers of children with GTs prior to hospital discharge 90% of the time. 	<ol style="list-style-type: none"> 1. The author will submit an <i>OT Practice</i> article describing the PATCH Program’s application of occupational therapy principles in the management of pediatric GT care. 2. The author will submit a proposal to present either a poster or session at a symposium or conference of the Occupational Therapy Association of California (OTAC). 3. The author will submit a proposal to present either a poster or short session related to the PATCH Program to be presented at an annual conference of the American Occupational Therapy Association (AOTA). 4. The author will submit a research article for publication that describes the PATCH Program and results obtained through its evaluation plan.

Target Audience

The sustainability of the PATCH Program relies heavily on the support and participation of two main populations: (1) healthcare professionals responsible for treating children with GTs (e.g., general surgery and gastroenterology physicians, nurse practitioners, bedside nurses, social workers, dietitians, occupational therapists) and (2) caregivers of children with newly placed GTs or of children anticipated to receive GT placement. Both these populations will serve as the target audiences for the dissemination of the PATCH Program and its successes in achieving positive outcomes of improved caregiver self-efficacy and reduced facility rates of pediatric GT-related emergency department visits and hospital readmissions.

Healthcare professionals involved in the care of children with GTs and their families fulfill an integral role in promoting the PATCH Program to potential participants through verbal discussion and recommendations during pre- and post-surgical consults and care. Additionally, the support of these professionals adds credibility to the PATCH Program as an effective means for preventing negative pediatric GT outcomes. The dissemination of the PATCH Program to these healthcare professionals will focus on conveying the following key messages:

- *The PATCH Program is effective for reducing negative post-surgical outcomes of emergency department visits and hospital readmissions for children with newly placed GTs within the first 30 days following surgery.* This speaks to one of the primary goals of healthcare professionals involved in the care and monitoring of children with newly placed GTs, which is to ensure their health and wellness

following the procedure. Additionally, this emphasizes the role of the PATCH Program in reducing facility rates of preventable emergency department visits and hospital readmissions, a topic that has gained great attention and consideration due to changes in healthcare culture.

- *The PATCH Program is a distinct caregiver empowerment program rooted in occupational therapy principles and informed by the literature regarding self-efficacy enhancement and parent education/training.* This demonstrates the distinct value of the PATCH Program, establishing it as a unique initiative whose approach and related benefits cannot be obtained through other available methods.

The PATCH Program was designed specifically for caregivers of children with GTs, establishing this population as a primary audience for the dissemination of the PATCH Program's purpose and benefits. The dissemination of the PATCH Program to this audience is necessary to educate caregivers of children with GTs regarding the personal and familial benefits associated with participation in this program.

Dissemination of the PATCH Program to caregivers of children with GTs will focus on conveying the following messages:

- *The PATCH Program helps caregivers feel more confident about caring for their children with GTs.* This demonstrates the effectiveness of the PATCH Program in empowering participating caregivers to experience increased feelings of confidence in their ability to manage their children's GT care following hospital discharge. This message also speaks to the overwhelming or anxious feelings that caregivers of children with GTs may experience when learning how to integrate

their children's GT care into everyday routines.

- *The PATCH Program helps keep children with GTs healthy and decreases their chances of needing to visit the emergency room or be readmitted to the hospital after their surgery.* This message speaks to caregivers' goal of ensuring their children with GTs remain healthy following GT surgery. Additionally, it demonstrates the association between caregiver program participation and improved outcomes for children with GTs.

Influential spokespersons may assist in adding credibility to and spreading these key messages to each of the populations. Among healthcare professionals involved in the care of children with GTs, RCHSD general surgery and gastroenterology department chiefs can serve as spokespersons and program champions. These individuals are respected by their professional colleagues for their leadership skills and extensive experience in the field. Collaboration with each of these department chiefs can aid in garnering professional support for the continuation and promotion of the program, as well as in prompting assistance with additional participant recruitment.

Among caregivers of children with GTs, professional expertise and personal experience both hold significance. A general surgeon with a reputation for positive surgical outcomes with pediatric GT placements can serve as an influential spokesperson to convey key messages to caregivers of children with GTs. This individual can draw on their professional expertise to speak to the need for the PATCH Program, as well as to its effectiveness in promoting positive health and wellness outcomes for caregivers and their children with GTs. A caregiver of a child with a GT who has participated in the PATCH

Program and who has experienced positive benefits for their child's health and for their family's overall functioning following the program's completion can also serve as a spokesperson to convey key messages to fellow caregivers. Having personally participated in the program, this individual can attest to the effectiveness of the PATCH Program in promoting caregiver self-efficacy and empowering caregivers to independently problem-solve and manage their children's GT care needs following discharge. He or she can serve as a role model for fellow caregivers of children with GTs, conveying the key messages through their own experiences.

Dissemination Activities

A number of methods for dissemination of the PATCH Program are available through RCHSD. Program dissemination within RCHSD will occur through a variety of these outlets in an effort to ensure that the greatest number of individuals belonging to each of the target audiences is reached. Dissemination of the PATCH Program beyond RCHSD is also considered in this section. Planned dissemination activities for both within and outside RCHSD are outlined from highest priority to least priority as follows:

Dissemination Activities within RCHSD

- **Lunch-and-Learn in-service:** The facilitator will prepare and deliver a 45-minute in-service presentation for hospital administrators and department chiefs. This in-service will be paired with lunch to incentivize attendance and to better accommodate schedules of those individuals attending. During the presentation, the facilitator will discuss the program's purpose, format, activities, and outcomes. Emphasis will be given to explaining the association between PATCH

Program implementation and a reduction in facility rates of pediatric GT-related emergency department visits and hospital readmissions. All attendees will be provided with a copy of the Executive Summary (included at the end of this doctoral project).

- Presentations at departmental meetings: The PATCH Program facilitator will collaborate with hospital managers to arrange for a 20 to 30-minute presentation at a department-wide meeting. During this presentation, the facilitator will provide an overview of the PATCH Program's purpose, format, activities, and evaluation results. If the meeting space allows, the facilitator will utilize visuals including graphs, tables, and/or images of participant comments via PowerPoint presentation to assist in demonstrating program effectiveness. The facilitator will also provide printed handouts outlining the program's major outcomes.
- Informational meetings for caregivers of children with GTs: The facilitator will collaborate with a caregiver who has participated in the PATCH Program to host a weekly informational meeting for caregivers of children with newly placed GTs who are interested in participating in the program. The facilitator will describe PATCH Program activities and structure. The co-facilitating caregiver will speak from personal experience and share how the PATCH Program influenced his or her personal and familial health, wellness, and routines.
- Article in RCHSD email newsletter: The facilitator will write and submit a brief article outlining the PATCH Program's purpose and outcomes to be included in one of the hospital's weekly newsletters. This newsletter is distributed to all

hospital employees and contractors at the main campus and at satellite sites. The facilitator's contact information will be included within the article so that individuals seeking additional information may contact the facilitator at their convenience.

Dissemination Activities Outside of RCHSD:

- Publication in peer-reviewed journal: The facilitator will collaborate with program co-facilitators and the data analyst to co-author an article outlining the evaluation process and results of the PATCH Program. This article will be submitted for publication in a peer-reviewed journal to disseminate the overall results obtained from the PATCH Program's implementation. It is the goal that this publication will prompt other hospitals and healthcare professionals to consider implementing a similar program to meet the needs of caregivers of children with GTs.
- Poster or short session at an annual conference of the AOTA: The facilitator will submit a proposal to present a poster or short session to share the outcomes of the PATCH Program with fellow occupational therapists. The poster will focus primarily on communicating the positive effects of the PATCH Program as they relate to caregiver self-efficacy and to facility rates of pediatric GT-related emergency department visits and hospital readmissions. The short session will focus on briefly describing the PATCH Program structure and activities, evaluation plan, and overall outcomes.

- *OT Practice* article: The facilitator will write an article describing the PATCH Program and its unique approach to filling an identified gap in GT education and training initiatives. The *OT Practice* article will emphasize the distinct value that occupational therapy adds to this program, detailing the specific ways in which occupational therapy approaches or perspectives were applied through program format and activities.
- Poster or short session at OTAC Symposium or Conference: The facilitator will collaborate with the co-facilitating certified occupational therapy assistant (COTA) to submit a proposal to present a poster or short session at an OTAC Symposium or Conference. RCHSD is based in southern California and a presentation at the OTAC Symposium or Conference would be beneficial for disseminating the program's purpose and outcomes to occupational therapists representing facilities that may be close geographically to RCHSD. This OTAC Symposium or Conference presentation may lay the groundwork for future collaborations with other California-based facilities to implement the PATCH Program at their sites.

Dissemination Budget

The following table presents an overview of anticipated expenses associated with the dissemination of the PATCH Program. The expenses for the dissemination of the program both within and outside of RCHSD are presented. These expenses are separate from those detailed in the funding plan presented in Chapter 5. Total expenses are calculated as a yearly total.

Table 6: Projected Budget for Dissemination of the PATCH Program

Budget Item	Years 1–3 Costs <i>Dissemination at RCHSD</i>	Years 3–5 Costs <i>Dissemination outside of RCHSD</i>
<i>Personnel</i>	<ul style="list-style-type: none"> • Lead occupational therapist - direct time (i.e., departmental meetings, information sessions, lunch in-service): 5 hrs./month x \$36.11/hr = \$180.55 <p><i>Total Yearly Personnel Cost:</i> \$2,166.60</p> <p>It is estimated that on average, the lead occupational therapist will dedicate approximately 5 hours each month towards hosting and presenting at departmental meetings, caregiver information sessions, and lunch in-services. Although the mission of the PATCH Program aligns with that of RCHSD, participation in the dissemination of its purpose and outcomes is considered separate from employee responsibilities. Therefore, RCHSD will be unable to pay for clinician time dedicated to the program.</p>	<ul style="list-style-type: none"> • Lead occupational therapist - indirect time (i.e., poster and session preparation): 10 hrs./month x \$36.11/hr = \$361.10 • Assisting certified occupational therapy assistant (COTA): 5 hrs./month x \$28.51/hr = \$142.55 <p><i>Total Yearly Personnel Cost:</i> \$6,043.80</p> <p>It is estimated that on average, the lead occupational therapist and co-facilitating COTA will dedicate approximately 10 hours and 5 hours each month respectively towards preparing poster presentations, conference short sessions, and publication proposals. These tasks are separate from employee responsibilities and funding will need to be acquired to compensate for clinician time.</p>
<i>Supplies</i>	<ul style="list-style-type: none"> • Printed handouts and executive summaries: \$0.00 	<ul style="list-style-type: none"> • Printed 48” x 36” academic poster (FedEx, 2019): \$87.00 x 3 conferences = \$261.00

	<p><i>Total Yearly Supplies Expense: \$0.00</i></p> <p>As an RCHSD program, the PATCH Program has access to hospital printing services.</p>	<ul style="list-style-type: none"> • Printed presentation handouts: \$0.06 per black and white page; \$0.30 per colored page. Recommended total budget of \$100.00 per conference <p><i>Total Yearly Supplies Expense: \$561.00</i></p> <p>It is planned that the lead occupational therapist will attend three conferences each year.</p>
<p><i>Other expenses</i></p>	<ul style="list-style-type: none"> • Boxed lunches for in-service meeting: \$500 per meeting <p><i>Total Yearly Expense: \$2,000.00</i></p> <p>It is anticipated that the lead occupational therapist will host a quarterly lunch in-service meeting for departmental chiefs, managers, and hospital administrators. Quarterly meetings allow flexibility for individuals to attend, increasing the likelihood that more chiefs, managers, and administrators will attend.</p>	<ul style="list-style-type: none"> • AOTA Annual Conference registration fee (AOTA, 2019): \$650 • OTAC Symposium registration fee (OTAC, 2019): \$288 • OTAC Conference registration fee (OTAC, 2018): \$379 • Travel and lodging: Variable, although recommended budget is \$1,000 per conference for a total of \$3,000 per year <p><i>Total Yearly Expense: \$4,317.00</i></p> <p>It is anticipated that the lead occupational therapist will attend three conferences or symposiums a year to disseminate the PATCH program to other occupational therapists and healthcare professionals.</p>

<i>Estimated Yearly Cost to Disseminate the PATCH Program</i>	\$4,166.60	\$10,921.80
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Evaluation of Dissemination Efforts

An evaluation of the PATCH Program dissemination efforts will be guided by the short- and long-term goals stated at the beginning of this chapter. Table 7 details how each of the short-term goals related to dissemination of the PATCH Program within RCHSD will be objectively measured and how results will indicate dissemination success. Table 8 details how each of the long-term goals related to dissemination of the PATCH Program beyond RCHSD will be objectively measured.

Table 7: Evaluation of Dissemination Efforts Within RCHSD

Short-Term Goal	Method of Measurement
At least 95% of RCHSD gastroenterology and general surgery physicians and nurse practitioners will have attended an in-service on the purpose and benefits of the PATCH Program.	The lead occupational therapist will obtain from hospital administration a list of all currently employed RCHSD physicians and nurse practitioners within the general surgery and gastroenterology departments. The lead occupational therapist will then transfer this information to a master online spreadsheet. The lead occupational therapist will require all in-service attendees to complete a sign-in sheet at the start of each session. Following each in-service, the lead occupational therapist or assisting COTA will then mark off on the master online spreadsheet who has attended an in-service. At the end

	<p>of the year, a percentage of gastroenterology and general surgery physicians and nurse practitioners will be calculated as number of those who attended an in-service over total practitioners.</p> <p>Success will be determined by a percentage of 95% or higher.</p>
<p>A one-sheet overview detailing the purpose of the PATCH Program along with upcoming session dates and times will be included in 100% of GT care binders provided to families following the child's GT placement.</p>	<p>The lead occupational therapist will collaborate with the quality improvement team assigned to developing, reviewing, and finalizing the GT care binders to ensure that the PATCH Program one-sheet overview is included in the digital master copy of the binder. The master copy serves as the most current copy of all GT care binder revisions and additions. All GT care binder pages are printed from this master copy; therefore, inclusion of the PATCH Program overview as a page within this master copy ensures its inclusion in 100% of printed GT care binders.</p> <p>Success will be determined by inclusion of the one-sheet overview in the master digital copy of the GT care binder.</p>
<p>At least 95% of RCHSD inpatient social workers will have attended an in-service on the purpose and benefits of the PATCH Program.</p>	<p>The lead occupational therapist will obtain from hospital administration a list of all currently employed RCHSD inpatient social workers. The lead occupational therapist will then transfer this information to a master online spreadsheet. The lead occupational therapist will require all in-service attendees to complete a sign-in sheet at the</p>

	<p>start of each session. Following each in-service, the lead occupational therapist or assisting COTA will then mark off on the master online spreadsheet who has attended an in-service. At the end of the year, a percentage of inpatient social workers who have attended an in-service will be calculated as number of individuals who attended over total practitioners.</p> <p>Success will be determined by a percentage of 95% or higher.</p>
<p>Social workers will recommend participation in the PATCH Program to caregivers of children with GTs prior to hospital discharge 90% of the time.</p>	<p>At their first GT follow-up appointment, which is typically scheduled within the first week after hospital discharge, caregivers will be asked on an intake survey whether or not they were informed about the PATCH Program prior to their children's hospital discharge. They will also be asked to indicate from a series of choices who recommended the program to them. The percentage of caregivers who indicated a social worker informed them of the program prior to hospital discharge will be calculated from the total number of responses.</p> <p>Success will be determined by a percentage of 90% or higher for caregiver responses indicating a social worker informed them of the PATCH Program prior to hospital discharge.</p>

Table 8: Evaluation of Dissemination Efforts Outside of RCHSD

Long-Term Goal	Method of Measurement
The author will submit an <i>OT Practice</i> article describing the PATCH Program's application of occupational therapy principles in the management of pediatric GT care.	Success will be indicated by acceptance of the article for publication in an edition of <i>OT Practice</i> .
The author will submit a proposal to present either a poster or session at a symposium or conference of the Occupational Therapy Association of California (OTAC).	Success will be indicated by acceptance of either a poster or session at an OTAC Symposium or Conference. Further success will be measured by number of inquiries received during the symposium or conference from occupational therapists interested in implementing the PATCH Program at their sites.
The author will submit a proposal to present either a poster or short session related to the PATCH Program to be presented at an annual conference of the American Occupational Therapy Association (AOTA).	Success will be indicated by acceptance of either a poster or short session at an annual conference of the AOTA. Further success will be measured by number of inquiries received during the conference from occupational therapists interested in implementing the PATCH Program at their sites.
The author will submit a research article for publication in a peer-reviewed journal that describes the PATCH Program and results obtained through its evaluation plan.	Success will be indicated by acceptance of an article for publication in a peer-reviewed journal. Further success will be measured by number of online inquiries (e.g., email, ResearchGate contact, etc.) received from healthcare professionals interested in learning more about the PATCH

	Program and/or implementing the program at their sites.
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Conclusion

Outlined in this chapter is a plan for the dissemination of the PATCH Program both within Rady Children's Hospital-San Diego (RCHSD), the anticipated site of program initiation, as well as outside of RCHSD. In both contexts, dissemination targets two primary audiences: (1) healthcare professionals involved in the care of children with GTs and (2) caregivers of children with newly placed GTs. Dissemination key messages and activities consider the unique needs and perspectives of each of these populations in an effort to provide comprehensive, yet understandable information outlining the distinct purpose and benefits associated with participation in the PATCH Program. Priorities for dissemination may change as the program continues to be implemented; therefore, the plan outlined in this chapter is subject to revision as additional target audiences are identified or as novel dissemination outlets emerge.

CHAPTER SEVEN - Conclusion

A gastrostomy tube (GT), or G-tube, is a surgically placed tube that enables children who are unable or unsafe to eat a full diet by mouth to receive the nutrition needed for healthy growth and development (Russell et al., 2018). GT placement has been identified as the third most common non-cardiac inpatient surgical procedure performed within the pediatric population (HCUPnet, 2009). Despite being a relatively routine pediatric procedure, a recent study found that GT placement was associated with high rates of emergency department visits (8.6%) and hospital readmissions (3.9%) during the first 30 days after hospital discharge (Goldin et al., 2016). These frequent hospital readmissions and emergency department visits negatively impact not only the health of children with GTs, but also hold negative implications for the overall health, wellness, and participation of their caregivers and families as well. The physical, emotional, social, temporal, and financial demands associated with managing a child's GT care and complications increase caregiver stress and anxiety, as well as strain family dynamics and functioning (Franklin & Rodger, 2003; Hewetson & Singh, 2009; Russell et al., 2018).

While the origins of this problem are diverse and multifaceted, healthcare providers and families of children with GTs have commented on the failure of current GT education programs to adequately prepare and meet the needs of caregivers of children with GTs (Berman et al., 2017). GT education programs, completed either before or after surgery, are considered best practice for teaching caregivers the skills needed to manage and problem-solve the child's GT care after discharge from the hospital (Boullata et al.,

2017). However, healthcare providers and caregivers of children with GTs have called for greater efforts towards providing family-centered education and cultivating family empowerment within GT education and management initiatives (Berman et al., 2017; Franklin & Rodger, 2003; Russell et al., 2018). Despite there being an evident need for initiatives that recognize and address the needs of caregivers of children with GTs, there is a sparsity of literature regarding pediatric GT home management and more generally, education and support programs for caregivers of children with medically complex or chronic conditions.

The PATCH Program: Promoting and Teaching Confidence for the Home was developed to address this identified need and to contribute to the literature base regarding pediatric GT home management. The PATCH Program is an outpatient, group-based home management program for caregivers of children who have recently undergone GT placement and returned home. Through the use of a four-week integrated formal education and practical skills training curriculum, the PATCH Program aims to achieve the following outcomes: (1) increased caregiver self-efficacy with managing the child's GT care from pre- to post-program and (2) reduced facility rates of pediatric GT-related emergency department visits and hospital readmissions within the first 30 days after initial discharge home.

The PATCH Program lends its distinct value to its occupational therapy foundation, which recognizes and respects that pediatric GT home management is a highly individualized process shaped by the unique circumstances, routines, and values of each child and family. Theory-driven and evidence-based, the PATCH Program adopts a

family-centered care approach that goes beyond offering solutions. Rather, the PATCH Program empowers and enables caregivers to feel confident in their ability to apply learned skills to their daily routines, ultimately allowing them to problem-solve and create care solutions that best fit the needs of their children and families.

The PATCH Program offers an innovative approach to educating and supporting caregivers of children with GTs that adopts a strong family-centered perspective and values family empowerment. The PATCH Program is unique from current GT education and management programs because of its foundation in the field of occupational therapy. Occupational therapists are skilled and capable of providing family-centered psychosocial interventions within the context of health management programs to promote caregiver and familial empowerment, to enhance the child-caregiver relationship, and to support family involvement (Franklin & Rodger, 2003; Henton, 2018). The PATCH Program contributes to the literature regarding pediatric GT home management by demonstrating the distinct value occupational therapy offers to promoting caregiver self-efficacy with managing a child's GT care and to reducing negative outcomes for children with GTs and their families. Shaped by its occupational therapy roots, the PATCH Program provides an innovative approach to addressing the current gap in GT education and home management programs and to improving the overall health, wellness, and participation of children with gastrostomy tubes and their caregivers.

APPENDIX A: Individualized Family Interview Prompts

Family & Individual

1. Tell me about yourself.
 - What does a typical day for you look like?
 - What types of activities do you enjoy doing?
 - What roles do you have in your life that are important to you?
2. Tell me about your family.
 - How many people live with you? How are they related to you?
 - Do you have any other family members living nearby? Do you have any family members living farther away? Do you stay in contact? How do you stay in contact and how often?
 - Does your family help you with caring for your child?
 - What does your family value most?
 - What are your family's daily priorities?

Physical & Social Environment

1. Tell me about where you live.
 - Do you live close to this hospital?
 - Do you live close to an urgent care center or emergency room?
2. Tell me about how you get around outside of the house and in the community.
 - Do you use (a) private or (b) public transportation?
 - For (a), use the following questions:
 - Do you drive or does someone else drive you?
 - If someone else drives you, how flexible is their schedule? How often are they able to drive you? If they weren't able to drive you somewhere, how else would you get to where you need to go?
 - Do you own your car?
 - Is your car reliable?
 - For (b), use the following questions:
 - Is public transportation easy to get to and use?
 - Do you live close to a public transportation station or stop?
 - Do you need to walk a lot? How far do you typically walk?

Condition Specific

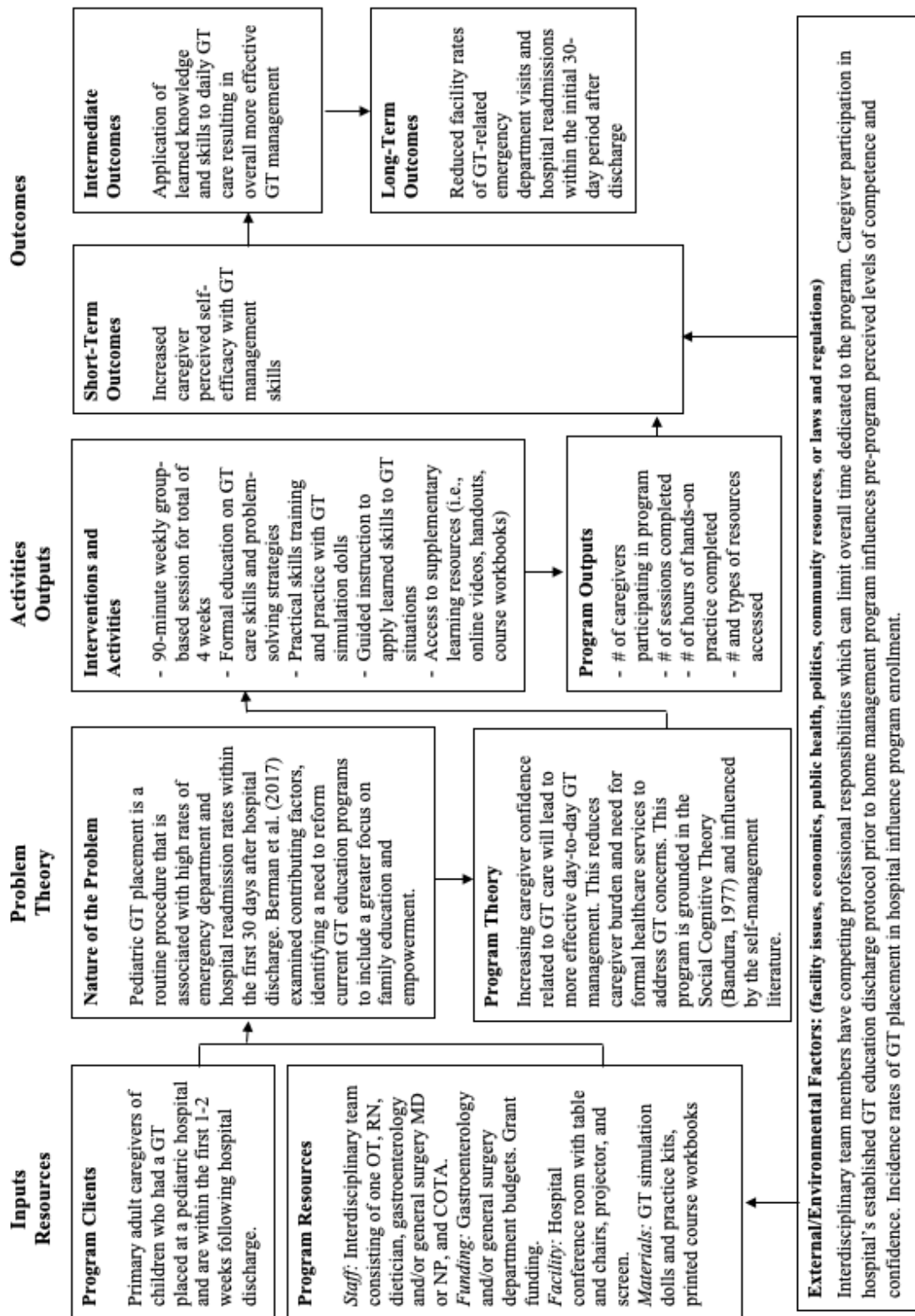
1. Tell me about why your child needed a gastrostomy tube (G-tube).
 - Does your child have any medical diagnoses or chronic conditions?

- Did your child have any type of feeding tube (e.g., NG, NJ, OG) before getting the G-tube?
 - Did your child ever have a swallow study under x-ray?
 - Did your medical team talk about if the G-tube is temporary?
 - If tube is temporary → Did your medical team talk about a plan for weaning your child from the tube?
2. Tell me about how your child is doing now that they have the G-tube.
- Have they had any complications since surgery?
 - Have you had to bring them to the doctor's office or the emergency room since discharge because you thought something was wrong?
 - Are they able to eat by mouth or do they only eat through the G-tube?
 - Is your child receiving any therapies (i.e., speech, occupational, physical, behavioral)?
 - What medical specialists (i.e., ENT, gastroenterology, genetics, etc.) are following your child?

Knowledge & Beliefs

1. Did you participate in any type of pre-discharge training or education for your child's G-tube?
2. Tell me about how you felt when you were told your child needed a G-tube. How do you feel now that your child does have a G-tube?
 - Are there any things you are nervous or stressed about with the G-tube?
 - Do you have any questions about G-tube care that you haven't had answered yet?
3. How much experience would you say you have when it comes to medical care and/or caring for a child with a G-tube?
4. How confident have you felt about managing your child's G-tube care needs since discharge?
 - Is there anything you don't feel confident doing?
 - Is there anything you wish you felt more confident about?

APPENDIX B: Logic Model of the PATCH Program



**APPENDIX C: Adapted Version of the General Self-Efficacy Scale (GSE) for Use
During the PATCH Program**

For each of the statements below, please select the level to which you agree or disagree with it.

I am confident I can integrate GT care into my family's routines.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1	2	3	4	5

I can always manage to problem-solve GT care difficulties if I try hard enough.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1	2	3	4	5

I am confident that I could deal efficiently with common GT complications (e.g., skin irritation, minor bleeding, tube dislodgment, etc.).

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1	2	3	4	5

I am confident that I could deal efficiently with unexpected GT events.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1	2	3	4	5

I can remain calm when facing GT difficulties because I can rely on my coping abilities.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1	2	3	4	5

When I am confronted with a problem, I can usually think of several solutions.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1	2	3	4	5

Adapted from the General Self-Efficacy Scale (GSE; Schwarzer & Jerusalem, 1995)

APPENDIX D: Post-PATCH Program Participant Survey

1. Please tell us how much you liked the following aspects of the PATCH Program:

	Dislike Very Much (1)	Dislike Somewhat (2)	Neither Like nor Dislike (3)	Like Somewhat (4)	Like Very Much (5)
Organization of program					
Length of sessions					
Start and end time of sessions					
Session location					
Session staff					

2. For each program topic, please tell us how useful the information has been for you:

	Not at all useful (1)	Not very useful (2)	Neither (3)	Somewhat Useful (4)	Very Useful (5)	N/A, Did Not Use
Review of GT care skills						
General problem-solving training						
Applying problem-solving to common GT issues						
GT care and management resources						

3. Based on your experience, what did you find to be most helpful or useful about the PATCH Program?

4. Please tell us about a time that you were able to use information and/or skills learned in the PATCH Program in your daily life. How has this affected you or your family?

5. Please tell us your overall level of satisfaction with the PATCH Program:

Very Dissatisfied (1)	Somewhat Dissatisfied (2)	Neither satisfied nor dissatisfied (3)	Somewhat Satisfied (4)	Very Satisfied (5)

6. Based on your experience, how can we improve the PATCH Program to better support you and other caregivers?

APPENDIX E: Post-PATCH Program Semi-Structured Interview Sample**Questions**

1. Tell me about what program component(s) you found most useful or beneficial.
 - a. Why did you think this component was most useful/beneficial?
2. Tell me about what program component(s) you thought were least useful or beneficial.
 - a. Why did you think this component was least useful/beneficial?
3. Tell me about what program component(s) you would want to see changed.
 - a. Why would you like to see this changed?
 - b. How do you think this component should or could be changed?
4. Tell me about how participating in the program affected your ability to provide and manage your child's GT care.
5. Tell me about how participating in the program affected your confidence with managing your child's GT care.

EXECUTIVE SUMMARY

Introduction

A gastrostomy tube (GT), or G-tube, is one method for children who are unable or unsafe to eat by mouth to receive full or supplemental nutrition needed for healthy growth and development (Russell, Jewell, Poskey, & Russell, 2018). GT placement involves a surgery during which a tube is inserted through the skin and stomach wall to allow for food to be given directly into the stomach (Davis, 2011). According to the United States Department of Health and Human Services, GT placement is identified as the third most common non-cardiac inpatient surgical procedure performed within the pediatric population (HCUPnet, 2009). Despite being a relatively routine pediatric procedure, a recent study found that GT placement was associated with high rates of emergency department visits (8.6%) and hospital readmissions (3.9%) during the first 30 days after hospital discharge (Goldin et al., 2016).

While the origins of this problem are diverse and multifaceted, healthcare providers and families of children with GTs have commented on the failure of current GT education programs to adequately prepare and meet the needs of caregivers of children with GTs (Berman et al., 2017). GT education programs, completed either before or after surgery, are considered best practice for teaching caregivers the skills needed to manage and problem-solve the child's GT care after returning home (Boullata et al., 2017). However, healthcare providers and caregivers of children with GTs have called for greater efforts towards providing family-centered education and cultivating family empowerment within GT education and management initiatives (Berman et al., 2017;

Franklin & Rodger, 2003; Russell et al., 2018).

The implications of inadequate GT education and management initiatives extend beyond higher rates of hospital readmissions and emergency department visits after discharge. A lack of comprehensive and client-centered education increases the likelihood that caregivers of children with GTs will experience poor health and wellness outcomes. The physical, emotional, social, temporal, and financial demands associated with managing a child's GT can increase caregiver stress and anxiety, as well as strain family dynamics and functioning (Franklin & Rodger, 2003; Hewetson & Singh, 2009; Russell et al., 2018). Additionally, poor caregiver preparation can place the child with a GT at an increased risk of developing preventable GT complications, disrupting his or her growth, development, and overall health and wellness.

PATCH Program: Promoting and Teaching Confidence for the Home

Inspired by this call to action from healthcare providers and caregivers of children with GTs, the PATCH Program: Promoting and Teaching Confidence for the Home was designed to empower and enable caregivers of children with GTs to effectively manage and problem-solve their children's GT care needs. Drawing from the evidence-based literature regarding self-efficacy enhancement and parent education, the PATCH Program combines formal education and interactive skills training to support caregivers in learning the knowledge and skills needed for successful GT home management. The PATCH Program adopts a modular format delivered over four weekly sessions. The PATCH Program utilizes a variety of multimodal instructional methods and learning activities, including visual presentations, group discussions, hands-on skill practice, and

worksheets, to reinforce learning while accommodating individual learning preferences. The PATCH Program is facilitated primarily by an occupational therapist and a rotating group of co-facilitators comprised of healthcare professionals typically involved in the care of children with GTs (i.e., general surgery and gastroenterology physicians and nurse practitioners, bedside nurses, dieticians, social workers, peer mentors, etc.). The PATCH Program is delivered to caregivers of children with GTs on an outpatient basis after the child has been discharged from the hospital and has returned home after GT placement. Through a group-based delivery format, the PATCH Program creates a communal and supportive context that allows participants to learn from and grow with peers.

The PATCH Program is unlike other GT education and training programs. Its distinct value comes from its occupational therapy roots. Developed by a pediatric occupational therapist, the PATCH Program adopts a strong family-centered perspective that encourages and honors the unique skills and goals of all participants involved. Through an occupational therapy lens, the PATCH Program acknowledges that successful GT home management is a product of careful consideration of the individual's and the family's environment, context, structure, and circumstances. Through this occupational therapy approach, the PATCH Program goes further than to offer solutions; it empowers caregivers of children with GTs to competently and confidently problem-solve and create solutions that best fit their needs and priorities.

Theoretical and Evidence Base for the PATCH Program

The PATCH Program's family-centered focus and application of self-efficacy

enhancing components is informed by the Individual and Family Self-Management Theory (IFSMT). Influenced by traditional self-management models, the IFSMT focuses on understanding and describing the process by which individuals and families assume responsibility for the care of a chronic or complex health condition and adopt behavior changes that influence immediate and long-term outcomes of health and wellness. The IFSMT adopts a dynamic systems perspective that acknowledges how the chronic health condition of one family member, such as a child, can affect other individuals in the family system (i.e., parents, siblings, extended relatives, etc.) and impact the function of the family unit as a whole (i.e., routines, habits, traditions, etc.). The IFSMT states that self-management is complex and dynamic in nature, requiring consideration of three dimensions: context, process, and outcomes (Ryan & Sawin, 2009).

The IFSMT views context as the environmental, familial, and individual characteristics that support or inhibit the self-management process (Ryan & Sawin, 2009). The PATCH Program applies this concept of context through its client-centered structure and delivery, which acknowledges that the characteristics, beliefs, skills, goals, and resources of each family shape their process of managing a complex health condition. The IFSMT emphasizes that self-efficacy, or the degree of confidence that an individual has in his or her ability to address both positive and negative health condition-related situations, heavily influences this process (Ryan & Sawin, 2009). The PATCH Program shares this perspective, as shown in the program's use of self-efficacy enhancing components to empower caregivers and enhance their confidence as a means to achieving efficient home management of their children's GT care. The process as it is viewed in the

IFSMT ultimately results in an individualized journey that culminates in immediate and long-term self-management and health outcomes (Ryan & Sawin, 2009). The PATCH Program reflects this in its mission to bring about the immediate outcome of enhanced caregiver self-efficacy and the long-term outcome of reduced pediatric rates of GT-related emergency department visits and hospital readmissions.

The PATCH Program's distinct approach to supporting caregivers of children with GTs and to reducing facility rates of pediatric GT-related emergency department visits and hospital readmissions is informed by the evidence literature regarding the positive benefits and outcomes associated with education, training, and family support interventions. The PATCH Program integrates evidence from both the healthcare domain, as well as from the social sciences domain to address the medical and psychosocial complexities involved with managing a child's GT care. Following is a brief overview regarding the evidence demonstrating the effectiveness of individual PATCH Program components:

Peer-Peer Support: Overall, quantitative and qualitative data obtained from studies examining the effectiveness of group-based caregiver interventions support the inclusion of peer-peer connection components, specifically group-based delivery, facilitated group discussion, and opportunities for peer modeling and social reinforcement, within the PATCH Program. Positive outcomes associated with peer-peer connection components include increased caregiver self-efficacy (Churchill & Kieckhefer, 2018; Goodier et al., 2014), enhanced caregiver coping and mental health (Churchill & Kieckhefer, 2018; Jackson, Liang, Frydenberg, O Higgins, & Murphy,

2016; Mirza, Krischer, Stolley, Magaña, & Martin, 2018), increased feelings of peer support (Ufer et al., 2018), and enhanced caregiver problem-solving (Jackson et al., 2016).

Formal Education: There is general agreement within the healthcare literature that formal, structured education approaches when applied to caregiver support programs enhance caregiving knowledge and understanding of child's health care needs.

Specifically, inclusion of formal education through didactic presentation, expert lecture, and a predefined program curriculum, all of which have been incorporated in the PATCH Program, can support caregivers to efficiently manage their children's complex medical condition and reduce their likelihood of experiencing negative health outcomes.

Specifically, formal education prepares caregivers to anticipate and recognize possible health concerns and emergencies early (Coller et al., 2017), to understand technical aspects of medical care (e.g., GT replacement, cleaning, flushing, etc.; Arnold & Diaz, 2016; Schweitzer et al., 2014; Thrasher et al., 2018), to adopt efficient problem-solving strategies (Arnold & Diaz, 2016; Caldwell et al., 2018; Kieckhefer et al., 2014; Shahine, Badr, Karam, & Abboud, 2014), and to access and use resources (Mirza et al., 2018).

Practical Skills Training and Practice: Overall, skills training and practice, applied in the PATCH Program through the use of role play, hands-on skills practice, and simulated practice scenarios, has been associated with positive outcomes for both caregivers and their children with medically complex conditions. These outcomes include increased caregiver self-efficacy (Goodier et al., 2014; Kieckhefer et al., 2014; Mirza et al., 2018), improved use of learned strategies following program completion (Caldwell et

al., 2018), enhanced problem-solving skills (Jackson et al., 2016), improved familial quality of life (Kieckhefer et al., 2014), improved caregiver coping (Kieckhefer et al., 2014; Mirza et al., 2018), decreased caregiver depressive symptoms (Kieckhefer et al., 2014), reduced rates of unplanned emergency department visits (Schweitzer et al., 2014), and reduced rates of hospital readmission post-discharge (Coller et al., 2017; Thrasher et al., 2018).

Future Direction of the PATCH Program

The PATCH Program has not yet been implemented. However, it is anticipated that a large, multi-site pediatric children's hospital will serve as the flagship location for implementation of the PATCH Program. A plan for evaluation and dissemination of the PATCH Program following initiation has been developed and is as follows:

- Completion of a two-group intervention and control evaluation design at the PATCH Program flagship site to establish program effectiveness. The overall goal of this evaluation is to demonstrate that participation in the PATCH Program is associated with enhanced caregiver perceived self-efficacy and reduced facility rates of pediatric GT-related emergency department visits and hospital readmissions.
- Dissemination of the PATCH Program within the occupational therapy and greater healthcare communities. This may subsequently lead to implementation of the PATCH Program at outside facilities beyond the PATCH Program's initial site.

Conclusion

The PATCH Program: Promoting and Teaching Confidence for the Home is a home management program designed to empower and enable caregivers of children with gastrostomy tubes (GTs) to effectively manage and problem-solve the care needs of their children with GTs. The PATCH Program was developed by an occupational therapist in response to a call for greater focus on family-centered education and family empowerment within GT education initiatives. Evidence-based and grounded in theory, the PATCH Program stands as a distinct approach combining formal education and practical skills training to support caregivers in developing the knowledge, skills, and confidence needed to successfully manage their children's GT care after they return home from the hospital. Future directions for the PATCH Program include comprehensive program evaluation demonstrating the program's effectiveness in promoting positive outcomes among children with GTs and their caregivers, as well as dissemination of the program and its benefits within and beyond its initial operating site. The PATCH Program demonstrates the value of occupational therapy in supporting caregivers of children with GTs and in reducing facility rates of pediatric negative post-surgical GT outcomes.



PATCH Program for Caregivers of Children with Gastrostomy Tubes: Promoting and Teaching Confidence for the Home

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Introduction to the Problem

- A gastrostomy tube (GT), or G-tube, is a surgically placed tube that allows food to be given directly into the stomach (Davis, 2011).
- A GT is one method for children who are unable to eat by mouth to receive full or supplemental nutrition needed for healthy growth and development (Russell, Jewell, Poskey, & Russell, 2018).
- The United States Department of Health and Human Services identifies GT placement as the third most common non-cardiac inpatient surgical procedure performed among children (HCUPnet, 2009). However, pediatric GT placement is associated with high rates of emergency department visits (8.6%) and hospital readmissions (3.9%) during the first 30 days after hospital discharge (Goldin et al., 2016).
- Current GT education initiatives have been identified as a contributor to these high rates of negative outcomes. Healthcare professionals and caregivers of children with GTs view them as ineffective for preparing families on how to manage GT care in the home (Berman et al., 2017; Franklin & Rodger, 2003; Russell et al., 2018).

Introduction to the Solution: PATCH Program

- The PATCH Program integrates theory with evidence-based education and skills training approaches to answer the call for GT education reform.
- Developed by a pediatric occupational therapist, the PATCH Program adopts a strong family-centered focus that honors the unique skills and goals of all caregivers involved.
- The PATCH Program goes beyond offering solutions. It empowers caregivers of children with GTs to competently and confidently problem-solve and create care solutions that best fit their needs and priorities.



Summary of the PATCH Program

- **Group-based format** creates a community-style context that allows caregivers to learn from and support one another.
- Through **problem-solving training**, caregivers learn to apply problem-solving steps of problem assessment, goal setting, reflective thinking, action planning, action implementation, and self-evaluation to common and personally experienced GT care issues.
- Interactive skills training with **pediatric GT simulation dolls** enables caregivers to cultivate competency and confidence related to managing GT care in the home.



Impact on Future Occupational Therapy Practice

- Current healthcare climate emphasizes patient autonomy and empowerment. The PATCH Program attests to the contribution that occupational therapists offer for preparing and supporting families in achieving effective **medically complex condition management**.
- Passage of the Affordable Care Act led to increased interest among healthcare facilities for programs and initiatives that **reduce patient readmission rates**. The PATCH Program demonstrates the distinct value that occupational therapy offers to support this goal.
- The PATCH Program demonstrates the distinct value that occupational therapy offers for **preventative care** and **health and wellness promotion**.

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